# ACHIEVING SOCIAL JUSTICE FOR PSYCHIATRIC SURVIVORS: CAPABILITIES AND ADVANCE CONSENT TO MENTAL HEALTH TREATMENT

by

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# ABSTRACT

This thesis uses a socio-legal methodology to investigate the desirability of advance consent to mental health treatment. Advance consent to mental health treatment is an anticipatory directive whereby a mentally ill patient may self-bind to future treatment in specific circumstances. Currently, there is no such provision available in English law. To assess the desirability of advance consent, this thesis asks the following questions: 1) To what extent would advance consent to mental health treatment be able to minimise coercion in the experiences of treatment? 2) What role, if any, should the mental capacity assessment play in facilitating a legal framework for advance consent? 3) Which capabilities are valued by psychiatric survivors, and to what extent can advance consent translate into securing those? 4) What are the sources of injustice experienced by psychiatric survivors, and what challenges/barriers do they pose for advance consent? These questions are grounded in original empirical data based on 21 interviews with 12 psychiatric survivors using narrative and photo-elicitation methods. These methods are considered novel for the socio-legal inquiry into mental health law. Thus, this thesis suggests a new methodological approach for studying lived experience of mental health law in everyday life. This socio-legal analysis is driven by the capabilities approach developed primarily by Martha Nussbaum and Amartya Sen.

I argue that social justice is best understood through capabilities and practical alternatives to what is currently experienced as injustice in people's lives. I suggest advance consent can aid the individual experience or achievement of social justice by supporting capabilities necessary for bodily integrity, health, emotions and safety, making it a desirable mechanism. This is the first study to use the capabilities approach to conceptualise lived experiences of mental health and treatment to provide a new contribution to existing debates on advance consent. In my investigation, I find that coercion, insufficient information, insight, stigma and mental capacity are experienced as injustice. I argue that legally binding, voluntary, informed, sufficiently safeguarded, and carefully implemented advance consent can minimise these experiences of injustice. Using empirical data alongside the capabilities framework enables a more holistic and practical consideration of the value of advance consent in everyday life and in relation to social justice.

# DEDICATION

To my siblings (pikelki),
Jarek and Natalia

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| | |
|---|---|
| ACC | Advance Consent to Confinement |
| ACD | Advance Choice Document |
| ADRT | Advance Decision to Refuse Treatment |
| AMHP | Approved Mental Health Professional |
| CBT | Cognitive Behavioural Therapy |
| DHSC | Department of Health and Social Care |
| DoLS | Deprivation of Liberty Safeguards |
| ECHR | European Convention on Human Rights |
| ECtHR | European Court on Human Rights |
| ECT | Electro-convulsive therapy |
| LPA | Lasting Power of Attorney |
| LPS | Liberty Protection Safeguards |
| MCA 2005 | Mental Capacity Act 2005 |
| MHA 1983 | Mental Health Act 1983 |
| MHA 2007 | Mental Health Act 2007 |
| NHS | National Health Service |
| SOAD | Second Opinion Approved Doctor |
| UN CRPD | United Nations Convention on the Rights of Persons with Disabilities |
| WESSELY | Independent Review of the Mental Health Act 1983 |
| WHO | World Health Organisation |

# CASE LAW

*A Local Authority v E* [2012] EWHC 2508

*Aintree University Hospitals NHS Foundation v James* [2013] UKSC 67

*Airedale NHS Trust v Bland* [1993] 1 ALL ER 821

*Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582

*Chatterton v Gerson* [1981] 1 Q.B. 432

*Chester v Afshar* [2005] 1 AC 134

*P v Cheshire West and Chester Council and another* [2014] UKSC 19

*Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11

*R v Bournewood Community and Mental Health NHS Trust Ex Parte L* [1999] 1 AC 458

*R (Burke) v General Medical Council* [2005] EWCA Civ 1003

*R (on the application of Oliver Leslie Burke) v The General Medical Council* [2006] QB 273

*Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129

*Re C (Refusal of Medical Treatment)* [1994] 1 W.L.R. 290

*HE v A Hospital NHS Trust* [2003] 2 FLR 408

*Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48

*Re MB (Adult Medical Treatment* [1997] 2 F.L.R. 426

*Re QQ* [2016] EWCOP 22

*Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52

*Re T (Adult: Refusal of Medical Treatment)* [1992] 4 ALL ER 649

*Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871

*W v M and others* [2011] EWHC 2443

## European Human Rights case law

*Herczegfalvy v Austria* (1992) 15 EHRR 437

*HL v United Kingdom* (2004) 40 E.H.R.R. 761

*Pretty v United Kingdom* [2002] ECHR 427

*Stanev v Bulgaria* [2012] ECHR 49

# LEGISLATION

## Domestic legislation

Human Rights Act 1998

Mental Capacity Act 2005

Mental Health Act 1959

Mental Health Act 1983

Mental Health Act 2007

## India

Mental Healthcare Act 2017

## International Instruments

Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms*, as amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5.

United Nations *International Covenant on Economic, Social and Cultural Rights* (1966) *Treaty Series* 999, 171.

United Nations *Convention on the Rights of Persons with Disabilities* (2006) Treaty no. 44910. *United Nations Treaty Series*, 2515.

# CHAPTER 1: INTRODUCTION

## 1.1. Introducing the socio-legal thesis to the study of advance consent

It is a well-known fact that mental ill-health touches the lives of many people. The MIND Charity (MIND 2020) estimates that 1 in 4 people suffer from a mental health problem in any given week, while 1 in 8 people globally develop mental ill-health at some time during their lives (WHO 2022). However, the number of people affected by mental illness is much higher; the remainder of the population is likely to have a secondary experience of mental ill-health through knowing, caring for, or loving someone who is struggling. Therefore, it is crucial that an array of speedy and appropriate responses to mental ill-health exist that allow people to live the kind of lives they value. The relevance of law in creating such responses must not be underestimated. The law currently empowers healthcare professionals to "limit bodily integrity[,] privacy … and capacity to act" as well as dictating how individuals with mental ill health are to live in society (Gostin 2010, v). These limitations to bodily integrity, privacy and ability to act in accordance with one's wishes exist primarily in the form of involuntary confinement, involuntary treatment and other coercive interventions that may take place in everyday life settings. Gooding (2017, 69-70) suggests that it can be argued that mental health law exists "to protect individuals and create opportunities for social justice" because involuntary treatment is arguably better than no treatment and the law provides a framework for civil rights protection and for safeguarding those subjected to such interventions (Jagodic et al. 2008). In contrast, in the spirit of empowering an individual at the heart of those limitations, this socio-legal thesis draws on narrative and photo-elicitation interviews with psychiatric survivors to understand how mental health treatment and the law is experienced by them and whether an introduction of advance consent in mental health contexts could empower individuals and improve their interactions with mental health care. It also provides a social justice argument for increasing decision-making opportunities for people who live with mental ill-health.

As an idea, advance consent, also known as a Ulysses Arrangement/Contract, finds its roots in Greek mythology: specifically, Homer’s *Odyssey* and the story of Ulysses. On his way back from the Trojan War, Ulysses wanted to sail past the Sirens to hear their magnificent singing. The beauty and the strength of the Sirens’ voices meant that, at this point, Ulysses would be tempted to leave the ship and swim over to the Sirens where he would be faced with undeniable death. To prevent this from happening, while also still experiencing the singing of the Sirens, Ulysses ordered his oarsmen to bind him to the mast of the ship so that he could still enjoy the Siren’s music without being in danger of losing his life. When the time came, Ulysses pleaded to be unbound, but his oarsmen refused. In this way, Ulysses was able to sail past and enjoy the beautiful sound without putting himself at any risk. Drawing on the story of Ulysses, advance consent in health care decision-making more broadly allows a person to bind themselves to a future treatment (or non-treatment) in circumstances under which the person does not expect to be able to make that decision for themselves, either because they would not be able to make the ‘right’ decision or because their decision-making would be constrained by the law. Thus, advance consent’s empowering premise lies in allowing people to exercise autonomy at times when they would not ordinarily be able to do so. In this context, Gremmen et al. (2008, 79) argue that “legal Ulysses arrangements will have the greatest chance of being successful both as a form of the prevention of coercion and as an ultimate form of care”. Moreover, as Saks (2002, 58) notes, the benefits of advance consent are also relational and grounded in everyday reality because just as advance consent leads to regaining mental well-being, it also:

> allow[s] mentally ill people to avoid all the often-terrible consequences of being in an actively ill state. These include events that are not sufficient to justify civil commitment but that everyone would find dreadful: going through hundreds of dollars; alienating family and friends – indeed, losing them; losing one's job; becoming homeless; suffering medical conditions that, though not life-threatening, could nevertheless be very troubling; and – last but not least – suffering tremendously.

Despite its apparent benefits, advance consent remains a legally and ethically controversial idea which warrants careful exploration. In investigating advance consent's potential, this thesis understands improving experiences of mental health care as a matter of social justice. Here, mental health is not a mere alleviation of disturbing symptoms, but rather it is understood in its widest possible sense (Stavert and McGreggor 2018; WHO 2013). The World Health Organization (WHO 2013) conceptualises mental health as an end in itself, rather than focusing merely on the absence of illness or symptoms:

> as a state of wellbeing, in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

Therefore, I argue that adopting such a subjective understanding of mental health requires a framework of social justice which asks questions like "What is a person able to do and be in their everyday life contexts?" and "Is a person able to live the kind of life they want to live?", and I maintain that these questions are best addressed by the capabilities approach founded primarily by Amartya Sen (1999; 2009) and Martha Nussbaum (2006; 2011). Thus, I use the capabilities approach in this thesis to conceptualise both the lived experiences of mental health and the potential of advance consent. This offers a more practical, rather than abstract, way of thinking about social justice and requires a more holistic view of advance consent as existing indivisibly from people's everyday lives. Consequently, the overarching argument in this thesis is that advance consent is a desirable legal mechanism which promotes social justice.

In this chapter, I set out the key terms which permeate this thesis (advance consent, psychiatric survivors, and social justice as capabilities) before offering a background story of advance consent which is necessary for understanding the research questions guiding this socio-legal study. I will then provide a wider research context in which I set out the relevant legal frameworks, scholarly debates, and contributions that my thesis makes. Finally, I summarise the ambit of this research before providing a chapter-by-chapter overview of this thesis.

## 1.2. Key terms

### 1.2.1. Advance consent to mental health treatment

The key concept this thesis interrogates is advance consent to mental health treatment. Advance consent is not a new concept, and in literature, it exists under many different guises such as Ulysses Arrangements, Ulysses Contracts, advance directives/decisions, advance statements, advance care plans, crisis plans and other similar terms.[1] Although the formulations, scope and legal enforceability of advance consent are aspects of variations in the definition, all such definitions possess three common characteristics: they all focus on anticipatory treatment, highlight the value of autonomy and promote independent decision-making (Weller 2013). In this thesis, I adopt the term ‘advance consent’ for clarity, even when discussing literature which uses a variation of this term or discusses advance decisions more broadly.

This thesis began with advance consent being loosely defined as an instrument allowing people to decide what mental health treatment they would like to undergo in the future at a time

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[1] For variation of definitions see Dresser (1982), Howell, Diamond and Wikler (1982), Szasz (1982), Spellecy (2003), Sheetz (2006), Gremmen (2008), Walker (2012), Bielby (2014).

when they do not expect to be able to make those decisions. However, grounded in the data, I suggest that advance consent should be a legally binding decision to consent to a specific mental health treatment that was previously experienced by an individual, invoked by circumstances specified by that individual. Thus, anyone with prior experience in mental health treatment should be able to make an advance consent if they wish to.

It is generally accepted that patient choice regarding treatment is limited to treatment options offered by a healthcare professional. Accordingly, advance consent would be a voluntary instrument limited to consenting to a form of treatment that has previously been received. This ensures that the consent is sufficiently informed and that the treatment is appropriate and clinically safe. As advance consent takes a hard enforceability position, mental health professionals would be required to follow advance consent in the first instance unless it was no longer medically appropriate: for example, because of a change in a person's medical history. Moreover, by being invoked in situations specified by the person themselves ('a material time'), it is not envisioned to come into effect on incapacity. Furthermore, advance consent in this thesis precludes changes of mind at the material time, which might include times in which the person may or may not have the mental capacity to make decisions. Finally, advance consent should be flexible enough to allow people to delegate some decision-making powers to others, to whom I refer to as nominated trusted persons.

The premise of advance consent lies in empowering people to make independent decisions, increase their participation in treatment decision-making, respect the self-knowledge they hold about their own mental health and treatment experiences, minimise coercion and improve access to treatment. Most importantly, advance consent, I argue, by allowing people to be treated in accordance with their wishes, enables them to live the lives they value and to fulfil their life, social and relational roles which allows them to experience social justice.

### 1.2.2. Psychiatric survivors: a note on terminology

In this thesis, I adopt the term ‘psychiatric survivors’ to describe people who either currently access mental health services, have experiences of intervention by psychiatry or are ex-users of mental health services. Most importantly, they are people who self-identified as psychiatric survivors and who took part in the research for this thesis. This term is more appropriate than referring to people as service users (because they may no longer be service users) or people with mental illness or disability (as they may no longer have illness or disability or may not identify with either the illness or the disability). Therefore, the main reason for adopting this term is for breadth and clarity. In this thesis, I also refer to psychiatric survivors as ‘patients’ at times to reflect the specific nature of a doctor–patient relationship to the law, which is one of being a patient. In these instances, I often mirror the language used by my participants. In addition, I also refer to psychiatric survivors as ‘my participants’ when I speak of their particular experiences. Mainly, I refer to psychiatric survivors as ‘people’, ‘individuals’ and ‘persons’ to emphasise the equality between people regardless of the status of their mental health or disability.

Historically, the term finds its roots in the psychiatric survivors’ movement, which was a civil rights movement which came about in response to the abuse experienced by people in psychiatric settings which began to be vocalised (Creswell 2005). However, it has become associated with emphasising the value of self-knowledge as held by an individual about their mental health which stresses the importance of individuals’ awareness, their traumas throughout the life course and their personal journey, all combined as a form of expert data, making psychiatric survivors experts by experience (Cresswell 2005, 1668). In this way, psychiatric survivors began to challenge the traditional power of psychiatry which emphasises professional expertise and generalises the human experience of mental ill-health. However, the term ‘psychiatric survivor’ must not be understood as being inherently anti-psychiatry. Instead, a psychiatric survivor is a person who holds intimate knowledge about their own mental health, who has experienced treatment in the past and understands that this might help them decide what interventions are appropriate for them in the future.

Nonetheless, it is important to note that the term ‘psychiatric survivors’ can give rise to both negative and positive connotations (see Cresswell 2005, 1671). Campbell (1999, 197) developed the term “legends of oppression” and developed a strategy of sharing painful memories of negative experiences of mental health services. In this context, a psychiatric survivor is a persona[2] of someone who has survived abuse and oppression and criticises the efficacy of psychiatric treatment. Cresswell (2005, 1671) suggests that there are two camps of thinking about “legends of oppression”; the first being people who simply claim that psychiatry has not helped them and the second being those who claim that they were actually harmed by psychiatry. Therefore, the term psychiatric survivor may sometimes imply negative attitudes towards mental healthcare.

On the other hand, Campbell (1992; 1999) notes that the term “survivors” has positive expressions, signifying groups of people who help to inform various developments (both clinical and in policymaking). Using their lived experience, they differentiate between helpful and unhelpful interventions to improve mental healthcare provided to others in the future. In

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[2] In Chapter Three, section 3.1.1. I discuss the limits of ‘psychiatric survivors’ as an identity.

this sense, in essence, psychiatric survivors are experts by experience (Cresswell 2005, 1671). Hence, the positive connotation associated with psychiatric survivors fits the premise and the methodology adopted in this thesis.

### 1.2.3. Social justice as capabilities

Another concept which permeates this thesis is social justice which, I suggest, is best understood through capabilities. Capabilities are real and actual opportunities through which a person can achieve desired outcomes (Nussbaum 2011, 18). They are not achievements in their own right but rather opportunities for such achievement and are fundamental entitlements of all people, thus, a matter of social justice (Nussbaum 2011, 19). Relying on Nussbaum's (2011, 33–34) list of central capabilities, I argue that the capabilities for bodily integrity, emotions and health can be used to gain important insight for conceptualising lived experiences of mental health treatment and advance consent. In addition, I develop a new capability for safety in the context of mental health. Drawing on Sen (1999; 2009), I argue that social justice is also about examining the real lives of people and, from there, developing alternatives to their lives as they currently are which improve people's ability to be who they want to be and do what they value. In mental health contexts, advance consent is presented as an alternative to current negative experiences of mental health treatment. The capabilities approach founded by Sen (1999; 2009) and Nussbaum (2006; 2011) provides a theoretical framework for this thesis, which I detail in Chapter 2.

## 1.3. Background: the full circle of advance consent to mental health treatment

The idea of psychiatric advance decisions gained momentum in the early 1980s. Szasz (1982), a well-known, influential and prominent critic of psychiatry, saw advance consent as a new way for exercising patient autonomy; an alternative to coercion and what he referred to as “an olive branch” to psychiatry. Indeed, autonomy has become an inherent selling point behind this notion and, thus, seen as something that should be perceived as inherently good and moral (Sarin 2012, 2006). In the same year as Szasz (1982), Howell, Diamond and Wikler (1982, 3–4) offered the first detailed legal proposal for advance consent in psychiatry, which they called “a voluntary commitment contract”, designed to apply both outside and inside the hospital, for people who suffer from a recurrent mental illness. Advance consent here was envisaged as a way for a person to receive treatment that they would later be likely to resist but which does not meet grounds for involuntary detention. Without advance consent, they would be unable to receive such treatment, which circumstance would have devastating consequences for their health and everyday life.

However, these proposals were received with substantial scepticism. The conceptualisation of advance consent as an olive branch in Szaszian thinking was soon relabelled as a “thorny thicket” by Chodoff and Peele (1983, 11). Dresser (1982; 1995), the most prominent legal sceptic of advance consent and advance decisions more broadly, was quick to point out the futility of autonomy arguments when it came to translating advance consent from theory to legal reality. For Dresser (1982), developing a justification for privileging earlier wishes over later wishes could only be legally valid if advance consent was invoked on incapacity (or incompetence), but, even then, she considered the limits placed on the future liberties of a person would be unconscionable and unconstitutional. Indeed, the question that bothered many scholars was: what should happen if, when the advance decision is supposed to come into effect, the person attempts to revoke their decision at that material time? For Dresser (1982) this was legally solvable through working competence/capacity into such decisions. Ethically, the question was harder to reconcile. This thorny dilemma has led to arguments and debates over what competence and capacity are, how this relates to the nature of ‘self’ and whether people have autonomy in the present to constrain their autonomy in the future (see Sarin 2012; Bielby 2014; Hayes 2015 for an overview). Hereabouts, the questions that this scholarship was concerned with were to do with whether a person is made up of one ‘self’ or different ‘selves’ and whether a past self can bind the future self to do or not do something (see Atkinson 2007; Hayes 2015).

Although such conceptualisations have led to helpful ethical accounts of the nature of autonomy (e.g. Davis 2002; 2009a; 2009b) or personhood (e.g. Savulsescu and Dickenson 1998; Hayes 2015), they have tended to be in conflict with one another. Additionally, they are frequently discussed in the abstract and more often than not widen the gap between the theory and legal implementation. Indeed, legislating the notion of self is not an easy task (Hayes 2015). Certainly, the inability to reconcile these different ethical positions and a lack of empirical research in which to ground those arguments led to stagnation of advance consent debates in legal scholarship. The differences between proponents and opponents were ultimately and fundamentally dependent on the worldview held by an individual entering this debate, resulting in policymaking in this area being extremely challenging (Sarin 2012, 207). Consequently, the questions concerning the validity, applicability and implementation of legally binding psychiatric advance consent remained underexplored.

Whereas other jurisdictions, like the US (Swanson et al. 2006), began to recognise the value of some forms of psychiatric advance directives, English law concerned itself with advance decisions in the context of physical health and end-of-life care, first developed in common law and later in statute.[3] At the same time, the clinical evidence pointing to the usefulness and effectiveness of advance decisions in the psychiatric context was growing, both in the UK (e.g. Henderson 2004) and elsewhere (e.g. Swanson et al. 2003; 2006).[4] Eventually, advance statements in psychiatric care were included in the Mental Health Act Code of Practice (Department of Health 2008 revised in 2015), encouraging their use yet not putting them on a statutory footing. This demonstrates the law's manifest discrimination against 'mental health patients'; whereas an individual is able to make a legally binding advance decision to refuse even life-saving treatment for a physical ailment, a patient with a mental health condition is only able to make an advance statement setting out their preferences, but it does not carry the same legal force.

Meanwhile, the introduction of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has led to a global revival of debate about advance decisions in the mental health context (e.g. Weller 2013; Stavert 2013; Gooding 2017). Article 12 of the CRPD requires that all individuals, regardless of their disability, be treated with equality before the law. Recognising that some people with disabilities may require support to exercise their legal capacity, the Committee on the Rights of Persons with Disabilities (2014) has explicitly highlighted the value and potential of advance decisions, viewed as supported decision-making mechanisms. However, the Committee on the Rights of Persons with Disabilities (2014) also urged that the timing of advance decisions coming into effect and ceasing to have effect should be up to each individual to make and must not be based on an assessment of a person's mental capacity. This poses a challenge to English law (and many other jurisdictions) which conceive of advance decisions as being invoked on incapacity. At the same time, the Committee's on

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[3] See section 1.5.2. of this chapter for detailed overview.

[4] There is also a growing literature on the barriers to using psychiatric advance decisions in clinical practice, e.g. Shields et al. (2014).

the Rights of Persons with Disabilities (2014) view potentially takes the debate right back to the early 1980s when proponents conceived of psychiatric advance decisions in a similar way – i.e. not based on incapacity – thus completing the circle.

In England, advance consent in a mental health context is currently on the law-making agenda and represents a bone of contention for policymakers (Independent Review of the Mental Health Act 1983 (*hereinafter* Wessely Review) 2018; Department of Health and Social Care 2021a; Department of Health and Social Care 2021b; Department of Health and Social Care 2022a). Whereas the Government has recognised that advance consent is a legally valid principle in English law (e.g. Wessely Review 2018, 82),[5] the policy considerations regarding the appropriateness of advance consent and the limitations of such measures, as well as access/or non-access to safeguards, have not yet led to firm recommendations in this area (Wessely Review 2018; Department of Health and Social Care 2021b). In addition, policymakers have regarded advance consent to confinement rather than to mental health treatment in general as a more likely possibility (Department of Health and Social Care 2021b). This confused approach has led to the debate on advance consent to mental health treatment stalling in England and Wales in favour of advance consent to confinement.

Despite coming full circle – from initial arguments, stagnation of debates and revival of the discussion – advance consent to mental health treatment requires further exploration. To establish the legal desirability of such an instrument, its legal enforceability, implementation and appropriateness requires contributions which provide new ways of thinking about advance

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[5] See this chapter, section 1.5.2. for detailed discussion.

consent, putting at the forefront people who are at the very heart of the debate. This thesis aims to provide such a contribution.

## 1.4. Research questions and aims

The above background guides the aims and research questions of this thesis. Its overall aim is to examine the desirability of advance consent to mental health treatment based on the lived experiences of those who have previously undergone such treatment. Increasing decision-making opportunities about one's treatment is therefore crucial. As a consequence, the thesis is primarily exploratory in nature as it attempts to ascertain what kind of advance consent to mental health treatment is desirable and what characteristics advance consent should have. Rather than relying on purely doctrinal or purely theoretical analyses, this thesis' overarching research question is grounded in original empirical data, and the desirability of advance consent is assessed from the narratives told in this thesis conceptualised through the capabilities approach. Therefore, the overarching question this thesis asks is:

- How desirable is advance consent to mental health treatment in English law based on lived experiences of psychiatric survivors?

To address this overarching research question, I ask the following four research questions which guide this thesis:

> RQ1: To what extent would advance consent to mental health treatment be able to minimise coercion in the experiences of treatment?

RQ2: What role, if any, should mental capacity play in facilitating a legal framework for advance consent?

RQ3: Which capabilities are valued by psychiatric survivors, and to what extent can advance consent translate into securing those capabilities?

RQ4: What are the sources of injustice experienced by psychiatric survivors, and what challenges/barriers do they pose for advance consent?

As discussed in the previous section, some proponents of advance consent see it as a substitute for coercion (e.g. Szasz 1982; Gremmen et al. 2008). Indeed, in a more recent literature review, Gooding et al. (2018) highlighted that advance directives are systematically proposed as an alternative to coercion. However, discussion about coercion in such literature is often limited to what is understood by coercion in law, i.e. involuntary detention or compulsory treatment. In this thesis, I examine coercion more broadly to extend beyond legal definitions of coercion in mental health settings. To do so is especially important because there is a particular relationship between advance consent and coercion which cannot be ignored. Sarin (2012, 206), in discussing the biggest difference between an advance decision in a physical health context and psychiatric advance decisions, eloquently emphasises this relationship:

> while the use of the advance directive in terminal illness is rather straightforward, as the expression of intent for a time when the individual may be incapable of expressing intent, in psychiatry this is different. It is an expression of intent of expected treatment for a time when the expressed intent may actually be saying completely the opposite. It is an attempt to reconcile the facts of patient autonomy and choice, with the possibility of involuntary treatment that has been agreed upon in advance. It is thus an attempt to reconcile seemingly irreconcilable issues, namely, those of choice and involuntarity.

In examining advance consent's ability to minimise coercion, it is also important to investigate whether advance consent can actually create coercive situations and thus understand its real potential for reducing coercion in mental health care. This potential coercion lies in a situation in which a person makes an advance consent but, when it is supposed to come into effect, they attempt to revoke it or resist treatment previously requested (e.g. Bielby 2014). In these circumstances, fulfilling the wishes expressed in an advance consent might therefore require some force and coercion. It is thus important to understand what psychiatric survivors understand as coercion and whether they think that advance consent should or should not preclude changes of mind. These questions are also indivisible from questions of invocation and revocation of advance consent.

For advance decisions in a more general health care context, the question of invocation and revocation is often addressed by the notion of mental capacity (a legal test for an individual's ability to make a particular decision).[6] This means that advance decisions can only be made by someone with mental capacity, invoked when capacity is lost and revoked only when capacity is present. However, as Sarin (2012) notes, the context in which psychiatric advance decisions are designed to work and apply differs significantly from the contexts for which advance decisions for physical health are made. In addition, English law has become accustomed to thinking about decision-making in healthcare and advance decision-making as inseparable from the binary distinction of those who have the capacity and those who do not (Clough 2022), a distinction which is unable to capture the nuance of mental ill-health. It is, therefore, crucial to examine the role and appropriateness of mental capacity in relation to advance consent.

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[6] E.g. Mental Capacity Act 2005, ss 24-26.

Theoretically, the aim of this thesis is to provide a new framework for conceptualising advance consent, and so the capabilities approach is used to make an argument that creating decision-making opportunities about their mental health care is a matter of social justice for psychiatric survivors. Following on from this, thinking about advance consent through relevant capabilities allows me to investigate its premise and practical benefits. As this approach encourages an exploration of the sources of injustice (‘unfreedoms’), I can also anticipate how advance consent might address injustice. Moreover, this allows me to forestall arguments about how these unfreedoms pose challenges for advance consent in practice.

Another aim relevant to all the research questions is to ground my conclusions in empirical data which allows me to move beyond strictly doctrinal or ethical approaches to the study of advance consent that are unable to provide practical insights into the everyday reality of mental ill-health in which advance consent ought to operate. In the context of policymaking, recent policy developments have been informed by the voices of people with mental health diagnoses, in particular, bipolar disorder (see e.g. Wessely Review 2019). However, this is not a novel approach, because, as Lewis (2009) points out, in some fields it has been common practice for some time, particularly in policymaking for health and social care matters. Lewis (2009, 257) asserts that the justification for this inclusive practice has always been linked to the assumption that keeping people at the heart of policymaking is likely to lead to a higher standard of care in both policymaking and practice and that such inclusion is an active democratic technique. Examining the extent of such inclusion in policy and legal developments, Hui and Stickley (2007, 422) concluded that references to psychiatric survivors’ voices are “tokenistic”, making them “silent partners if they can be described as partners at all”, and that their input features as the last consideration after the concerns of statutory bodies, the law and stakeholders. In light of those insights, it is therefore crucial that empirical academic research conducted on mental health laws is data-driven and not data-complemented, so that the voices of psychiatric survivors are privileged. Furthermore, it is essential to find promising and new ways of engaging with lived experiences through socio-legal scholarship and especially in the context of the mental health law. Thus, a consequent aim of this research is to explore the effectiveness of a novel methodological research design for socio-legal research in mental health law and more broadly. Although the methods I use – narrative and photo-elicitation methods – are not new for social sciences and health research, this particular design is, to a certain extent, an innovative way of 'doing' socio-legal research, thus contributing to the field of socio-legal research more broadly.

This approach also takes into consideration how the law impacts or has a profound ability to impact on the ways in which individuals experience mental health care because it sets out rules on the provision of treatment and dictates how much decision-making power an individual holds about their own treatment. Law is, thus, integral to the daily lived experiences of psychiatric survivors, and, consequently, should be subject to continual scrutiny while also acting as a tool for creating opportunities that allow people to make independent decisions about their treatment.

## 1.5. Research context

### 1.5.1. Understanding the genesis of the relationship between the law and the mental health treatment

The 1950s were marked by advances in psychiatry, specifically advances in medications, which initiated the need for regulatory frameworks for mental health services and for the provision of psychiatric treatment, and so the idea emerged that psychiatrists would now be able to cure mental illnesses, just as other doctors were able to cure physical ailments (see Busfield 1998; Hodges, Inch and Silver 2001; Bentall 2009; Klein and Glick 2014; Hale et al. 2017). Hale et al. (2017, 2) suggest that these advancements enabled mental health professionals to "persuade law-makers that both they and their patients should be freed from legal constraints" that were typical in a psychiatric context because people with mental illness could now be treated on a par with patients who have physical ailments, also arguing that people could be treated outside of hospital settings in a community. This led to the introduction of the Mental Health Act 1959 which afforded significant power to clinicians – with minimal formality – allowing them to override treatment refusals and ensuring that compliance with doctors' advice was part of a regulatory framework. In this thesis, I contribute to the critique of 'compliance' in psychiatry by examining the relationship between law and the clinical concept of insight discussed in Chapter 5. The 1959 Act wholly recognised the medical model in psychiatry, which is concerned with biological shortcomings that could now be fully addressed via medical responses.[7] It could be argued that the 1959 Act led to the professionalisation[8] of law by the likes of – and straight into the hands of – psychiatrists. The law was exercised and applied by mental health professionals with minimal oversight from the legal profession itself, thus the medical profession has had a tremendous impact on the development of law, not just in statute, but also in practice. Meanwhile, scholars like Morse (1978) began to argue that there are significant limits to the expertise of mental health professionals in dealing with complex laws and statutes and how much they can offer in their provision of information to the legal system.

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[7] For scholarly application of medical model to psychiatry see for instance Guze (1992). For critique of the medical model in this context see for instance Leifer (2001).

[8] There is an interesting socio-legal work which uses the theoretical framework from the sociology of professions and applies it to the explain the policy, the law and the roles of institutions to explain developments in medical law and rights, see Krajewska (2021). Here the context is on abortion law, using Poland as a case study. In mental health context, it is clear that mental health professionals played an important role in legal developments in this area.

With growing general criticism of the medical model in favour of the social model of disability,[9] the antipsychiatry movement emerged, ostensibly beginning within the psychiatric profession itself (Cooper 1967; Crossley 1998; Szasz 2009). The movement contended that mental illness cannot be classified as an objective scientific fact, signalling distrust in the mental health profession as a branch of medicine. Meanwhile, the law of lawyers or lawmakers was concentrated on offending mental health patients who entered the criminal justice system (Hale et al. 2017) which was reflected in the policymaking, as the protection of the public and the potential of law-breaking by people with mental ill-health formed the basis of the Butler Report (1975). At the same time, the MIND charity[10] began to scrutinise the Mental Health Act 1959 (Gostin 1975; 1977) arguing for in-patient consent to treatment and better safeguards among other patient-centred developments.[11] This eventually led to the Mental Health Act 1983 (MHA 1983) being enacted. Ostensibly, the MHA 1983 has not provided a comprehensive change to the previous mental health legislation, but it has introduced procedural safeguards and also enabled greater scrutiny of what happens in mental health institutions. Considering the focus of the MIND charity being on amending English law in line with developments in the United States (US) (Gostin 1975, 1977), it appears to have been a missed opportunity for considering advance consent and advance decisions more broadly, which at that time formed part of a significant debate in legal scholarship, particularly in the US (e.g. Dresser 1982).

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[9] Medical model views illness as a result of a biological shortcoming which is intrinsic to an individual and can be remedied by medical interventions. Social model recognises that people are disabled by systemic and societal barriers rather than by their ‘impairment’. There is also a biopsychosocial. For literature on different models of disability, see for instance: Oliver (1990), Shakespeare (2006) and Scully (2014), Clough (2015).

[10] The MIND charity was then known as the National Association for Mental Health. Gostin was their legal officer and the 1975 and 1977 studies were aiming at bringing the English law in line with the developing US mental health law.

[11] Hilton (2007) suggests that these proposals by Gostin were strongly associated with anti-psychiatry.

Following the growing awareness of the relevance of human rights in a mental health law context and the introduction of the Human Rights Act 1998,[12] the Government began a lengthy review process of the MHA 1983, appointing an expert committee led by Professor Genevra Richardson which resulted in the notable Richardson Report (1999) proposing a full replacement of the 1983 Act. These proposals were met with a significant backlash from mental health professionals and other stakeholders. Primarily, this was due to proposals suggesting indefinite detention of those individuals who were seen as posing a risk to the public and which would allow the treatment of those people even if the benefit of such treatment was not apparent (Hale et al. 2017, 4). The lengthy and tiresome process of reform resulted in the 1983 Act remaining in force until it was amended by the Mental Health Act 2007 (MHA 2007), which while not resulting in significant changes to the existing legislation, did improve some of the available safeguards, such as disallowing the provision of electro-convulsive therapy and neurosurgery without valid consent in most circumstances (s 58A, MHA 1983).

Around the same time, the issue of treatment of the physical ailments of patients who had a mental illness or other disabilities and were deemed unable to make decisions for themselves was being investigated by the Law Commission (1995), which eventually resulted in the Mental Capacity Act 2005 (MCA 2005), currently in force.[13] The Act put the assessment of capacity, previously developed at common law as functional assessment,[14] on statutory footing. Section 3 of the Act contains the functional test which states that “a person is unable to make a decision for himself if he is unable to a) understand the information relevant to the

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[12] Note, the Human Rights Act 1998 is currently under scrutiny with the government proposing a Bill of Rights (2022) in its replacement. It is unclear what effect this will have in the mental health law contexts.
[13] There are changes incoming to this Act which will be amended by the Mental Capacity (Amendment) Act 2019 upon implementation of Liberty Protection Safeguards which is expected to happen later in 2022. For overview of this see Harding (2021).
[14] *Re C* [1994] 1 W.L.R. 290 and *Re MB* [1997] 2 F.L.R. 426 are common law provisions which established the common law functional test of incapacity.

decision, b) retain that information, c) to use or weigh that information as part of the process of making the decision or d) to communicate his decision (whether by talking, sign language or any other means)".[15] Section 2(1) of the MCA 2005 imposes a diagnostic requirement where a person can only lack capacity if "he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain". The fact that incapacity must stem from an impairment under the Act has been criticised not only for being discriminatory but also incompatible with human rights and, in particular, the CRPD (e.g. Cave 2015; Harding 2017a; Arstein-Kerslake and Flynn 2017; Clough 2022). The presence of capacity for a specific decision allows people to make their own independent decisions and lack thereof warrants a decision being made on a person's behalf in their best interest[16] which can be displaced by an Advance Decision to Refuse Treatment (if relevant)[17] or by the appointment of an attorney through a Lasting Power of Attorney.[18] In Chapters 5 and 6, I contribute a critique of the mental capacity assessments in relation to mental health treatment and advance consent in the same context.

In 2005, the European Court of Human Rights challenged the lack of formality under the 1983 Act in relation to the detention of people in hospital for the treatment of their mental illness in the case of *HL v United Kingdom*.[19] The Court held that lack of procedural safeguards when one is deprived of one's liberty constitutes an infringement of Article 5(1) of the

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[15] Mental Capacity Act 2005, s 3(1)(a)–(d).

[16] Best interests is contained in section 4 of the Act and provides a checklist against which a decision must be made. It should be noted that there is no hierarchy in the elements of this checklist but judicial developments, notably in the case of *Aintree University Hospitals NHS Foundation v James* [2013] UKSC 67, where Lady Hale at [45] affirmed that "the purpose of best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail." For the critique of the test see for instance Donnelly (2011; 2016).

[17] MCA 2005, ss 24-26. See section 1.5.2. of this chapter for discussion as well as Chapter 6, section 6.4.1.

[18] MCA 2005, ss 9-14. See Chapter 5, section 6.5.3 for more discussion.

[19] *HL v United Kingdom* (2005) 40 E.H.R.R. 761.

Convention.[20] This gap in the law was addressed by the introduction of the Deprivation of Liberty Safeguards, inserted into the MCA by the MHA 2007, soon to be replaced by the Liberty Protection Safeguards.[21] These developments muddied the waters between the MHA (1983) and the MCA (2005), leading to a complex legal framework covering treatment decisions (and other decisions) pertinent to psychiatric survivors. This means that both the MHA 1983 and the MCA 2005 may apply to the same person. For instance, when the person needs treatment for their mental disorder, the MCA 2005 may apply if the person complies, but if they do not they may be detained under the MHA 1983. In search of solving this complicated legal situation at hand, academics are currently debating the creation of a fusion law, bringing both Acts together.[22]

The MHA 1983 appears to be surviving the test of time. As it is concerned with the protection of and safety of the public (arguably to a greater extent than the protection of the rights of patients), this means that the law allows involuntary detention, coercion and non-consensual treatment (regardless of mental capacity status), which also means that the law continues to clearly discriminate between medical decision-making and mental health decision-making by not affording the same level of autonomy to mental health patients, leading to experiences of injustice.[23] The MHA 1983 found itself under scrutiny again in 2018 by the likes of the Wessely Review (2018; 2019), which aimed to modernise mental health law in the

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[20] Article 5(1) of the ECHR states: “Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law (…)”. For relevant literature see: Cairns, Richardson and Hotopf (2010), Series (2022).

[21] See Harding (2021) for overview on this. The detailed consideration of Deprivation of Liberty Safeguards (DoLS) and Liberty Protection Safeguards (LPS) is beyond the remit of this thesis, but it forms part of background information.

[22] See for instance Applebaum (2010). This is unlikely to take place in the English context for now (Wessely Review 2018; Department of Health and Social Care 2021b). An example of the first fusion law in this context is from Northern Ireland: Mental Capacity Act (Northern Ireland) 2016.

[23] I consider the relevant provisions of this Act in later empirical chapters, where I also offer critique of specific provisions. See Chapter 5, 5.3.1. for overview of relevant legal provisions.

spirit of reducing compulsion and increasing choice in mental healthcare. Recognising the problem of rising detentions rates and the complexity created by the two legal frameworks, the Wessely Review (2018) rejected the fusion law proposals and instead suggested strengthening the safeguards: choice and autonomy, least restriction, therapeutic benefit and treating the person as an individual. The Government, in its White Paper (Department of Health and Social Care 2021a), affirmed its commitment to those principles. The most relevant proposals for the purposes of this thesis are included under the choice and autonomy principles of which the Review spoke in the following way:

> If there is one theme that runs through this Review, it is to ensure that the voice of the patient is heard louder and more distinctly and that it carries more weight than has been the case in the past. We intend that even when deprived of their liberty, patients will have a more significant say in decisions, including decisions about how they are treated. We also want to make it harder to have those decisions overruled.
>
> We want to do this for several reasons. First, because it is the right thing to do. Even when someone has been detained, they should still be able to have their choices, wishes and preferences respected more than they currently are. Secondly, because as we said in the interim report, the greater the say a person has in as many aspects of their care and treatment as possible, the better the outcome for that person. So, our principal objective in this Review is to increase the number of ways the patient's voice is heard recorded and considered, and that patients are treated with the dignity and respect that all individuals are entitled to. (Wessely Review 2018, 69).

In the spirit of this new principle, the Wessely Review (2018) considered advance decision-making in the context of mental health, which I discuss in the following section, but also contribute to in Chapter 7. In addition, this thesis contributes an understanding on how various potential legal provisions may be experienced by people in practice.

### 1.5.2. Tracing the contours of advance consent in English law

The developments at common law in relation to advance decisions can be traced back to a range of key decisions on the right of individuals to refuse treatment. The case of *Bland*,[24] reiterating principles set in *Re T*,[25] confirmed that individuals could refuse treatment in advance if the decision was conveyed with sufficient clarity. Both judgments were later applied in *Re C*[26] and further clarified in *Re JT*[27] and in *Re MB*.[28] However, the two crucial cases which refined the common law position on advance refusals are *Re AK*[29] and *HE*.[30] In *Re AK*, Hughes J stated that:

> an advance indication of the wishes of a patient of full capacity and sound mind is effective, but care must be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient.

In the case of *HE*, the High Court considered a refusal of life-sustaining treatment. While she was a Jehovah's Witness, *HE* made an advance decision to refuse a blood transfusion, but as her family contended that she had reverted to Islam, the Court ruled in favour of administering treatment and invalidating the advance decision. Most notably, Munby J offered a clear judgment asserting the common law on advance decisions:

> Some propositions are, in my judgment, now so well established in our law as no longer to require either justification or elaborate citation of authority … a competent adult patient's anticipatory refusal of consent (a so-called 'advance directive' or 'living will') remains binding and effective notwithstanding that the patient has subsequently become and remains incompetent.[31]

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[24] *Airedale NHS Trust v Bland* [1993] 1 ALL ER 821 (HL)

[25] *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 ALL ER 649 (CA)

[26] *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 W.L.R. 290

[27] *Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48 (CA)

[28] *Re MB (Adult: Medical Treatment)* [1997] 2 FLR 426 (CA)

[29] *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129 (FAM)

[30] *HE v A Hospital NHS Trust* [2003] 2 FLR 408

[31] *HE v A Hospital NHS Trust* [2003] 2 FLR 408, 19 (Munby J)

The existence of common law advance refusals was unquestionable. Advance Decisions to Refuse Treatment (ADRTs) were put on a statutory footing by the MCA 2005, allowing persons aged 18 and over to make advance refusals which are subject to stringent validity and applicability criteria.[32] The effect of a valid and applicable ADRT is the same as if the treatment was refused by a person with capacity. Therefore, ADRTs act as a contemporaneous refusal at a material time. ADRTs are thus a way of displacing best interests assessment for situations of future incapacity. ADRTs were designed with a patient in mind who wishes to refuse treatment for physical ailments or a treatment that is life-sustaining (Exworthy 2004). Although a person could make an ADRT for the treatment of their mental disorder, in this context that would not carry the same legal enforceability. Under sections 58 and 63 of the MHA 1983, the treatment can be provided notwithstanding a valid and capacitous refusal, and so an ADRT would not be valid in this context. At best, a mental health professional might wish to consider such a directive when choosing treatment for their patient under ss 58 and 63. Exworthy (2004, 129) criticised the development of statutory ADRTs for not giving consideration to psychiatric advance decisions, describing this as "an opportunity missed".

Recognising ADRTs first in common law and then in the statute suggests a shift from welfare concerns and medical paternalism to autonomy (Weller 2013, 79). The triumph of human rights and autonomy rationales permeated the law on informed consent too (see Whiteman 2013; Weller 2013, 80). In the case of *Chester v Afshar*,[33] which considered non-disclosure of risks of paralysis relevant to the facts at hand, Lord Steyn quoted directly from Dworkin (1993):

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[32] See Ruch Keene (2020) for overview on the legislative history re ADRTs, in particular page 2. See Chapter 6.4.1. on discussion in relation to ADRTs and the meaning of 'doing something inconsistent'.

[33] *Chester v Afshar* [2005] 1 AC 134

> The most plausible [account] emphasises the integrity rather than the welfare of the choosing agent … the value of autonomy, recognising an individual right of autonomy makes self-creation possible.[34]

Finally, the growing recognition of autonomy was tested in the case of *Burke*.[35] Mr Burke made an advance decision to request the continual provision of clinical artificial nutrition and hydration, a treatment he was expected to need at some point in the future due to his medical condition. Mr Burke argued that the General Medical Council's Guidelines which allowed for withdrawal of clinically assisted nutrition and hydration on medical grounds were in direct contradiction to his rights protected under the European Convention on Human Rights (ECHR). In his judgment drawing on common law, human rights and the principle of autonomy, Munby J held that:

> The personal autonomy which is protected by Article 8 embraces such matters as how one chooses to pass the closing days and moments of one's life and how one manages own death.[36]

Therefore, the Court held that at least some aspects of the General Medical Council's Guidelines, which favoured medical paternalism over patient autonomy, were invalid. Nonetheless, this view was rejected in the Court of Appeal, finding the guidelines valid and within the law, emphasising the right to refuse treatment but no right to demand it, suggesting that preferences for treatment or demands for treatment do not carry the same legal enforceability.[37]

Pattinson (2015) criticises the decision in *Burke* for failing to recognise advance requests for treatment in favour of upholding medical paternalism rather than the principle of

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[34] *Chester v Afshar* [2005] 1 AC 134, 18 (Lord Steyn)

[35] *R (Burke) v General Medical Council* [2005] EWCA Civ 1003

[36] *R (Burke) v General Medical Council* [2005] EWCA Civ 1003, 62 (Munby J)

[37] *R (on the application of Oliver Leslie Burke) v The General Medical Council* [2006] QB 273, 31 (Lord Phillips).

autonomy. The decision clearly tested the limits of autonomy that the courts are willing to accept. Others like Whiteman (2013) and Weller (2013) have instead interpreted the judgment as a clear rejection of the patient's positive right to choose treatment. However, it could be argued that the decision in *Burke* does not explicitly prohibit advance consent as conceived in this thesis. In this thesis, it is accepted that advance consent would be limited to treatment previously experienced by a psychiatric survivor, thus taking into account the limitation to choice in this context, which is different to an advance directive made by Mr Burke in anticipation of treatment he had no prior experience of. Moreover, considering the emphasis on autonomy over welfare in courts, the consideration of autonomy principles in policymaking (Wessely Review 18, Department of Health and Social Care 2021a), and in light of the law allowing for coercive non-consensual treatment for mental disorders, it appears difficult to make an argument against the recognition of autonomy expressed in an advance consent to mental health treatment over preference for non-consensual interventions. The provision of non-consensual treatment under mental health law which allows doctors to override competent refusals is a caveat that has not been considered in *Burke* or any other case law in this context.

The issue of advance consent was raised by the Law Commission (2017). Here, the Law Commission (2017) proposed an introduction of statutory advance consent to confinement which would otherwise amount to a deprivation of liberty. This, of course, is quite different to advance consent to a specific treatment. However, it nonetheless concerns the principle of positive anticipatory decision-making, and the difference is well articled by the Law Commission (2017, para 15.3):

> Advance consent, in this context, refers to the ability of a person to consent in advance to specific care or treatment arrangements that would otherwise amount to a deprivation of liberty. This would mean that the subjective element of deprivation of liberty (that a person has not validly consented to the confinement

> in question) would not be present and Article 5 would therefore not be engaged.[38]

In considering the Law Commission's proposals, the Joint Committee on Human Rights (2018, paras 56–58) acknowledged that appropriately safeguarded, advance consent to confinement could offer people greater autonomy, choice and control over their lives. Responding on behalf of the Government, Lord O'Shaughnessy noted that, while he recognised the praiseworthy aims of the Law Commission in proposing this approach, the Government was concerned about the provision or lack of sufficient safeguards in the Law Commission proposals.[39] Lacking evidence in the English context, Baroness Finlay drew on evidence from Canada (Ontario) which showed that people's knowledge and awareness of advance care planning was very poor. She was not in favour of the proposal. Among her concerns, she contended that advance consent is restricting, especially in light of developing technologies, treatments and medicine, more generally, leaving people less empowered.[40] Consequently, no advance consent of this nature has been included in the Mental Capacity (Amendment) Bill. It is, therefore, perhaps, surprising that advance consent to confinement has been included in the Draft Mental Capacity Code of Practice (Department of Health and Social Care 2022a), raising questions about the enforceability of such an instrument without clear statutory provisions. However, advance statements have arguably found their way into practice in a similar vein. The Richardson Report (1999, paras 17–18) advocated for the use of non-legally binding advance statements to enable patients to express their treatment wishes, recommending that advance statements should be considered every time a decision is made on behalf of an individual. Advance statements were not included in the resulting MHA 2007 but have instead

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[38] For discussion relevant to Article 5 issues see paras 2.27-2.28 in Law Commission (2017). It remains unclear whether Article 5 allows for advance consent that would amount to deprivation of liberty and undoubtedly warrant further doctrinal examination, which for now remains outside of the scope of this thesis.

[39] *Hansard*, HL Deb. vol 793, col 736. 22 October 2018.

[40] *Hansard*, HL Deb. vol 793, col 736. 22 October 2018.

been included in the Mental Health Act Code of Practice in 2008 (Department of Health and Social Care 2008 reviewed in 2015, paras 9.3.-9.5.).

Following the Law Commission's (2017) proposals, the Wessely Review (2018, 81-84) again considered advance consent to confinement. Here, the reviewers were not able to make firm recommendations due to the lack of consensus on the issue which is riven by worries about safeguards. I will explore this in more detail in Chapter 7, however, it is worth noting here that advance consent to confinement as conceived of in the Review would result in people automatically opting out of safeguards available to involuntary patients under the MHA 1983 or those available under the Deprivation of Liberty Safeguards. The Government, following its consultation on this issue, highlighted in its response the prevalence of worries around safeguards among the consultees (Department of Health and Social Care 2021b).

What is significant, however, about the inclusion of advance consent to confinement in policymaking is that its challenge lies in the provision of appropriate safeguards rather than on the validity of advance consent as a legal concept. Tracing the legal bases on which this assertion exists is not an easy task, as they are not explicitly referred to in policy documents. The Wessely Review (2018, 82) by reference to Lord O'Shaughnessy's statement, noted that advance consent exists in the context of palliative care even though there is not any explicit statutory basis for this. Similarly, Exworthy (2004, 141) states that it is generally accepted that advance consent is given before surgery, and this survives the incapacity caused by general anaesthesia. Accordingly, in this sense, it is recognised that advance consent is valid even though it is not possible to anticipate all circumstances surrounding the surgery (Exworthy 2004, 141). The Government's line of analysis was related to advance consent in this context, but it primarily followed the recognition of advance refusals at common law and the appreciation of some forms of precedent autonomy. Consequently, if the law based on the principle of precedent autonomy (as stressed out in *Chester v Afshar*[41] discussed previously) recognises the right to refuse treatment in advance, it may also recognise advance consent as a right.[42] Although, following this line of argument appears to support advance consent to a specific treatment more so than to confinement.[43] Recognising advance consent as a legally valid principle, the Government in its response to the consultation (Department of Health and Social Care 2021b) asserted that it continues to explore the place of advance consent in English law, however, the Draft Mental Health Bill (Department of Health and Social Care 2022b) does not include provisions for advance consent.

Instead, the Review proposed putting the Advance Choice Document (ACD) on a statutory footing. The ACD would provide valuable information on the person's treatment preferences and other important aspects related to the individual's broadly understood welfare.[44] Although, the Government committed to introducing ACDs in its White Paper (Department of Health and Social Care 2021a), the Draft Mental Health Bill (Department of Health and Social Care 2022b) does not include provisions for those and instead focuses on doctor-created care and treatment plans.

Tracing the contours of advance consent in English law suggests that there is a growing appetite for exploration of advance consent, making this thesis a timely pursuit. The empirical research in this area is therefore vital for informing future policy developments, and it is important to move beyond the doctrinal analysis to understand the meaning of advance consent in the everyday experiences of those receiving mental health treatment.

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[41] *Chester v Afshar* [2005] 1 AC 134

[42] This line of analysis adopted by the government was confirmed in personal communication with Alex Ruck Keene who served as a legal adviser on the Wessely Review (2018).

[43] It is worth noting that advance consent to specific mental health treatment, albeit only to electro-convulsive therapy and neurosurgery was discussed, an agreement on this issue could be reached (Wessely Review 2019).

[44] See Chapter 7, section 7.4. where I discuss this proposal in more detail.

### 1.5.3. Advance consent and scholarly debate: in search of legitimacy

As discussed earlier in this chapter, advance consent to mental health treatment (and advance decisions generally) has been subject to a scholarly debate since the 1980s (e.g. Dresser 1982; Howell, Diamond and Wikler 1982; Szasz 1982) across law (e.g. Dresser 1982; Bielby 2014), bioethics (e.g. Buchanan 1988) and philosophy of psychiatry (e.g. Radden 1994; 1996); and eventually found its way into research in psychiatric clinical settings (e.g. Henderson et al. 2004; Swanson et al. 2003; 2006; 2008; Wilder et al. 2013; Ruchlewska et al. 2016). Whereas empirical clinical studies have focused on legitimising psychiatric advance decisions on the basis of their clinical benefits, for instance, improving experiences of a mental health crisis (Henderson et al. 2004; Ruchlewska et al. 2016), reducing the need for the use of coercion (e.g. Swanson et al. 2006; 2008) and greater compliance with treatment (e.g. Wilder et al. 2010), scholars across law, bioethics and philosophy have been more concerned with arguments for or against the ethical and legal legitimacy of advance consent.

The notion of autonomy, which Callahan (2003, 288) finds to be the most cited principle in bioethics, has been applied widely to the idea of advance consent and advance decisions more generally. There are, however, a number of different conceptions which have been used. In the previous section, I showed how Lord Steyn, in his judgment,[45] quotes directly from Dworkin's (1993) work on precedent autonomy, which has been used to legitimise the idea of anticipatory healthcare decisions (Davis 2002: 2009b). In simple terms, the notion of precedent autonomy recognises the right of an individual who has the mental capacity to make decisions for a time when they lack capacity. Indeed, the presence of precedent autonomy can

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[45] *Chester v Afshar* [2005] 1 AC 134

be observed in common law as early as in the case of *Bland*, where Butler-Sloss LJ has already contended that: “the right to reject treatment extends to deciding not to accept treatment in the future by way of advance directive”.[46] In her key article on Ulysses Contracts in psychiatry, Dresser (1982, 836) argues that to accept the idea of advance consent is to accept that one set of wishes expressed by a person (earlier wishes) is better than a subsequent set of wishes (later wishes), which she finds to be legally challenging and as such proposes that advance consent could only exist if treatment specified in advance consent followed a determination of one’s incapacity:

> If there is no such determination of legal incompetence at the time of confinement and treatment, then the paternalistic implications of the contract proposal become more stark: the state is deciding that a past decision is ‘‘better’’ than a present decision of equal legal competence and should be enforced even over the individual’s strenuous objection (Dresser 1982, 836).

Davis (2002; 2009b) develops the notion of precedent autonomy, primarily in the context of dementia, and argues that it is possible to privilege the earlier wishes of a person when a subsequent condition, like dementia, prevents them from reflecting on their earlier and later wishes. He also takes the notion of extension view, associated with John Stuart Mill (1986), to argue that individuals hold authority and autonomy over their current affairs as much as they do over their future affairs, which provides an argument for self-binding directives (Davis 2009a).

However, Davis (2002; 2009a; 2009b), alongside other scholars such as Saks (2002), Spellecy (2003) and Bielby (2014), points to the futility of such conceptions of autonomy, and precedent autonomy in particular, due to their reliance on the notion of capacity or competence. Saks (2002) argues that such conceptions do not capture the nuances of mental illness, where advance consent would be most beneficial before a determination of incapacity occurs and

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[46] *Airedale NHS Trust v Bland* [1993] 1 ALL ER 821, 816 (Butler-Sloss LJ).

before the need for confinement arises. In a similar vein, Bielby (2014, 117) focuses on what he calls a competence-insensitive Ulysses Arrangement, which is an advance directive that precludes capacitous "changes of mind on the authority of the patient's own prior agreement". This represents what Radden (1994, 791) refers to as "hard case" specific and likely to occur in a psychiatric context but ignored by a heavy focus on the notion of capacity in precedent autonomy arguments. Bielby (2014, 121) and Saks (2002, 203) suggest that the conception of autonomy adopted by Feinberg (1986) might be more useful in legitimising psychiatric advance consent, which operates outside of capacity frameworks. Feinberg (1986, 83) privileges the earlier choice over the later choice on the basis that "the earlier choice being the genuine choice of a sovereign being, free to dispose of his own lot in the future, must continue to govern". According to Bielby (2014, 121), this conception allows one to make an autonomy-based argument for respecting the earlier wishes in an advance consent which precludes changes of mind. Nonetheless, others like Srebnik and Kim (2006, 506) are clear in their formulation that someone with mental capacity should always be able to revoke advance consent. Ultimately, the permissibility of advance consent on those accounts will always depend on one's ethical and legal stance in relation to concepts like autonomy or capacity. However, it is clear that the notions of autonomy on which these arguments hinge conceptualise it as connected to authenticity rather than autonomy understood as sovereignty (Atkinson 2007, 88).

Many scholars, like Dresser (1995), Maclean (2006) and Wrigley (2007), find autonomy arguments to be insufficient in legitimising a legally binding advance decision, particularly when a significant amount of time passes between the making of an advance directive and when it comes into effect. Maclean (2006, 298) proposed that such conceptions of autonomy in relation to advance decisions lend themselves to the problem of personhood:

"if advance directives are predicted on the basis of personal autonomy, then their authority only applies to an individual if he or she is the same moral entity that created the directive", posing a challenge to the legitimacy of advance decisions. Theories of personhood allow us to distinguish between mere biological organisms and those organisms that have certain rights, thus enjoying personhood (Hayes 2015, 94). Wrigley (2007, 386), applying the animalistic version of personhood, argues that, as long as a person remains the same biologically, then this justifies the creation of an advance decision which is made by and for the same person. Hayes (2015, 95) argues that such a conception cannot be accepted by the law because its implication could mean that a deceased body would hold the same rights as a living body if the two remained the same biological entity.

Parfit's (1987) theory of psychological personhood has been cited and adapted much more readily in relation to personhood and advance decisions (e.g., Savulescu and Dickenson 1998; Holm 2001; Atkinson 2007; Hayes 2015). For Parfit (1987, 266–270) personhood is psychologically derived and exists in the continuity of the degree of psychological connectedness within a person at different points in time, and this connectedness results in the person remaining the same, despite some changes, for as long as the connectedness is preserved. However, such applications and theories often exist on an abstract level. Thus, Hayes (2015, 100) suggests that lawmakers should have greater regard for the practical implications of the ways in which they legislate for advance decisions. This is particularly important for making progress in moving away from abstract thinking to putting policies into practice. Outside of conceptualisations of autonomy and personhood, other accounts have attempted to argue for the legitimacy of advance consent based on theories of practical reason (e.g. Spellecy 2003), complex conceptualisations of rationality (e.g. Nozick 1993; Atkinson 2007) or obligations and responsibilities (e.g. Brock 1998).

However, practical considerations are also present throughout the literature. Buchanan (1988, 279) argues that even a well-informed advance decision will be ill-informed compared to a contemporaneous decision. This is because the contemporaneous decision will have a full appreciation of current medical and therapeutic developments, which may have been unavailable at the time of making an advance decision. Consequently, this is linked to the fact that the decision-maker could not fully appreciate the conditions and circumstances in which the advance decision would be implemented, thus weakening its legitimacy. Finally, Buchanan (1988, 279) argues that contemporaneous decisions benefit from an informal safeguard of consulting about the decision with people who are important to an individual, like their family. Similarly, Dresser (1995, 33) contends that advance decisions are ill-informed in comparison to contemporaneous decisions because the creator does not have all the relevant information at the time of making an advance decision. Dresser and Robertson (1989) also maintain that, instead of relying on advance decisions, the medical best interest should prevail when dealing with an individual unable to make decisions for themselves.

However, others, like Clausen (2014), emphasise that medical and therapeutic developments have been slow in this area, suggesting that Buchanan's (1988) critique is less applicable to psychiatric advance decisions. Indeed, one might wish to work into one's decision that such developments would invalidate an advance consent. Clausen (2014) also suggests that psychiatric advance consent could be safeguarded by adopting a requirement for frequent reviews and limiting treatment requests to those previously experienced to ensure that a person is as familiar with the conditions and circumstances of receiving treatment as possible.

Moving away from conceptions of autonomy concerned with the authenticity of wishes, and the problem of personhood, Gremmen et al. (2008) propose that understandings from ethics of care, vulnerability and relationality might offer a better, more practical framework for thinking about psychiatric advance decisions. Gremmen et al. (2008) argue that autonomy can be realised with the assistance of others, especially when a person's vulnerability is raised beyond everyday levels due to their mental ill-health. Relationality also considers the wider context of the person's life, which provides a broader framework for justifying the use of advance consent. For Bielby (2014, 124), relationality means that the hard-line distinction between autonomy and paternalism is no longer antagonistic (see also Moody 1988). Instead, an agent is someone who remains autonomous regardless of the amount of support that they receive. However, Bielby (2014, 124), drawing on the work of Gewirth (1996, 117), suggests that notions of individual autonomy may also have relational understandings: "rational autonomy, far from being self-centred, incorporates [...] interconnectedness and concern for others" and recognises that individuals make decisions in the context of their social worlds. This appreciation of relational interests in a conception of autonomy has led to Bielby (2014, 135–136) proposing two models of competence-insensitive Ulysses Arrangements which also give a varying degree of legal authority to another trusted person who can support the premise and the implementation of this instrument in practice. Therefore, Bielby (2014) suggests that giving others a role may act as an important safeguard for translating psychiatric advance decisions from theory to practice.

Finally, advance decisions in mental health contexts have been framed through rights-based approaches. For instance, Weller (2013) has considered mental health advance directives in light of current human right debates, pertaining in particular to the UN CRPD, and argues that this new era of human rights enables the framing of mental health advance decisions as an example of supported decision-making necessary for the protection and realisation of people's human rights (see also Gooding 2017). Stavert (2013), drawing on the principle of autonomy in medical ethics, the rights under Articles 8 and 5 of the European Convention on Human

Rights and the rights contained in the UN CRPD, suggests that it might be time to seriously consider psychiatric advance decisions as a mechanism for realising important human rights.

My thesis contributes to these scholarly debates in several ways. Firstly, I offer a new framework for conceptualising advance consent: a capabilities approach. This is the first study to propose this approach as a framework for advance consent in mental health contexts, providing a social justice argument. Doing so enables me to move away from dominating approaches of narrow conceptualisations of autonomy or personhood and consider advance consent in a more practical and holistic way, highlighting its more practical and everyday life benefits. I argue that agency freedom, which I set out in Chapter 2, is a higher-level capability, requiring one to think of advance consent in terms of autonomy as sovereignty and offering a certain freedom to pursue a version of treatment that one is willing to accept. Additionally, I adopt relational understandings of agency but argue that relational understandings exist on a micro, meso and macro scale and are not limited to interpersonal networks. Moreover, as this thesis argues for advance consent which is invoked at a time specified by an individual rather than on incapacity, I contribute to the scholarly debate by offering empirical insights into the changes of mind dilemma and consider whether advance consent which precludes changes of mind can constitute coercion in itself, taking into account appropriateness and the role of mental capacity in this context and the desirability of giving a role to a nominated trusted person in one’s advance consent. Thus, the thesis builds on existing knowledge to provide empirically guided insights informed by a new theoretical framework brought to the issue of advance consent.

### 1.5.4. The relevance of human rights law

Throughout this introductory chapter, I alluded to the relevance of human rights when thinking about the rights of psychiatric survivors.[47] Advance consent to mental health treatment as a type of advance decision-making is a measure that enhances patient autonomy, and patient autonomy finds its support and expression in numerous international instruments (Stavert 2013). Undoubtedly, governments and scholars concerned with the implementation and legal validity of advance consent to mental health treatment ought to pay attention to human rights standards to create a robust legal framework for advance consent. As discussed throughout this Chapter, advance consent emerged in the US, first in scholarship and later in formal recognition of mental health directives across various states in the US (e.g. Gruskin 2005; Atkinson 2007). Gruskin et al. (2005) point out that the formal recognition and implementation of mental health directives in the US have coincided with the legal recognition of the right to health enshrined in Article 12 of the International Covenant on Economic, Social and Cultural Rights[48] and argues that both, the formal recognition of the right to health and mental health advance directives are a direct result of the health and human rights movement. Consequently, it has been argued that psychiatric advance decisions have been regarded as human rights tools for some time (Gruskin et al. 2005).

Underpinning the right to health is the principle of informed consent (Article 25(d)) which also forms a crucial aspect for thinking about advance consent (see, e.g. Howell, Diamond and Winkler 1982; Szasz 1982; Dresser 1982; Bielby 2014). Whereas critics like Dresser (1982) suggest that advance consent cannot be considered informed because people cannot foresee how they will behave and feel at a material time (when advance consent is supposed to apply),

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[47] See section 1.5.1 and 1.5.3. of this chapter, in particular pp. 28-29; and section 1.5.3., in particular pp. 38-39.

[48] International Covenant on Economic, Social and Cultural Rights, (adopted opened for 16 December 1966, entered into force 3 January 1976) 999 UNTS 3

proponents suggest that advance consent is limited to previously experienced treatment promoted informed consent and extends beyond what is needed in medical ethics to obtain it (e.g. Howell, Diamond and Winkler 1982; Bielby 2014). Analysing the extent to which consent ought to be informed to satisfy the requirements underpinning the right to health will be an important aspect of conducting a human rights analysis on the compatibility of advance consent with the International Covenant on Economic, Social and Cultural rights.[49]

Another human rights framework relevant specifically to advance consent in the English context is the European Convention on Human Rights, incorporated into the national law through the Human Rights Act 1998. Exworthy (2005), Richardson (2011) and Weller (2013) credit the development of advance decisions to refuse treatment in English law to the Richardson Report's attunement to human rights arguments. Following the cases in the European Court on Human Rights (ECtHR), like the case of *Herczegfalvy v Austria*, which recognised that people who struggle with severe mental illness are particularly vulnerable to human rights abuses and, as such, the human rights considerations should be at the forefront of the minds of those responsible for psychiatric interventions[50] or *Pretty v UK*[51] which stated that medical treatment might fall within the prohibition of Article 3, played important parts in arguing for legal recognition of advance refusals in England and Wales (Richardson 2011; Weller 2013).

However, the process of recognising human rights in the development of mental health advance decisions has proven challenging and largely an issue for the European Court on Human Rights (ECtHR) to decide in the future (e.g. Szmukler 2006; Richardson 2011; Weller 2013; Stavert 2013). This may be particularly true for advance consent to mental health

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[49] See Chapter 5 for my empirical and theoretical contributions to the notion of informed consent.

[50] *Herczegfalvy v Austria* (1992) 15 EHRR 437 [82]

[51] *Pretty v UK* [2002] ECHR 427

treatment which has not yet been debated equally to advance refusals in light of these human rights standards and especially following the judgment in *Burke*[52], where an argument for advance consent to treatment in light of Convention rights, was ultimately rejected in favour of longstanding principles in English medical law.

In particular, the question surrounding Article 5 rights to liberty, security and freedom from unreasonable detention appears to be a thorny one when thinking about advance consent. In previous sections,[53] I noted that the Joint Committee on Human Rights (2018) recognised advance consent as a legally valid principle. In contrast, when considering a specific type of advance consent, such as advance consent to confinement, the Joint Committee on Human Rights (2018) and the Wessely Review (2018) raised questions surrounding its compatibility with Article 5. Similarly, any attempts to implement advance consent to mental health treatment might be met with a similar challenge, especially in light of notable cases regarding depravation of liberty, such as the case of *HL*[54] or *Stanev*[55] which are both important cases to consider in creating a human rights-based framework for advance consent. In this case, Mr Stanev had been diagnosed with schizophrenia in 1970s; a diagnosis which was not supported by the relevant symptoms, and which was later considered to be incorrect. Despite this, Mr Stanev was placed under guardianship and transferred without prior consultation to a social care facility. The ECtHR decided that Mr Stanev was deprived of his liberty, and the reasoning was akin to the one in *HL*[56], further reiterating the conditions required for the deprivation of liberty not amount to the breach of Article 5 rights:

> [a]s regards the deprivation of liberty of mentally disordered persons, an individual cannot be deprived of his liberty as being of 'unsound mind' unless the following three minimum conditions are satisfied: firstly, he must reliably be shown to be of unsound

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[52] See section 1.5.2. for discussion on *R (Burke) v General Medical Council* [2005] EWCA Civ 103

[53] See sections 1.5.1 and 1.5.2. of this Chapter.

[54] *HL v United Kingdom* (2004) EHRR 761, see discussion in section 1.5.1 from page 38

[55] *Stanev v Bulgaria* [2012] ECHR 49

[56] *HL v United Kingdom* (2004) EHRR 761, see discussion in section 1.5.1 from page 38

> mind; secondly, the mental disorder must be of a kind or degree warranting compulsory confinement; thirdly, the validity of continued confinement depends upon the persistence of such a disorder.[57]

Considering the position of the ECtHR on the issue of deprivation of liberty, it is unsurprising that the policymakers were concerned about advance consent to confinement, which included opting out of safeguards available to those involuntarily detained under the MHA 1983. A similar challenge may arise in relation to advance consent to mental health treatment. For instance, when thinking about implementing advance consent as irrevocable at a material time despite an individual's changes of mind might raise questions pertinent to Article 5, Article 3 (prohibition of torture, inhuman or degrading treatment) or Article 8 (respect for family and private life). This might be especially true when some level of "force" will be required to implement advance consent in those circumstances.

Despite those clear challenges, Stavert (2013) argues that advance directives could be developed in line with the underlying principles of the ECHR and with the utmost respect for the Convention's rights. However, Stavert (2013, 233) admits that "greater guidance and direction from Strasbourg would be helpful" in this context. Therefore, for now, the questions of advance consent's compatibility with the Convention rights remain open. However, as Stavert (2013) argues, the ECtHR, at the very least, is clear that appropriate safeguards must be put in place when the possibility of coercion arises. Thus, the ECHR might be an important starting point for clinicians when implementing advance consent to ensure that Article 3 and Article 5 rights are not violated.

A clearer human rights framework for analysing advance consent to mental health treatment and for providing robust human rights arguments in favour of such a measure can be found in

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[57] *Stanev v Bulgaria* [2012] ECHR 49 [145], see also analysis in Series (2022)

the CRPD. Previously, in this chapter, I argued that the CRPD led to a global and more concrete revival of the debate about advance consent in mental health and advance decisions more broadly because of the principle of legal capacity, equality and supported decision-making contained in Article 12.[58] In an attempt to strike a fair balance between autonomy and protection of those who are considered more vulnerable in everyday life, the Convention places a particular emphasis on the diversity among humans, on the equality of legal capacity and thus on human rights being tools for the protection of one's wishes and preferences. This balance aims to protect people with disabilities from compromising their bodily and mental integrity (Article 17) whilst emphasising the need for empowering individuals to exercise choice and self-determination. Weller (2013) notes that this is comparable to how the right to health adopts a similar approach of respect for individuals' wishes through the principle of informed consent.

Stavert (2013; 2022), Weller (2013), Farrell et al. (2017) and Gooding (2017) are among the scholars who argue that mental health advance directives are capable of giving effect to the principles and the rights contained in the CRPD because they provide a tangible measure for recording one's wishes and preferences. Indeed, Weller (2013, 84) refers to them as a "ready-made method" for implementing the CRPD and formalising supported decision-making promoted by Article 12. However, most notably, the CRPD Committee (2014, [17]) itself has expressly recognised the value of advance decisions:

> For many persons with disabilities, the ability to plan in advance is an important form of support (…). All persons with disabilities have the right to engage in advance planning and should be given an opportunity to do so on an equal basis with others.

Gooding (2017, 181) has argued that advance decision-making might be a way of achieving a rights-based framework and some level of CRPD compliance "notwithstanding the

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[58] See section 1.2.3 of in particular pp 28-30 and section 1.5.1. pp. 38

incongruence of mental health law (at least in its current form) and the CRPD." However, most frameworks for mental health advance decisions are based on legislation which retains mental capacity as a threshold requirement for a valid advance decision and can be overridden by compulsory treatment ever so present across mental health legislation.[59] Both of these aspects are true for English law, as already discussed elsewhere.[60] Nonetheless, the CRPD and the corpus of associated general comments and concluding observations provides for a clear human rights basis for implementing psychiatric advance decisions. Overall, scholars (Stavert 2013; Weller 2013; Gooding 2017) have considered that advance decisions for mental health provide a mechanism that realises choice, entitlement, and legal capacity and respects human rights when carefully enforced in line with appropriate safeguards. However, as will be discussed in Chapter 6 of this thesis, there are aspects of the CRPD, particularly concerning implementation of advance decisions, that may require further clarification from the committee before one can argue that any version of advance consent is compatible with the CRPD.[61] This is because of the basic yet novel idea behind the CRPD is the recognition that the person whom the decision concerns is indeed best placed to choose "the constellation of rights, entitlements and protections that are relevant" in the matters regarding their mental health and mental health treatment (Weller 2013, 24). This means that advance decisions are to be implemented with a high level of flexibility. Still, it is unclear if each design will be Convention-compatible, as I note in Chapter 6.

It is clear that the relevance of human rights in creating a robust framework for thinking about and especially for implementing advance consent to mental health treatment cannot be

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[59] See Weller (2013) for analysis of various jurisdictions
[60] See section 1.5.1. of this Chapter. Chapter 5 discusses the relevance of mental capacity framework more broadly
[61] See section 6.3 pp 227-229 for more details

understated. This is especially true as the analysis in this section demonstrates that advance consent and advance decisions more broadly cannot be fully appreciated as human rights tools just yet and indeed, different human rights instruments might have differing approaches to the issue. Although this thesis does not provide a human rights analysis, it makes theoretical arguments that can be seen as complementing and, in places, even going beyond what human rights are capable of offering at this moment. For instance, in Chapter 5, I argue against expanding mental capacity assessments to advance the consent framework, suggesting that mental capacity is a key barrier to achieving social justice, bodily integrity and a type of advance consent envisioned as desirable by psychiatric survivors. In turn, in Chapter 6, I suggest a framework for revoking and invoking advance consent which gives individuals freedom in choosing the ways and circumstances in which advance consent can be invoked and revoked, regardless of their "capacity". There, I suggest that advance consent might improve English mental health law's compliance with the CRPD. A growing corpus of general comments, state parties' concluding observations, judgments of the ECtHR and other international instruments might eventually provide greater clarity on the vision of advance consent which can be regarded as a human rights tool. For now, this thesis is concerned with theoretical contributions which provides a clear conceptual framework for tackling issues related to advance consent. Additionally, the framework underpinned by the capabilities approach might aid future interpretation of human rights standards, especially if, as Stavert (2022) suggests, the capabilities approach is a particularly useful framework for implementing human rights standards into mental health laws.

## 1.6. The ambit of this research

As is clear by now, this thesis focuses exclusively on advance consent to mental health treatment rather than on advance refusals, or both. Much of the debate, and especially developments in English law, have focused on advance refusals of treatment. In this thesis, I wanted to devote the space and detail to advance consent to specific mental health treatment, considering the growing interest in the premise of this mechanism, the developments in English policymaking and the need for developing appropriate and timely responses to peoples' mental ill-health. Here, it should also be noted that I choose to focus on advance consent to specific mental health treatment more so than advance consent to confinement, which features heavily in current debates. By focusing particularly on advance consent to specific mental health treatment, I address the gap in recent debates, providing insight on an issue that policymaking has been unable to recommend due to a lack of consensus in the debate. In my consideration of recent policy developments in England, I consider Advance Consent to Confinement and Advance Choice Documents, but examination of other policy developments is beyond the scope of this thesis. I do, however, appreciate the value and importance of advance refusals in the mental health context.

Focusing on the conceptual contributions offered by the capabilities approach, I do not offer human rights analysis relevant to advance consent apart from the introductory discussion in section 1.5.4. Undoubtedly, the human rights approaches carry a significant potential in the development of mental health advance directives, as explored by Weller (2013), Gooding (2017) and Stavert (2013; 2021). Indeed, Stavert (2022) has offered a compelling suggestion that the capabilities approach offers a new way of thinking about human rights in the context of mental health. My decision not to pursue the human rights approach was motivated by my aim of developing a new theoretical framework for thinking about advance consent in broader terms that extend beyond human rights developments as previously explained.

A final note that I want to offer regarding the remit of this thesis is that this research is data-driven rather than being complemented by the data (where data serves as a support for pre-existing arguments). This means that, while I am able to explore certain aspects of advance consent in depth within the bounds of this research, other aspects, particularly in relation to implementation, remain more open and invite further study. Nonetheless, this approach has allowed me to unearth unexpected findings which enrich the existing debate, like the relevance of the clinical concept of insight when thinking about advance consent which I discuss in Chapter 5.

## 1.7. Overview of the thesis

I begin answering my research questions in Chapter 2, where I set out the theoretical framework – namely, the capabilities framework for social justice in mental health, which is a novel way of thinking about advance consent. The aim of this chapter is to introduce and explain the capabilities approach, its previous applications, and relevant critiques. It then moves on to setting out how and why the approach will be applied throughout the thesis. I argue that social justice in mental health contexts is a relational experience, underpinned by a strong commitment to human diversity. I lay out the relevant capabilities which I use in this thesis – bodily integrity, health, emotions and safety – and I argue that agency freedom – a higher level capability – is an integral part of advance consent. I then offer the discussion of relevant critiques of this approach.

In Chapter 3, I set out the methodological approach developed for this thesis and the methods chosen to carry out the empirical research in which this thesis is foregrounded. In doing so, I demonstrate how I developed a methodological approach which I call ‘a feminist material-narrative methodological approach’ to the study of mental health law and lived experiences of mental health treatment. The approach was broadly inspired and developed by drawing on the work of narrative and feminist approach of Ward (2009; 2012) and the photo-elicitation approach developed by Erdner and Magnusson (2010). I also explain and offer the rationale for the methods chosen: namely narrative interviews and follow-up photo-elicitation interviews. I discuss their value and usefulness but also their limitations in uncovering aspects that are invisible to law and in understanding lived experiences of mental health treatment. I explain the practicalities of carrying out this research and the ethical issues that arose during this project, followed by reflexive remarks that conclude the chapter. Throughout this chapter, I offer a rationale for all methodological decisions which I have taken.

Chapter 4 is the first chapter in which I examine my empirical data. This chapter is a meta-narrative of heterogeneous lived experiences that tells a story about how psychiatric survivors experience injustice in their everyday lives, highlighting that mental health treatment is a part of that daily reality rather than being abstracted from it. Here, a meta-narrative should be understood as an overarching interpretation of people’s stories associated with their mental health and is based on the narrative analysis of turning points by drawing on the methodological work of Ward (2009; 2012), Czarniawska (2004) and Strauss (1959), explained in Chapter 3. It paints an overall picture of what it means to be a psychiatric survivor and experience treatment and how taking the capabilities approach to those experiences gives them meaning. Using the approach, I argue that psychiatric survivors’ experiences are best understood as three separate but interrelated relationships: 1) a relationship that a psychiatric survivor has with themselves; 2) the relationship between experiences of mental health treatment and professionals who facilitate it; and 3) the relationship between a psychiatric survivor and society. In the first relationship, I argue that the psychiatric survivor tries to preserve their agency freedom by ‘holding off a breakdown’ until this mental health breakdown reaches what I describe as the ‘tipping point’. I suggest that once the tipping point is reached, the most important relationship a person has is with their mental health professional(s). Here, I examine how coercion is ‘actually’ experienced rather than how it is prescribed for in law. I explore how capabilities could be developed by supporting individuals to make more independent treatment decisions. In the third relationship, I suggest that stigma is experienced as structural violence, an example of visible and invisible injustice. This chapter as a meta-narrative naturally informs the remaining chapters.

Using the narrative and capabilities-informed analysis, Chapter 5 interrogates the practical benefits of advance consent and its barriers. I begin this chapter by discussing the relevance of the clinical concept of insight in the shaping of people’s experiences of unfreedom and the challenges it poses for the development of bodily integrity as a capability. The concept permeates the entirety of this chapter. In the following part, I argue that there are three main practical benefits to advance consent which could not only improve experiences of treatment but also support the development of bodily integrity in the context of mental health treatment. These benefits include minimising the need for coercion, provision of a real opportunity for giving informed consent and improving access to and promptness in the provision of treatment. To illustrate how these benefits are secured by advance consent, I interrogate the experiences of formal legal coercion and maintain that insight is used as an extra-legislative criterion for coercion, and I also scrutinise experiences of informed consent to demonstrate the limited opportunities for the provision of and, finally, the accessibility of mental healthcare. Here, I argue that the use of mental capacity assessments for invoking advance consent would undermine the premise and benefits of advance consent. Finally, I set out how insight could become a serious barrier to the provision of empowering advance consent in practice.

Following on from my argument in Chapter 5 that advance consent should not be invoked by incapacity, I explore when advance consent should be invoked instead and whether it should preclude changes of mind at a material time. I begin this chapter by setting out the interrelated and interconnected capabilities for health and emotions which, I argue, are supported when developed with compassion; this serves as a theoretical driver for this chapter in which I ground the forthcoming arguments. I argue that advance consent should come into effect at a material time, specified clearly by each person making an advance consent, in order to maximise its benefits. However, making this argument is indivisible from embarking on one of the most controversial aspects of the advance consent debate: ‘the changes of mind dilemma’. This dilemma refers to a situation where a person who has made an advance consent tries to revoke it at the material time. Here, the controversy stems from scholarly proposals supported in this chapter, suggesting that advance consent should preclude changes of mind at the time it is designed to apply, and this should include capacitous changes of mind (revocations made by people who are in florid stages of mental illness but retain mental capacity as understood within the law). Additionally, critics may argue that advance consent which does not preclude changes of mind might indeed become a forced treatment in provision. Drawing on my participants’ experiences and attitudes toward the changes of mind dilemma, I argue that advance consent should preclude changes of mind and that it would not be coercive because the treatment provided would be consensual. Moreover, this supports capabilities for health and emotions. Additionally, the wishes expressed in an advance consent should be safeguarded by allowing for a legally binding advance consent. Following on from this, I interrogate the possibility of a nominated trusted person framework for mitigating any practical dilemmas arising from this position.

Chapter 7 is the last empirical chapter in this thesis. In this chapter, I explore the overall desirability of advance consent by drawing on my empirical data and recent policy developments. I argue that advance consent to mental health treatment supports the development of a central capability for psychiatric survivors – a capability for safety. I argue that the capability for safety requires a properly safeguarded provision of advance consent to mental health treatment more so than to confinement, as suggested by current policymaking. I explore both the benefits and the limitations of the proposed framework for Advance Choice Documents. This chapter makes an original contribution to the capabilities approach by offering a definition of safety as a capability.

Finally, Chapter 8 brings all these different findings and concepts together to conclude the thesis and explain how I answered the research questions posed. I also provide suggestions for the direction of future legal reform and policymaking. In addition, I discuss the shortcomings of this thesis and how these translate into future research opportunities and I then move on to providing my final, concluding reflections.

## 1.8. Conclusion

It is of fundamental importance that psychiatric survivors are empowered to choose to make decisions regarding their future treatment and care for future situations when they expect not to be able to do so. Therefore, the need for socio-legal and empirical research into the premise and the potential of advance consent is axiomatic. In this thesis, using the capabilities approach, I shed light on how advance consent can meet some of the important needs of psychiatric survivors in order to achieve social justice. In this introductory chapter, I have set out the background in which this thesis exists, research questions and aims which guide this thesis and set out the wider legal and scholarly contexts. I have highlighted the ambit of this research. Finally, I have provided an overview of the thesis, including each chapter’s content and arguments. In the next chapter, I set out the theoretical framework of this thesis.

# CHAPTER 2: THE CAPABILITIES FRAMEWORK FOR SOCIAL JUSTICE IN MENTAL HEALTH LAW

## 2.1. Introduction

In outlining the research context in the previous chapter, I discussed a variety of the most prominent theoretical frameworks in the relevant literature on advance consent like conceptualisations of autonomy or personhood. I argued that these frameworks had been useful in providing normative and ethical arguments in support – or in opposition to – advance consent. In particular, these normative contributions were important in addressing difficult ethical questions such as the changes of mind dilemma (namely, revocation at the material time). However, the majority of these theories tend to exist on an abstract level and are often removed from contending with more practical, everyday considerations which makes them harder to apply to an empirical study. I also argued that these theories do not approach the issue of advance consent holistically, instead they focus on particular normative or more practical questions. Consequently, whether their premise can be recognised will depend on an individual's moral or ethical stance on that particular theory.

Unlike previous theoretical frameworks utilised for similar contexts, the capabilities approach requires a more holistic approach to social justice which focuses on developing and supporting capabilities, agency freedom and wellbeing whilst presenting a strong commitment to human diversity. Thus, this chapter concentrates on setting out the theoretical framework for investigating advance consent's desirability in a broader context of the lived experiences of those receiving mental health treatment. Moreover, the capabilities approach provides a social justice argument for increasing decision-making opportunities that address, to some extent, actual experiences of injustice. Ultimately, I set out a framework which conceptualises the lived experiences in which this thesis is grounded.

I begin this chapter by providing a general overview of the capabilities approach before sketching out relevant applications alongside critiques of this method. In the following part of this chapter, I set out my own capabilities framework for the study of mental health treatment experiences – the 'how' and 'why' of this framework in terms of this thesis. I argue that social justice is best achieved through a commitment to human diversity and is best understood through relevant capabilities. The relevant capabilities I set out in this chapter – and go on to develop in the empirical chapters – are bodily integrity, health, emotions and safety. I offer a rationale for focusing on capabilities rather than functionings which is grounded in my commitment to human diversity and thus social justice. I also maintain that my commitment to social justice is rooted in the choice to prioritise agency freedom which I suggest is a higher-level capability. In that discussion, I set out how this thesis understands individual agency to have relational and wider-structural understandings and explain that agency is, in fact, a background concern which need not be explicit; instead, the value of agency considerations when exploring advance consent is implicit and permeates this context, but ultimately it is the deliberation on capabilities that bridges the gap between theory and everyday life. I also explain what the sources of unfreedom are and why it is material to consider those when thinking about social justice for psychiatric survivors. I then move on to offer my concluding remarks. In that conclusion, I acknowledge that the use of capabilities in this thesis, with a specific focus on treatment experiences in a daily context, provides for a modest but important application. It is modest because it does not take into account the entirety of people's lives but, instead, focuses on their lives in the context of mental health treatment and on improving those experiences. However, it is important because, as a framework, capabilities encourage a strong focus on freedom and on developing opportunities for meaningful decision-making about treatment.

## 2.2. What is the capabilities approach?

### 2.2.1. Definition: the basics

Originating from economics and philosophy, Amartya Sen (1982) proposed an alternative or a counter-theory to thinking about evaluating human development, wellbeing and justice. Although the theory has been developed and refined in a multitude of works by Sen (e.g., 1999; 2002; 2005; 2009), its development must also be credited to Martha Nussbaum's work for her partial theory of social justice (e.g., 1992; 1999; 2000, 2006; 2011; 2020). At the basis of the approach are two main prescriptive claims. The first one is that it is important in the context of morality that people have the freedom to achieve wellbeing and that wellbeing should be understood through the lens of people's capabilities and functionings (Robeyns and Byskov 2021). Capabilities are the real freedoms and opportunities, the doings and beings that people can achieve if they choose to do so – such as being well-nourished, making decisions, and participating in processes. Correspondingly, a functioning is a realised or achieved capability or capabilities. Nussbaum (2011, 25) highlights the normative importance of the freedom to choose which is an intricate part of every capability. Similarly, Sen (1999, 15) argues that a 'capability' without a corresponding choice to select it is not a capability, instead, it might even be experienced as 'unfreedom' when imposed on an individual. Whether it is possible for an individual to convert a set of means and capabilities into functionings is dependent on various socio-economic, cultural, political, environmental, relational and other factors (e.g., Sen 1982, 19–21). Capabilities are real freedoms that must be distinguished from obstacles and sources of unfreedom (Robeyns 2017, 43). Accordingly, this analysis suggests that people are in fact entitled to capabilities (Nussbaum 2011).

Nussbaum (2011, 18), writing about the approach more generally, argues that there are two schools of capabilities thought: the first one is concerned with "comparative quality-of-life assessment" and the second theorises "about basic social justice". Regardless of the school of thought, the essential aspects of the capabilities approach are: taking each person as an end in themselves and evaluating the opportunities available to each individual; focusing on choice or freedom; recognising pluralism about value; being concerned with entrenched social justice and inequality (especially stemming from discrimination or marginalisation); and charging the government and its policies with an urgent need to improve people's lives – and, thus, their capabilities (Nussbaum 2011, 18-19). This distinguishes the capability approach from other normative frameworks, which focus on a singular relevant category like autonomy. However, Robeyns (2009; 2016; 2017) has consistently criticised Nussbaum for taking a narrow reading of the approach. Instead, Robeyns (2017, 60) proposes that treating each person as an end and recognising human diversity are the only essentials needed for all capability theories. From that, the approach adopted can differ significantly between scholars because it is flexible and open. Other scholars, like Qizilbash (2005; 2012), suggest that the capabilities approach is a thin theory which can be supplemented with a thick theory, but may also be applied purely by simply choosing to follow either Sen's broad technique or Nussbaum's narrower method, or, indeed, by a combination of the two. Sen's and Nussbaum's approaches to capabilities differ but need not be seen as in competition with one another but instead can be regarded as complementary, leading to a range of useful applications.

However, there are important distinctions between Sen's and Nussbaum's positions. Sen's (1999; 2005; 2009) capabilities approach is much broader and open-ended, evidenced by his non-commitment to a fixed list of capabilities, even though he admits that such might be developed for various purposes. Indeed, Sen (2009, ix) admits that his approach to justice, in particular, is "very broad". This attitude is also characterised by a markedly strong commitment to notions of freedom, choice and human diversity. He is critical of traditional, abstract and philosophical perceptions of justice[62] which are concerned with understanding what an ideal society would be and what ideal social arrangements would exist in such a society (Sen 2009, 8). Instead, Sen (2009, 8–10) argues that justice is about real people who live in real societies and not abstract, ideal worlds. This means that there is a normative need for moving away from traditional approaches to justice to more practical considerations about what social justice actually entails and whether people are free to do and be what they value. In essence, he suggests that justice is about comparing[63] human lives and investigating how alternatives in various social arrangements allow people to be whom they want to be and live the lives they value. At the same time, justice requires acknowledging, taking responsibility for and repairing injustices, or sources of what Sen (1999; 2009) refers to as unfreedom. Finally, justice for Sen (2009, 402) is a process of public reasoning which requires making decisions about how to classify or rank alternatives that are being considered in a particular context for specific people.

In contrast, Nussbaum (2011) developed a partial theory of social justice which is founded on her critique of other approaches to social justice within the liberal tradition.[64] This theory is based on the ten central capabilities which she holds are "minimum core social entitlements" of all people and include: life; bodily health; bodily integrity; senses; imagination and thought; emotions; practical reason; affiliation (towards others and self-respect for); other species; play; and control over one's political and material environments (Nussbaum 2011, 33–34). Most importantly, in Nussbaum's account (2006; 2011) all of these capabilities are required to meet the minimum threshold level of justice and are deeply rooted in the notion of

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[62] Here, approaches that Sen (2009) mentions are one of Rawls (1988) but also Kantian philosophical traditions.
[63] Some scholars have even referred to Sen's capability approach to justice 'a comparative theory of justice', see (Kukathas 2013).
[64] Most notably she engages with critique of Rawls' (e.g., 1988, 1999, 2009) theory of justice, see Nussbaum (2003; 2006; 2011).

human dignity. Nussbaum (2011, 35) argues that capabilities "belong first and foremost to individual persons, and only derivatively to groups".

Ultimately, the basic premise of the capabilities approach is about treating individuals as ends, which means that the experiences of individuals who are marginalised are considered right from the start and never trivialised. The capabilities approach takes into account individual lives as they really are (functionings) along with people's practical opportunities and freedoms (capabilities) to make alternative and better choices to support the way in which they want to live their lives in the name of achieving social justice. It recognises every person to be an agent who is free to determine who they are or will be in their life and how they want to live that life. The approach does not impose any specific account of what a good life is, instead it recognises that there can be a range of frames that exist in understanding what constitutes the good life. Finally, social justice based on this approach is best understood through capabilities that determine how free and supported people are in being and doing the things that they value.

### 2.2.2. The uses of the capabilities approach

The capabilities approach has been widely built upon by other scholars across many disciplines (e.g., Alkire 2002; Robeyns 2005; Mitra 2006; Claassen 2011, Drydyk 2013; Simon et al. 2013; Robeyns 2017). The clearest uses of the capabilities approach are for measuring human development – finding its most prominent application in the Human Development Index and Reports which are published by the United Nations (UN) Development Programme (1990) – or theorising about justice (e.g., Vallentyne 2005; Venkatapuram 2011; Carter 2014; Robeyns 2017; Robeyns and Byskov 2021). The capabilities approach has been influential in the field of public health ethics with scholars like Venkatapuram (2011) and Prah Ruger (2009) developing their own more complete theories on justice and health. Scholars like Nielsen (2015) maintain that ‘every’ capability theory must acknowledge the significance of health and health-related capabilities because of the role it plays in human wellbeing and agency.

The approach has also been used across a multitude of disciplines to think about disability (e.g. Nussbaum 2006; Terzi 2010; Bannister and Venkatapuram 2020), but it has also been used in legal scholarship to think about disability rights (e.g. Dhanda 2006; Harnacke 2013; Harding 2021; Lindsey and Harding 2021), rights in relation to mental ill-health (e.g. Stavert 2022) and children and healthcare (e.g. Thompson 2021). In particular, it has gained popularity among scholars concerned with the realisation of rights provided for by the UN Convention on the Rights of Persons with Disabilities (CRPD) (e.g. Dhanda 2006; Harnacke 2013; Bach and Kerzner 2014; Bannister and Vankatapuram 2020; Stavert 2022). Robeyns and Byskov (2021) argue that the usefulness of the capabilities approach in applying it to disability and feminist research stems from the critique of mainstream moral philosophical schools of thought (e.g., utilitarianism) which are characterised by the invisibility of marginalised groups within them. The commitment to human diversity in the capabilities approach is a driving force for considering the lives of those who have been invisibilised because of their disability or mental ill-health.

Stavert (2022) takes the capability approach a step further in socio-legal human rights scholarship by suggesting that it can be used to bridge the rights approaches which may in some respects seem to be at odds with another; namely, the European Court of Human Rights jurisprudence which limits the autonomy of people with mental ill-health and the CRPD which calls for the removal of all barriers to the legal capacity[65] of people with mental disabilities, thus requiring minimal interference in autonomy. Stavert (2022, 192) contends that the benefits

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[65] Please note that legal capacity is not the same as mental capacity. Legal capacity is “the formal ability to hold and exercise rights and duties. Everyone has a right to legal capacity” (Harding 2017c).

of adopting the capabilities approach to mental health laws, policy and practice can be summarised in the following way:

> It [the capabilities approach] strongly encourages sufficiency and efficacy of services and support, and addresses emergency, crisis and public safety situations. It also removes the primary focus away from – but still addresses – the highly contentious issue of non-consensual interventions and provides a framework for the revisiting of thresholds for non-consensual interventions such as mental capacity and risk assessments, which are currently widely considered, by patients, families and many clinicians as problematic.[66]

These advantages proposed by Stavert (2022) are discussed in more detail elsewhere in this thesis. In particular, the need for a reduction in non-consensual interventions is scrutinised throughout the empirical chapters while still recognising that they have a place and role.[67] Similarly, thinking about mental capacity assessments in connection with advance consent and considering its appropriateness in mental health settings more broadly is also considered.[68]

Finally, it is also worth noting the influence of the capabilities approaches in mental health research more broadly. For example, the capabilities approach has been used to develop the Oxford Capabilities Questionnaire – Mental Health (Simon et al. 2013; Vergunst et al. 2014), which measures the level of wellbeing achieved by mentally ill people and is aimed specifically at use in mental health research. This capabilities approach-informed questionnaire has also been considered to be particularly culturally relevant and appropriate for the UK population of people with mental ill-health (Vergunst et al. 2014; White, Imperiale and Perera 2016).[69] The

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[66] On these attitudes see McKay and Stavert (2017)

[67] In Chapter 5 I discuss the prominence of coercion and non-consensual interventions which extend beyond legal understanding and the role of advance consent in addressing that. In Chapter 6, I discuss how the capabilities approach enables individuals to accept certain levels of coercion while in Chapter 7 I discuss the primary need for reduction of non-consensual interventions.

[68] For instance, I suggest that mental capacity is a source of unfreedom in the mental health context (Chapter 5) and suggest that in the context of advance consent individuals wishes should specify when advance consent comes into effect rather than it being invoked on incapacity, which would be a more predictable approach to take based on current English law (Chapter 6).

[69] Note that the capabilities approach is not only appropriate for UK or other Western population but the original approach of Sen (1999) and Nussbaum (2000) does take into account cultural relativism, suggesting that the

Questionnaire takes into account Sen's (1999) approach more broadly but uses Nussbaum's (2011) list of central capabilities to inform its own development of the relevant capabilities for mental health research (rather than to think about justice). The capabilities in the list include: health disability; meeting socially with friends; losing sleep over worry; enjoying recreational activities; having suitable accommodation; feeling safe; likelihood of discrimination; likelihood of assault (including sexual and domestic); ability to influence local decisions; freedom to express personal views; appreciation of nature; respecting and valuing people; enjoying friendship and support; self-determination; freedom of artistic expression; and access to interesting activities or employment. Its use is suggested for measuring outcomes in mental health research rather than in justice studies (Simon et al. 2013; Vergunst et al. 2014). Meanwhile, Hopper (2007) applied the capabilities approach to inform the social recovery of persons with schizophrenia. He argued that the approach represents a shift away from restrictive ideas about mental health and forces one to consider environmental, societal and relational factors in mental health recovery and to address sources of unfreedom like stigma, discrimination and even misdiagnosis, which will become apparently relevant to lived experiences discussed in this thesis. Finally, Brunner (2015) conducted a sociological study applying the capabilities approach to reconceptualise the social justice experiences of people with mental ill-health. In this work, social justice was measured (rather than theorised about) using specifically developed outcomes based on capabilities.

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approach needs to be adapted appropriately into the cultural context. White, Imperiale and Perera (2016) have applied the capabilities approach to thinking about global mental health, particularly taking into account low income countries. See also Nussbaum (2020) also encouraged to think about the application of the approach beyond Western context and philosophies.

The breadth of the uses and application of the capabilities approach presented in this section illustrates the benefits and plasticity of this far-reaching and highly applicable theory when thinking about what individuals are able to do and be in their daily contexts, and how relevant capabilities enable these doings and beings. The uniqueness of the approach lies in viewing people's lives in a holistic way which appreciates the individual, social and wider structural needs of every single person.

## 2.3. The capabilities approach to the study of advance consent to mental health treatment and social justice

Because the capabilities approach is a broad approach, it requires some specification on how it is used in this thesis. Robeyns (2017, 16–17) maintains that it is necessary to be specific about the reasons for choosing to focus on capabilities rather than functionings or vice versa and about which capabilities are used and for what purpose. Alongside those specifications, there are also optional alternatives. At the core of my theoretical approach is the commitment to human diversity, a key conceptual component of capabilities. Matthews (1999) describes the law as "sanist"; a criticism that is still relevant today. As highlighted in the introductory chapter, rights in relation to making one's own healthcare decisions differ and are based on whether an individual is making these decisions about their physical health or mental health. I adopt the capabilities approach to conceptualise advance consent from the viewpoint of a particular marginalised group: namely, psychiatric survivors. Social justice in this thesis is relational and not individual, and it is best understood through relevant capabilities. It acknowledges the undeniable and implicit value of advance consent in enhancing agency, but it goes beyond that because it uncovers sources of unfreedom that curtail both agency and, thus, social justice. I begin by explaining the capabilities that are used in this thesis to conceptualise the lived experiences of mental health treatment and advance consent, followed by a rationale for choosing to focus on capabilities rather than functionings. I then move on to discussing how agency is understood in my framework and how it relates to sources of unfreedom.

### 2.3.1. The plurality of capabilities

#### *2.3.1.1. Bodily integrity*

Gostin (2010, v) argues that the law limits the bodily integrity of those who require psychiatric treatment and the lived experiences of people examined in this thesis concur with this arguments. Bodily integrity is therefore the first capability that I am concerned with in this thesis. The starting point for developing this capability is Nussbaum's central list of capabilities in which she defines bodily integrity as "being able to move from place to place, secure against violent abuse, have opportunities for sexual satisfaction, and choose reproductive matters". Bodily integrity in this thesis is about the much broader inviolability of the person, their self-ownership, sense of self and self-determination. Bodily integrity is used to conceptualise and oppose the excessive decision-making powers that are given to mental health professionals and an overall legal tolerance towards the infringement of bodily integrity.[70] The legal tolerance here is 'sanist'; infringements on bodily integrity are justified on the basis of protecting the dominant group from the marginalised group but also on the basis that such infringements are particularly justifiable when they protect members of the marginalised group from 'themselves' by bringing them closer to what society understands as desirable outcomes for someone who is suffering from mental ill-health. Bodily integrity allows me to conceptualise the nuances of non-consensual treatment in Chapter 5.

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[70] In Chapter 5, I discuss in detail how this occurs in law.

Bodily integrity as a capability is used in this thesis as a theoretical driver for thinking about the practical benefits of advance consent which enhance the bodily integrity of individuals, but also about the potential obstacles and challenges to its achievement. In terms of benefits, I will discuss advance consent's premise for reducing the need for coercion, for the provision of informed consent and for access to prompter treatment. In terms of sources of unfreedom which curtail bodily integrity, I will focus on non-consensual treatment, mental capacity and the clinical concept of insight. Although the infringements on bodily integrity due to paternalistic mental health laws have already been noted in legal scholarship (e.g., Fennell 1996; Bartlett 2011; Gooding 2017), I explore these laws as more specifically connected to advance consent.

#### *2.3.1.2. Emotions and health*

Moving on from bodily integrity, the next capabilities this thesis considers are emotions and health. Nussbaum (2011, 33–34) defines the capability for emotion as:

> being able to have attachments to things and people outside ourselves; to love those who love and care for us; to grieve at their absence; in general, to love, to grieve, to experience longing and justified anger. Not having one's emotional development blighted by fear and anxiety. Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.

In her work, Nusbaum (2011, 180) emphasises the role of human psychology in developing capabilities and suggests that it is emotions and "psychological dispositions that support and impede a program of realising human capabilities". It is therefore impossible to achieve capabilities without emotions like compassion or solidarity (Nussbaum 2011, 181).

Nussbaum (2011, 182) suggests that 'the future' of the capabilities approach hinges on frameworks that focus on emotions like compassion and respect, but the task of dismantling these emotions should be both laborious and cautious. Emotions are important because they are perceived to be the motivating force behind actions, yet they are felt "unevenly and are shaped by social influences" (Nussbaum 2011, 182). This unevenness of feeling emotions means that policies that curate emotions must not undermine important values that exist in any society. Thus, it will also be important to understand which emotions hamper capabilities. Nussbaum (2011, 183) suggests that understanding the primitive shame of helplessness which leads to the stigmatisation of others will enable a capability application to be used to understand how social interactions can either hinder or develop emotions as capabilities. At the same time, it is crucial to understand the limitations of emotions as capabilities because that is linked to human diversity. In thinking about emotions as capabilities, it is necessary to consider carefully which emotions are important and which emotions are controversial among different groups of people (Nussbaum 2011, 183); relying on such controversial emotions as capabilities will ultimately lead to injustice for others who hold different values. It is, therefore, imperative that my capability framework concentrates on workable versions of emotions that will not become sources of divisiveness among psychiatric survivors (Nussbaum 2011, 182). For this purpose, Nussbaum (2011, 183-184) suggests that research should focus on studying people's experiences and conducting experiments while also interpreting individual lives through biographies to fully understand human life and especially the lives of marginalised people. This plurality in methods to achieve an understanding of human emotions is important because emotions are particularly complicated elements of human lives but are at the same time closely linked to experiences of social justice and social stability which strongly hinge on emotions (Nussbaum 2011, 184).

Taking into consideration both the importance and the limitations of capabilities as emotions, I use the original definition developed by Nussbaum (2011) in her central list of capabilities. However, I argue that the underpinning emotion that is relevant to the experiences of psychiatric survivors is compassion. Nussbaum (1996, 2001) has developed a substantive philosophical work on the notion of compassion; however, I build on Bielby's (2021) response to this work, who argues for 'compassion towards thriving' in public health ethics. Bielby (2021) addresses the gap in more recent works in public mental health ethics and law (e.g. Coggon 2017; Coggon and Laing 2019) which does not tease out the importance of compassion or emotions more generally, but which has been a part of the wider research into mental health (e.g. Spandler and Stickley 2011; Crawford et al. 2013; Sales, Philip and Candillis 2021). I will use both Nussbaum's (2011) capability for emotions and Bielby's (2021) work on compassion to consider the complex questions of invocation and revocation regarding advance consent, as well as discussing the appropriateness of advance consent which precludes changes of mind. Here, compassion as an emotion is about improving people's wellbeing and agency and is therefore important for social justice. Finally, the underlying premise of relying on compassion is about prevention of future suffering (Bielby 2021) to allow people to live the kind of lives they want to live.

I also use health as a capability alongside emotion and compassion. Health is clearly an important capability for conceptualising experiences of mental health treatment. Nussbaum (2011, 33) defines health as "being adequately nourished, having good health, including reproductive health, and having adequate shelter". In this thesis, I adopt a broad understanding of health in line with scholars like Stavert and McGregor (2018), who argue for a definition of mental health in the widest sense possible. In this thesis, in line with the commitment to human diversity and social justice, I do not propose a specific definition of what good mental health is. Instead, I suggest that every person will have their own acceptable 'levels' of what having good mental health means to them. This might also mean that their optimal level of mental health could be understood as one that allows them to pursue their life roles and other goals, and so the capability for health extends beyond medical understandings. Thus, I suggest that people do not need to be free from symptoms of mental ill-health to have the capability for health. Instead, they require legal instruments, such as advance consent, to ensure that the individual level of health that each strives for can be achieved for specific circumstances. Similarly to Venkatapuram (2011; 2014) and Stavert (2022), I maintain that the capability for health includes planning for the life one wants to pursue, but also planning for one's mental health.

To support capabilities for emotions and health in the contexts of psychiatric survivors' experiences, I use Sen's (1999) capabilities approach to discuss the acceptable levels of coercion or force which might actually support those capabilities. I refer specifically to a question which follows from the development of advance consent which precludes changes of mind; if one makes an advance consent and attempts to revoke it at the material time but advance consent precludes such change of heart, then the question that follows considers whether the provision of treatment specified in an advance consent amounts to coercion and force. Insights from the Senian (Sen 1999) approach are useful for conceptualising these experiences.

Finally, I suggest that the capabilities for emotions and health underpinned by compassion can be further supported by adding relational dimensions to them. I suggest that relationality in the context of advance consent is best understood using Harding's (2017a, 116) definition:

> we mostly make decisions about our lives within the context of our relational networks: our family, our friends and our loved ones. When we make a decision, we often think about the effects it will have on those around us, as well as on ourselves. We evaluate whether it is the 'right' thing to do, in part, because of the potential effects on known (and unknown) others.

In recognising the relational dimensions of those capabilities, I propose that the securement of the capabilities for emotions and health could be supported by developing a framework of nominated trusted others who could support people in making decisions in challenging situations or ensuring that the decision followed in such a circumstance is a correct one. Other frameworks for relationality (e.g., Herring 2014; 2019) sometimes focus on the interdependence between vulnerable individuals and others who are not vulnerable or less vulnerable. The view of relationality I adopt is about enablement to curate capabilities, and only in necessary circumstances.

However, my understanding of compassion as part of the capability for emotion extends far beyond the everyday understanding of compassion in mental health which generally means taking action to alleviate the suffering observed in others (e.g. Nussbaum 1996). Instead I view compassion as an underpinning principle of the capability for emotion. This principle focuses on the notion of "compassion towards thriving" developed by Bielby (2021, 298) which is defined as "the prevention of potential future suffering through the facilitation of personal growth based on a 'psychosocial' understanding of mental health." The focus on the psychosocial understanding of mental health allows me to argue that advance consent is an expression of such compassion because it is designed to alleviate pre-existing suffering. Thus, it supports not only health capabilities, but also the capability for emotion by freeing people from the fear and anxiety of being treated in contradiction to their wishes. In addition, this understanding of compassion allows me to argue that advance consent is not just a medical or legal measure but it is also a way to ensure that people's relationships and life pursuits that are important to them are successfully preserved. Furthermore, in Chapter 6, I argue that this version of compassion understood as a principle underpinning the capabilities for emotion is helpful in developing a framework of support for times when one's wishes may not be as clear as they once appeared.

#### *2.3.1.3. Safety*

Safety is a new capability developed in this thesis and the only capability used which does not feature on Nussbaum's (2011) central list of capabilities. However, "feeling safe" features as a capability in the Oxford Capabilities Questionnaire – Mental Health (Simon et al. 2013; Vergunst et al. 2014). It will be developed in Chapter 7 and will form the analytical basis for that chapter. This capability is developed as a counter-balance to laws that are concerned with protecting the public from the mentally ill individual or with the meaning of safety as being associated with the notion of dangerousness which not only underpins mental health law but also features heavily in public perception that leads to stigma (e.g. Corrigan and Watson 2005). The development of this capability is grounded in my empirical data, and I define it as being free from unnecessary coercion and having alternatives to coercion; having opportunities for choice and active participation in decisions about treatment; being provided with a place of safety when needed; to have one's interests reflected in policy and legal developments; to be free from undue influence; and to be guilt-free in relation to one's mental ill-health.

In Chapter 7, I evaluate the different components of safety against the premise of advance consent. As I will argue in this thesis, coercion[71] experienced by psychiatric survivors is not constrained to interventions authorised by the law, but it is also present in everyday doctor–patient interaction. Thinking about alternatives to coercion in psychiatry is challenging

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[71] Note that I use the term coercion to encompass both coercion and compulsion. Coercion is often understood as being persuaded or forced into doing something whereas compulsion is an action forced by the state on an individual. Using coercion encompasses all of those aspects of force experienced by psychiatric survivors. Coercion also includes non-consensual treatment.

and the development of such frameworks will require painstaking efforts. I will use the capability for safety to argue that advance consent provides a partial alternative to coercion; it is unable to address ‘all’ coercion, but at the very least it deals with the issue of non-consensual treatment and might prevent unnecessary coercion in other situations. A review commissioned by the UN Committee on the Rights of Persons with Disabilities found that psychiatric advance decisions present a potential for an alternative to coercion (Gooding et al. 2018). This is significant as alternatives in this context are neither well developed nor well researched. I also suggest that advance consent makes people active participants in their decisions about treatment and respects their choices which are relevant to that decision. Moreover, I examine more recent proposals on advance consent in English policy and argue that the interests of psychiatric survivors are not adequately addressed because the suggested developments are unlikely to have a big impact on coercion. I argue that the provision for “the place of safety” in particular police stations may in fact hinder the capability for safety when it does not respect people’s needs. Finally, in developing the capability for safety, I do not rely on any supplementary theory but suggest that a notion of individual responsibility present in Sen’s (1999) work is useful in thinking about the safety of psychiatric survivors. In doing so, I argue that individual responsibility for choice enhances both safety and freedom.

Finally, as Chapter 7 will demonstrate, safety is a key capability which is currently missing from the central list of capabilities in Nussbaum’s work. Nussbaum’s mention of safety as being free from sexual violence in order to secure bodily integrity is not a sufficient expression of safety which covers all human beings. Safety, as will be argued, is about having a safe place, being free from unprecedented coercion, exercising individual responsibility where appropriate, exercising choice and being a participant in all aspects of one’s life – these capabilities are arguably not uniquely important to those with experiences of mental ill-health, but to all people. Hence, safety should be included in a central list of capabilities and be viewed as a basic entitlement of all humans.

#### *2.3.1.4. Choosing capabilities and social justice*

In this thesis, I maintain that social justice is achieved through the equality of capabilities which are real opportunities and real freedoms, enabling people to live the kinds of lives they want to live and value. There are several reasons for which I chose to focus on capabilities rather than functionings, and these reasons are both normative and conceptual. At the very basic level of the capabilities approach, there is a commitment to real freedom and to ensuring that people are as free as possible given the constraints of the societies they live in (Sen 1999, xii). This commitment to freedom calls for liberal or anti-paternalistic conceptualisations of social justice. In line with Sen (1999; 2009) and Nussbaum (2000; 2006; 2011), I do not privilege any single account of a good life for psychiatric survivors but instead accept that there is a wide range of possibilities of what good lives might look like to different individuals. Focusing on functionings over capabilities would require the imposition of the notion of wellbeing, and therefore good life, or the imposition of achieved outcomes that would need to be perceived as beneficial to all psychiatric survivors. In a similar vein, I do not propose to identify what good mental health or mental health outcomes are; instead I focus on the components of the capability for health, freedoms and opportunities that people are at liberty to choose.

Secondly, as mentioned in relation to the capability for safety, I argue that promoting individual responsibility for choices (Sen 1999) that people make is an important part of decision-making in the context of mental health and advance consent in particular. Therefore, my normative and conceptual commitment is to focus on equality of capabilities as opportunities and freedoms available to an individual which they can then choose or not.

Moreover, individual responsibility is desirable for psychiatric survivors for whom occurrences of having it denied have led to experiences of injustice. Thus, the achievement of social justice is about the equality of capabilities and choice in their realisation. Finally, Robeyns (2017, 67) argues that it is important to acknowledge meta-theoretical commitments when working with the capabilities approach as such commitments refer to specific disciplinary thinking. As this is a socio-legal study, it is key to note that my meta-theoretical commitment is to study law in everyday life and from a marginalised perspective. I also attest that every human being should be equal and that everyone's decision-making rights should be supported.

In my approach to social justice, the capabilities I discuss are conceptual spaces in psychiatric survivors' experiences that give them meaning and contribute to knowledge on advance consent. I focus on the capabilities of which expressions can be found in my data and examine how they contribute to the social justice of psychiatric survivors, but I do not offer a complete social justice. Instead, I begin to develop a list of relevant capabilities and capabilities components for advance consent and people's experiences. I begin to argue that capabilities can be interrelated and interdependent because some components of various capabilities overlap and may also complement each other, however, neither are they indivisible because it is possible to develop a hierarchy of capabilities as any capabilitarian theorist may wish to do so. For instance, Lindsey and Harding (2021,15) argue that, as Nussbaum maintains that all capabilities are required, then "it would not be sufficient to protect bodily health and bodily integrity by preventing disabled people from forming emotional attachments, intimate relationships and affiliations", which is where the interconnectedness comes from. There is an example of this in Nussbaum's (2011) central list too. For instance, both bodily integrity and bodily health relate to matters of reproduction in the list (Nussbaum 2011, 33). This interconnectedness does not mean that some capabilities cannot be prioritised over others, but it means that I am able to view the capabilities chosen for this thesis as interconnected because they all support and are related to advance consent and mental health treatment.

### 2.3.2. Agency freedom and sources of unfreedom

The specific or basic freedoms which underpin the capabilities approach are intersecting agency freedom and wellbeing freedom of which both are, to a greater or lesser extent, responsible for enabling an individual to live the kind of life they want to live (Sen 1999, 190). Wellbeing as freedom refers to the promotion of wellbeing in general terms; being healthy or well-nourished are clear examples of wellbeing freedoms. Agency freedom is about the extent to which an individual is free to pursue the kind of life they want, even at the expense of wellbeing (Sen 1999, 191). For example, a psychiatric survivor might choose to delay seeking help or treatment – or indeed not seek it at all – because this would interrupt life pursuits or life roles they value more. This means that an individual can exercise agency freedom that is at odds with wellbeing freedom,[72] and recognising this agency freedom allows people to pursue a wide range of doings and beings. Moreover, agency freedom has two components: autonomy and freedom, and this freedom is related to being able to choose the level of autonomy one wishes to exercise (Claassen 2016, 1281).

In taking this position, I counter the way in which mental health law imposes a certain version of wellbeing on individuals by limiting their agency. For instance, the law treats mental illness as something that requires the alleviation of symptoms, so much so that this justifies coercion. In addition, in line with the medical model it adopts, the law permits those granted such powers to control what society accepts as ‘undesirable’ or ‘disturbing’ behaviours by

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[72] Investigation of agency freedom in this way is presented throughout Chapter 4.

medicating individuals to achieve certain modifications in behaviour. In general, mental health law hugely neglects the agency of those who struggle with mental ill-health or crises by denying them the opportunity to make their own treatment decisions or not supporting them when they attempt to do so.

The capabilities approach is not committed to one particular theory of agency or autonomy, and so it can be fleshed out in many different ways. It might be tempting to argue that the capabilities approach is committed to individual agency due to the emphasis on individuals as an end and the explicit references in Sen's (1999, xii) work to individual autonomy. However, at the very least, the capabilities approach recognises that individual agency can be relational or constrained/enabled by wider social and structural contexts:

> Individual agency is, ultimately, central to addressing […] deprivations. On the other hand, the freedom of agency that we individually have is inescapably qualified and constrained by the social, political and economic opportunities that are available to us. There is a deep complementarity between individual agency and social arrangement. It is important to give simultaneous recognition to the centrality of individual freedom and to the force of social influences on the extent and reach of individual freedom. To counter the problem we face, we have to see individual freedom as a social commitment. This is the basic approach. (Sen 1999, xii)

This position on agency is consistent with Sen's (1999; 2009) focus on justice as being assessed through social arrangements based on either evaluating functionings (the actual achievements) or capabilities (the freedom to achieve, tightly connected to agency). As I will argue in Chapter 4, Sen's notion of social arrangements is helpful in conceptualising the importance of capabilities over functionings, i.e., the need to concentrate efforts on evaluating freedoms as well as sources of unfreedom.

Sources of unfreedom in the capabilities approach are also sources of injustice. These are created by people and exist in laws, institutions, policies, and social norms and are faced by particular groups or individuals and have a significant impact on people's capabilities (Sen 1999; 2009). For example, being discriminated against by law on the basis of having mental-ill health leads to the denial of decision-making opportunities, such as the option for advance decisions – a resource already available to those suffering from physical ill-health. However, sources of unfreedom can have a much greater reach, particularly on those capabilities that are not heavily dependent on resources but on other aspects like interpersonal relationships. For instance, Robeyn (2017, 65) argues that if people with mental health conditions are stigmatised, then they will inadvertently be treated with disrespect in many aspects of their lives which will significantly impair their emotional capabilities, for example having the chance to feel appropriate emotions or gain opportunities for friendships and emotions. I take stigma a step further in this thesis and argue that it is not only a source of unfreedom but also an example of structural violence which permeates the lives of psychiatric survivors and is likely to impair a wide range of their capabilities.[73]

In my application of the capabilities approach, I accept agency as being inherently important and relevant to advance consent. Indeed, autonomy has been a focal point of discussion in relation to advance consent (e.g. Szasz 1982; Dresser 1982; Dworkin 1993; Bielby 2014), and the importance of advance consent which lies in increasing autonomy is significant and key to its very premise. However, I do not plan to argue that any specific version of autonomy is better than another in conceptualising advance consent, nor will I try to justify advance consent purely on the basis of autonomy arguments. Instead, I maintain that autonomy alone does not capture the full potential of advance consent and is therefore unable to include the wider needs of psychiatric survivors or to fully understand how sources of unfreedom affect various doings

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[73] See Chapter 4, 4.4.

and beings that people pursue and which advance consent would permeate. Thus it does not capture the freedom(s) that is at the essence of 'being' and crucial to the pursuit of the lives that people value. However, I do maintain a version of autonomy as connected closely to sovereignty more than the authenticity of wishes (Atkinson 2007, 88). This allows me to assign more value to freedom to decide and voluntariness to decide, over concern for a person's mental capacity status as a prerequisite for autonomy, which is so present in precedent autonomy considerations (Atkinson 2007; Davis 2009a).

Agency can be viewed as both a capability and a functioning, depending on whether it is perceived as an achievement or an opportunity. In line with Claassen (2016), I suggest that agency is actually a capability, primarily because it is a freedom. It also consists of at least two functionings: autonomous decision-making or deliberation and free action (Claassen 2016, 1283). However, in my approach, agency is a higher-level capability that operates as a background to the pursuit of the lives that people want and, moreover, needs to be supported by basic capabilities. Agency as a capability can be observed in Nussbaum's (2011) list under practical reason. Practical reason as a capability engages in "critical reflection about the planning of one's life" (Nussbaum 2011, 34), but this only considers one component of agency: autonomy, and not freedom. This is because practical reason only extends to goal-setting, but agency freedom as a capability is about goal-setting and goal pursuit, requiring a much more active approach (Claassen 2016, 1283). However, relational dimensions can also be drawn out from Nussbaum's (2011) list, particularly when reading practical reason and affiliation capabilities together. Affiliation is about "being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interactions", and practical reason based on rationality recognises both that a person is a rational agent and also that they are a social inseparable from their social contexts (Nussbaum 2011, 34).

Relying primarily on Sen’s (1999) and Claassen’s (2016) versions of agency freedom, I suggest that agency freedom is socially embedded, I take for granted that agency freedom means to be able to make autonomous decisions; to have capabilities which enable decisions and choice about one’s goals; to be able to exercise capabilities and pursue goals without unnecessary interference from or manipulation by others; to be able to act freely; to have sources of unfreedom socially and relationally considered; and to have agency freedom supported through relationships or other measures such as advance consent (specific to the context of this thesis). It is clear that my version of individual agency has deeply relational understandings. However, I must point out that, unlike many relational scholars (e.g., Harding 2017a; 2017b), I view relationality as extending far beyond interpersonal relationships. I regard this relational agency freedom as existing in micro, meso and macro relationships. Micro relationships are about the individual agency that one has with oneself in the context of making decisions primarily in consideration of one’s personal needs, such as mental health treatment. However, a micro relationship can also include a connection that an individual has with another person whom they take into consideration or include in their decision-making process. Meso relationships are between an individual and their doctor, and, finally, macro relationships exist between an individual and wider societal structures like the law, institutions, the mental health care system and policy matters. In my conceptualisation, relationality can be both good and bad. When a particular relationship is experienced as constraining an individual’s agency and basic capabilities, it is a source of unfreedom, an injustice experienced by the individual. However, if a relationship is enabling the different components of agency and the exercise of basic capabilities, then that leads to social justice.

My approach to agency applied to advance consent is, therefore, about acknowledging the autonomy dimensions of advance consent. However, the approach goes further by situating advance consent in a wide relational context which means that sources of unfreedom can be identified and addressed by supporting relevant basic capabilities. Thus addressing, reducing, and eliminating unfreedoms can be perceived as important steps to achieving social justice.

## 2.4. Relevant critiques of the capabilities approach

The most prominent criticism of the capabilities approach is that it is too individualistic (Dean 2009; Sayer 2012; Clough 2022), and the criticism is particularly prominent among those who think about individuals and their agency in communitarian or relational terms (e.g., Deneulin and Stewart 2002; Stewart 2005; Clough 2022). Sayer (2012) and Clough (2022) both argue that the approach does not adequately theorise about a society which prevents full examination of the societal and structural constraints which exist in the achievement of capabilities. Countering this critique, Robeyns (2017, 183–186) evaluates different types of individualism to highlight the incompleteness of such a critique and unravel its weaknesses. At the heart of this argument is the principal encouragement in the approach to examining sources of unfreedom that an individual is faced with (i.e., structural, societal and relational constraints). I concur with Robeyn’s (2017) view, which is evident in the framework that I set out. The capabilities approach requires consideration of structural constraints from the start in order to discuss the possibilities presented by relevant capabilities (Sen 1999; 2009). Its focus on an individual or individual agency has relational, communitarian and social understandings, and it is up to each capabilitarian to choose how they conceive of the relationships between an individual and society. Dreze and Sen (2002, 6) capture this well in their empirical application of the capabilities approach:

> It is essentially a ‘people-centred’ approach, which puts human agency (rather than organisations such as markets or governments) at the centre of the stage. The crucial role of social opportunities is to expand the realm of human agency and freedom, both as an end in itself and as a means of further expansion of freedom. The word ‘social’ in the expression of ‘social opportunity’ … is a useful reminder not to view individuals and their opportunities in isolated terms. The options that a person has depend greatly on relations with others and on what the state and other institutions do. We shall be particularly concerned with those opportunities that are strongly influenced by social circumstances.

As Dreze and Sen (2002) suggest, the capabilities approach places an individual at the centre of any theory or framework while examining the social, relational, and structural aspects of that individual’s capabilities. Therefore, whether a capability theory is too individualistic significantly depends on how it is applied and interpreted by a particular scholar.

I am particularly mindful of the critique of Nussbaum’s (2006; 2010) approach. In her work (Nussbaum 2010) she develops a typology of cognitively disabled people and views substituted decision-making and associated legal instruments like guardianships as plainly unproblematic (Nussbaum 2006). Lindsey and Harding (2021, 75) argue that such a frame of cognitive disability in Nussbaum’s approach may be particularly problematic for scholars who are committed to the realisation of rights under the UN CRPD in light of its emphasis on the abolishment of substitute decision-making mechanisms. In a similar vein, Harnacke (2013) criticised Nussbaum’s (2006; 2010) approach as deriving from ableist ideas when it comes to thinking about cognitive disability. Furthermore, Nussbaum (2006), by using the umbrella term “mental impairments”, does not distinguish between the differing needs of people with learning disabilities and people with mental ill-health, which may lead to the questioning of her commitment to human diversity, especially as the differences between capabilities and needs are not analytically explored. This critique must be taken seriously. However, how Nussbaum’s approach to disability-related research is applied will ultimately depend on whether one would consider themselves a Nussbaumian purist and, in particular, whether they would try to reconcile Nussbaum's approach with other theoretical issues such as human rights commitments.

The concerns over Nussbaum's (2006) approach to disability have led to scholars like Holmwood (2013, 9) and Clough (2022, 114–129) criticising the capabilities approach for not providing an analysis of the vulnerability that individuals experience, all while accepting that dependency on others is unavoidable (because of Nussbaum's recognition of substitute decision-making). However, as Venkatapuram (2011, 151) notes, the capabilities approach is concerned with much more than "care" as narrowly understood because it is deeply attached to the social and structural determinants of what he calls "avoidable impairments". Instead of focusing on vulnerability, the capabilities approach shifts focus away from an individual to society and examines how an individual is deprived of capabilities in that society and what support is needed in order to access or provide capabilities for those individuals. Indeed, for individuals to have freedom and opportunities, a social commitment to providing and supporting capabilities is essential (Sen 1999; 2009).

## 2.5. Conclusion

In this chapter, I have set out my theoretical framework, which I build on, explain, and develop further in the remainder of this thesis. I have demonstrated that social justice for psychiatric survivors is primarily understood through capabilities. However, it is also about providing individuals with practical alternatives, such as advance consent, that address sources of unfreedom which obstruct an individual's ability to make their own decisions. My approach emphasises human diversity and treating individuals as ends, but social justice is a relational process. It is not possessed by an individual, but, rather, it is achieved relationally by working towards alternatives that offer the kinds of lives and treatment experiences that people want and which enhance important capabilities. This framework allows me to conceptualise lived experiences of mental health and offer new theoretical thinking about advance consent.

In the following chapter, I outline the feminist narrative-material methodology used in this thesis. Building on the capabilities approach, I examine its compatibility with my methodological framework and demonstrate its empirical potential. I also explain the methods used, how I collected the data and how I dealt with ethical concerns.

# CHAPTER 3: MATERIAL-NARRATIVE METHODOLOGICAL APPROACH TO THE STUDY OF MENTAL HEALTH LAW IN EVERYDAY LIFE

## 3.1. Introduction

In this chapter, I explain the methodological approach adopted in this thesis to understand the desirability and the potential of advance consent in mental health law through qualitative inquiry. I begin by explaining my methodological approach which I call 'the feminist material-narrative approach' to the study of lived experiences of mental health, treatment and the law in everyday life. Those experiences are socio-legal because, whether people acknowledge it or not, their mental health experiences are governed by complex legal frameworks at least to some extent. This methodology challenges the approach of existing legal frameworks by focusing on the social, legal, medical and relational aspects of people's experiences. As this thesis draws on the capabilities framework, I explain how this theoretical structure informs my methodological approach. I then move on to discuss my recruitment strategy, sampling and participants' demographics. I set out the empirical methods used: narrative and photo-elicitation interviews with psychiatric survivors in England. After that, I discuss my thematic-narrative and capabilities-driven evaluative approach to analysing data. This is followed by addressing some of the ethical concerns that arose in this thesis. Finally, I provide reflexive remarks before moving on to this chapter's conclusion.

## 3.2. The feminist material-narrative methodological approach to the study of advance consent

### 3.2.1. The material-narrative approach.

Clandinin and Rosiek (2019) note that, even though narrative inquiry in research is a well-established exercise, it may seem new or innovative in some disciplines. This is because the ‘narrative’ has become cross- and multi-disciplinary which means that what is now novel about a narrative inquiry is the emergence of diverse narrative methodologies that can have realist, modernist, and constructionist aspects (Riessman 2008; Ward 2012; McAlpine 2016; Clandinin and Rosiek 2019). Thus, scholars often disagree not only on the origins of narrative inquiry but also on its precise definition (e.g., Wengraf 2001; Czarniawska 2004; Riessman 2008; Ward 2012). In social sciences, there has been a clear turn towards a ‘narrative revolution’ which shifts methodologies in a remarkable manner because it “re[lies] on diverse theories and methodologies” (Riessman 2008, 17) just as the capabilities framework does (e.g., Alkire 2002; Drezer and Sen 2002; Hopper 2007; Nussbaum 2006; Robeyns 2017). Connelly and Clandinin (2000) are thought to have been the first to coin the term ‘narrative inquiry’ and, just as in their work, the narrative in this thesis is both a phenomenon and a method. It is a phenomenon because it belongs to an interpretivist paradigm, even though it is less well-known than grounded theory or phenomenological inquiry (McAlpine 2016, 34). This clarification is necessary to realise the potential of narrative as a method for contributing to the socio-legal study of advance consent, decision-making and mental health law surrounding mental health. As an interpretive approach, it is also used to inform the analysis of the data, as explained in part four of this chapter. In this thesis, as discussed in part three of this chapter, I also use narrative as a method through the use of narrative interviews.

Narrative inquiry is familiar to both law and broadly conceived research into mental health. Wolff (2014, 4) states that “law is narration: it is narrative, narrator and the narrated”. In agreement with Wolff (2014), Nurse (2020) notes that law in its simplest form is in itself a narrative. Case law tells a story of an event and judgments apply a variety of legal texts to that event to construct a legal narrative. In legal scholarship, narrative research has been utilised in a wide variety of fields, including by legal historians (e.g. Ball 1989), feminist scholars (e.g. Abrams 1991), environmental legal scholars (e.g. Nurse 2020) and in legal consciousness and socio-legal scholarship (e.g. Ewick and Silbey 1998; 2003; Harding 2011), just to name a few. Harding (2011) argues that narratives are commonplace in law and in everyday life. This is because people both live and tell stories about living (Harding 2011). As an approach, narrative inquiry has also been popular in broadly understood mental health research that developed as a response to the medical model of mental health research focusing on understanding pathology through a clinical positivistic approach (Spector-Mersel and Knaifel 2018). Here, studies have focused on narratives of mental illness and stories of recovery (e.g. Adame and Knudson 2008; Hoy 2014).

The methodological impetus for this narrative inquiry was bifold: to use a material-narrative approach (Czarniawska 2004; Ward 2012) underpinned by the capabilities framework (Sen 1999; 2009; Nussbaum 2006; 2011) and to conduct the research from a feminist epistemological standpoint (Harding 1993; 1997; Ward 2012; Beresford and Boxall 2015). A material-narrative framework aims to merge what are sometimes seen as competing or even conflicting philosophical perspectives: social constructionism and realism (Ward 2012, 188). Social constructionism in itself developed to understand what reality is (Stoppard 1997; Prior 1999; Andrews 2012). It is a theory of knowledge in which knowledge develops as a result of social interactions (Schwandt 2003, 293). The reality is therefore socially constructed through subjective experiences of everyday life (Hammersley 1992; Andrews 2012). Defined in this way, social constructionism is “unconcerned with ontological questions or questions of causation” (Andrews 2012, 2).[74] On the other hand, materialism, which is a form of realism in social sciences, is concerned with the objective world of truth within the world that exists independently of the social reality and can be concerned with both ontological questions and questions of causation (Guba and Lincoln 1994; Ward 2012). Combining these perspectives was particularly important for the study of mental health treatment experiences and advance consent because both offer analytical value, and adopting a simple constructionist or realist approach could be problematic as both have relevance to the study of psychiatric experiences within the socio-legal context. A material-narrative approach is therefore an extension of interpretative approaches that retain elements of social constructionism whilst recognising that constructs correspond with the material world (Barad 2003).

In this research, the social constructionist framework was valuable for understanding which experiences of mental health are constructed as either positive or negative, helpful, or unhelpful, life-changing or unimportant. It was also useful for identifying how mental health law regarding treatment and decision-making processes was constructed as either empowering or disempowering. Similarly, participants, by drawing on their experiences, constructed their own ideas and understanding of advance consent. Combining social constructionism with materialism allowed me to see where negative experiences of law, mental health treatment and decision-making intersect. In turn, this resulted in positioning lived experiences of psychiatric survivors as marginal. Consequently, this might lead to various possibilities of exclusion in everyday life and relationships, as well as in decision-making processes, especially in psychiatric and legal settings, and this refers to the material reality that psychiatric survivors might find themselves in. The material-narrative approach has the potential to discover the

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[74] Note that some social constructionist scholars, e.g. Berger and Luckmann (1991), use this theory of knowledge to develop a view of society as having both subjective and objective realities.

commonalities in socially constructed narratives that refer to some material realities of people's lives and the environments they find themselves in. This approach is therefore useful when making recommendations for law-making in this area.

### 3.2.2. The Influence of Feminist Standpoint: Finding Commonalities and situating Knowledge of Psychiatric Survivors.

Beresford and Boxall (2015, 77) argue that "in relation to the social hierarchy that polices and controls the production of knowledge about madness and mental health problems, mental health service users have been firmly located at the bottom". It was crucial to be mindful of this perspective when approaching research processes based on experiential knowledge of psychiatric survivors because, as mentioned previously, their lives or parts of their lives have been characterised by both exclusion and marginalisation. Additionally, designing a project that includes those marginalised voices does not automatically free it from the possibility of becoming exclusionary or even devaluing of these experiences.[75] To ensure that the voices of psychiatric survivors were placed at the heart of this research, I chose to adopt a feminist ontology. Feminist approaches vary, but what they have in common is that they are concerned with experiences of injustice, adopting research and ethical practices that privilege the minority voice or experience (Ward 2012, 189).[76] I adopted these general feminist principles in a number of ways. First, the focal point of this research is to examine whether advance consent as a decision-making mechanism in mental health care can achieve social justice understood through capabilities and become a tool that is perceived as empowering. This means that

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[75] See discussion in Chapter 1.4 and see Hui and Stickley (2007); Lewis (2009).

[76] For examples of feminist research concerned with injustice and minority voice, see Nedelsky (1990), Harding (1995), Nussbaum (1999), Harding (2011; 2017).

experiences of injustice, or sources of ‘unfreedom’ within the capabilities lexicon, are also analysed. Therefore, I focus on the marginalisation and the denial of decision-making abilities of mentally ill people within the legal frameworks, the mental health care environment and everyday lives. Finally, my focus on injustice was combined with an understanding of the current state of the mental health law as ‘sanist’ (Matthews 1999) to emphasise the existing marginalisation of mentally ill patients. In turn, this influenced the decision to conduct research with psychiatric survivors rather than, for instance, psychiatrists or carers. This is a way of acknowledging that psychiatric survivors may be marginalised within the structures of their own care and lives.

Nussbaum (2000; 2011) contends that, when one is concerned with living beings, this reflects an interest in realism. Rose (2009, 41), a survivor researcher, has suggested that, when it comes to research on mental health treatment, “there is no ‘universal knowledge’ but only particular knowledges produced through different standpoints. Different standpoints produce ‘different truths’.” Feminist standpoint theorists (Harding 1997; Hekman 1997) argue that purely positivist approaches create a reality which excludes experiences of women or marginalised groups in general whilst viewing such a reality as objective (Beresford and Boxall 2015). Rather, it is the marginalised group itself that has the potential to illuminate unexamined assumptions and biases in knowledge production, thus, leading to a version of objectivity with a more nuanced version of the reality of “relations between power and knowledge” (Harding 1997, 382). The account of capabilities in this thesis holds that achieving capabilities and thus social justice requires a multifaceted understanding of the survivors’ experience; for instance, what constitutes bodily integrity, and how structural factors can aid or hinder the achievement of that capability in that individual experience (Sen 2011; Nussbaum 2006).

The feminist standpoint view is based on the presumption that there are similarities between individuals within a defined marginalised group (Hartstock 1997; Beresford and Boxall 2015). This raises a question as to whether psychiatric survivors as individuals can have a common standpoint as a group. Beresford and Boxall (2015, 77) suggest that psychiatric survivors "like other groups of disabled people, have found themselves on the receiving end of collective solutions […] that result in the lives [of psychiatric survivors] 'being regulated by the state'". Thus, adopting a standpoint theory with regard to the experiences of psychiatric survivors illuminates the need to examine the injustices experienced by them in order to suggest ways of challenging or remedying them. In this way, I ensured that the experiences of psychiatric survivors did not become devalued in this research in the name of objectivity, which is well articulated by Harding (1993, 54):

> [Marginalised] experiences and lives have been devaluated or ignored as a source of objectivity maximising questions – the answers to which are not necessarily to be found in those experiences or lives but elsewhere in the beliefs and activities of people at the centre who make policies and engage in social practices that shape marginal lives.

The feminist epistemological position of this thesis is that the concept of advance consent to mental health treatment was approached from a perspective that it is a relational process (Harding 2011; Harding 2017b). The relational aspects of advance consent may be macro level, that is, concerned with the relationships between individuals and the state, individuals and the law; meso level, for example in relation to individuals and the mental health profession; and micro level, found in everyday relationships with friends, family or employment and even the relationship between an individual and their perceived achievement of any particular capability. Therefore, narratives become tools for analysing these different relationships. Consequently, I hold that knowledge is both socially and institutionally situated and relational and that this leads to at least some level of objectivity. The influence of feminist epistemology situates psychiatric survivors as a marginalised group and sheds light on biases present in the dominant group – the 'sane' – and what they are unable to see. The knowledge is then built upon that marginalised perspective, which highlights my commitment to human diversity in line with the theoretical driver of this thesis – the capabilities approach.

### 3.2.3. Consistency of this Approach with the Capabilities Framework.

The capabilities framework is well suited to many different types of methodological research and epistemological assumptions (Robeyns 2017, 72). Robeyns (2005, 367) further argues, that as a result, Sen's approach is more formally objectivist and concerned with questions of measurement while Nussbaum is experientially concerned with personal narrative, in order "to better understand people's hopes, desires, aspirations, motivations and decisions". It is thus more open to qualitative research and participative approaches. Indeed, there are successful examples of research that have combined narrative methodologies focusing on individual stories within a capabilities framework (Hulme 2004; Deneulin and Hodgett 2006). Using a narrative methodology is also ethically sound with the premise of capabilities by allowing participants the freedom to focus on the stories they value.

The material-narrative and feminist methodological approach adopted in this research is consistent with the capabilities framework, a theoretical driver of this thesis. The capabilities framework adopted assumes that lived experiences of mental distress are both constructed and material and provides a theory that helps conceptualise the relationship between the two. Combining materialism and constructionism when using capabilities as a theoretical or analytical frame for mental health research has previously been encouraged by Brunner (2019). Brunner (2019, 201) contends that this approach increases the explanatory potential of the capabilities approach that is adapted to an empirical inquiry. The result is that I am able to examine the relevant capabilities that advance consent has the potential to secure for psychiatric survivors. I am also able to explain why these specific capabilities are important. Through the lens of the capabilities approach, the experiences of psychiatric survivors are understood as relational and are influenced by the environments they live in as well as wider societal structures. The capabilities framework does not presume that society consists of independent citizens with the same needs and abilities. On the contrary, it requires that individual experience is socially and environmentally contextualised (Robeyns 2017). As discussed in Chapter 2, this framework demands an examination of sources of unfreedom, understood as structures, relationships and institutions that create or lead to experiences of injustice. The assessment of justice, therefore, begins with an individual experience which instigates the research process with the focus being on the marginalised individual from the start (Nussbaum 2006).

The narrative-material methodology underpinned by feminist values and conceptualised through a capabilities approach allows me to argue that what psychiatric survivors value is not immutable nor displaced from its contexts, be those legal, relational, medical, social or others. As the following empirical chapters show, the language and concepts accessed through the capabilities framework reveal that experiences of mental health treatment came to influence what psychiatric survivors had come to value in the broader context of their mental health. The empirical potential of the capabilities approach in the study of advance consent allows me to discern that the way in which participants talked about advance consent was not anecdotal or descriptive, but rather theoretical and analytical. Thus, by focusing on the sources of unfreedom, agency and the wider meaning of social justice, the capabilities framework complements the narrative methodology of this thesis.

## 3.3. Data Collection: Participants, Recruitment and Methods

### 3.3.1. Data Collection: Participants and Recruitment

Initially, I aimed to conduct eight to ten narrative interviews followed by the same number of photo-elicitation interviews. This is a lower number than considered sufficient in more traditional forms of interviewing (Guest 2016). However, narrative interviews with follow-up photo-elicitation interviews provide rich and in-depth data (Erdner and Magnusson 2011). This means that data saturation is reached with a lesser number of interviews. I recruited twelve participants, all of whom took part in the narrative interview and nine of whom also took part in the photo-elicitation interview. The population was defined as people who self-identify as psychiatric survivors, are aged eighteen or over and have an experience of receiving mental health treatment.

#### *3.3.1.1. Self-selecting, Strategic Opportunistic and Snowball Sampling Approach.*

Psychiatric survivors may be regarded as a closed-off or even hidden community as their experiences and lives are perpetuated by continuous experiences of stigma (Ward 2012, 192). The difficulty with closed-off groups is that there is a difficulty in recruiting participants outside of those who are ‘active’ within mental health communities like charities, local groups or those who engage in any form of self-activism (Kalathil 2015). It is crucial to speak to persons whose experiences might not be known even in those communities. In order to reach a wide range of psychiatric survivors, I followed a mixed recruitment method using used self-selecting, strategic opportunistic and snowball sampling approach in order to account for some diversity of experience (Ward 2012, 192). Demographic information is presented in Table 3.1.[77]

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[77] Table 3.1. is supplemented by Appendix 1: Demographic Sheet Questionnaire filled in by each participant voluntarily.

Table 3.1. Demographic Information.

| **Pseudonym** | **Gender** | **Age Group** | **Ethnic Group**[78] | **Do you consider yourself to have a disability?** | **Do you have a diagnosis of mental illness?** | **Do you have an Advance Decision to Refuse Treatment, an Advance Statement or a Lasting Power of Attorney?** | **Narrative Interview** | **Photo-Elicitation Interview** |
|---|---|---|---|---|---|---|---|---|
| Edward | Male | 55–64 | English | Yes. PTSD and disabling gunshot wounds. | Yes. PTSD. | LPA for health, welfare and financial (given to son). | Yes. | Yes. |
| Helen | Female | 65–74 | English | No. | Yes. Do not agree with the diagnosis (schizophrenia). | No. | Yes. | No. |
| Fred | Non-binary | 25–34 | Portuguese | No. | Yes. Anxiety and ADHD. | Advance Decision to Refuse Treatment. | Yes. | Yes. |
| Katie | Female | 25–34 | English | No. | Yes. Generalised Anxiety Disorder. | No. | Yes. | No. |

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[78] Please refer to Appendix 1. This question allowed participants to identify their ethnicity and nationality at the same time.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Lucy | Female | 35–44 | English | No. | Yes. Schizoaffective Disorder. | No. | Yes. | Yes. |
| Millie | Female | 25–34 | English | No. | Yes. Clinical Depression and Anxiety. | No. | Yes. | No. |
| Eliza | Female | 55–64 | Swedish/German/ English/Irish | Yes. Internalised disability due to forced treatment experiences. | Yes. Bipolar. | No. | Yes. | Yes. |
| Michael | Male | 25–34 | English | Yes. Asperger's and hypermobility. | Yes. Clinical Depression. | No. | Yes. | Yes. |
| Sophie | Female | 35–44 | English | No | Yes. Bipolar Disorder. | No. | Yes. | Yes. |
| Eve | Female | 55–64 | English | No | Previously. Bipolar. | No. | Yes. | Yes. |
| Albert | Male | 55–64 | Turkish | No. | Depression and Bipolar. | No. | Yes. | Yes. |
| Robert | Male | 45–54 | English | No | Depression. Bipolar. Anorexia. | No. | Yes. | Yes. |

Initially, my recruitment plan was to engage with the University of Birmingham-based mental health networks such as SureSearch[79] and the Institute for Mental Health,[80] the Centre for Health Law and Policy,[81] local and national charities, and social media such as Twitter. Appropriate recruitment materials were used.[82] In May 2019, I co-organised a workshop on advance decision-making.[83] At the end of the session, attendees, using the event's feedback form,[84] could indicate whether or not they wished to be contacted about partaking in research on advance decisions.[85] I began my recruitment by emailing those who were interested, which resulted in an invitation to speak at the SureSearch monthly meeting as a guest speaker. At the SureSearch meeting I presented the overview of my research topic. Consequently, I found a couple of participants and others contacting me as a result of snowballing.

Over the period of the first eight weeks, I created several tweets promoting the research.[86] These were shared by various related organisations and academics which meant that I received further expressions of interest. As a result, I reached some participants who are not active members of mental health-related communities through snowballing. At least five of my participants came through recommendation by another interviewee, admitting that they would not have known about the research or would not have considered taking part if it had not been

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[79] See SureSearch website here: https://www.suresearch.org.uk. SureSearch is a "service user involvement in mental health education and research". It is also a support network for service users.

[80] See the Institute of Mental Health website: https://www.birminghamhealthpartners.co.uk/programmes/a-draft-programme.

[81] See the Centre for Health Law, Science and Policy: https://www.birmingham.ac.uk/research/chlsp/about/index.aspx.

[82] Please see following Appendices: Appendix 2: Recruitment Materials including Recruitment Tweets; Poster; Website Text; Draft Emails to Charities and Organisations (which as indicated, was not used as charities were not contacted).

[83] Please see Appendix 3 for the flyer with information about the event.

[84] See Appendix 4: Feedback Form: The Future of Advance Decisions in Mental Health and Mental Capacity Law.

[85] Please refer to Appendix 4: participants also needed to actively agree that they understood the data protection notice and consented to their details being used in this way. Participants of this event were also informed about the possibility of withdrawing consent at any time.

[86] See Appendix 2 which shows the content of my tweets. These were included in the university's ethical approval process.

for their friend. The rest of the participants took part as a result of advertisement of this research project on Twitter. Overall, these recruitment techniques resulted in twenty-three expressions of interest from which twelve materialised into interviews. Thus, my recruitment techniques were successful, and I managed to recruit my participants within three months. There was no need to recruit participants via charity channels. Hence, I minimised the chances of reaching only active members of the various mental health communities. Participants were able to contact me using my University email provided as well as a phone number. This phone number was obtained specifically for the purpose of this research.

The snowball sampling recruitment strategy has proven successful in recruiting some participants but not others. Although it is hard to reach diversity with a small number of participants recruited for a qualitative research study, I found recruiting participants with specific sociodemographic differences challenging, even with the use of snowball sampling. Snowball sampling is based on the idea of contact tracing commonly seen in public health arenas, in which one person names all the other persons who were associated with a specific event/situation/characteristic (Sadler et al. 2010). This begins a process of snowballing whereby an identified individual with the desired experiences uses their social networks to inform others with similar experiences about the research, which launches a multistage process of recruitment. As a result, participants begin to 'recruit others', a process of recruitment that is often compared to "a snowball rolling down the hill" (Sadler et al. 2010, 370). The main advantage of snowball sampling is that participants who come through this way are likely to fit the criteria for participation easily. Another benefit of snowball sampling is that it produces a higher level of trust among potential participants, leading to those from hard-to-reach communities deciding to take part (Sadler et al. 2010, 370). The personal aspect inherent to this method shortened the time in which participants were recruited and also the period in which those participants who came through the snowball sampling, upon initial contact with me, expressed their willingness to take part, largely based on positive reports from their friends (the initial participants). Oftentimes, this was reiterated during the initial meeting.

Upon first expressions of interest, I noted that the research might struggle to attract a gender-representative sample. I asked the first few participants to encourage anyone else they might know to contact me about partaking. All but two participants who identify as males were recruited through snowball sampling. As a result, I recruited seven participants who identify as females, four as males and one as non-binary. As I received more expressions of interest and met with more participants, I noted that my recruitment efforts needed to be more conceived toward reaching participants from ethnic minorities as my data lacked diversity in this content. The empirical literature on mental health generally highlights the longstanding concern that research on mental health has extremely limited engagement with – and therefore lacks the perspective of – people from black communities and especially black women (see e.g., Kalathil 2009; Kalathil 2013). One of my participants is an active member of various mental health communities and has a special relationship with psychiatric survivors from black communities. The participant reached out to several potential respondents from those communities but later informed me that, although most appeared interested in the nature of the research, none of the individuals expressed a desire to participate even with the encouragement from the trusted individual. Kalathil (2009; 2013) suggests that it is both stigma and experiences of racism, not just in everyday life but in mental health research environments too, that lead to poor involvement. The reasons might also be more nuanced and intricate and related to the researcher's attunement to cultural and racial aspects of the lives and mental health experiences of individuals in such minority groups:

> Being a token 'black' person in an initiative whose structures and parameters are set up in a way that intimidates and silences one's cultural and/or racial identities is a common

> experience for many. In user-led spaces, the focus was on user/survivor identities and there was pressure to separate this part of your identity from other markers of identity, such as that of 'race', community or culture, or experiences of racialisation.
> (Kalathil 2013, 125; see also Kalathil 2009, 14–15)

Kalathil's (2009; 2013) insight is crucial to the understanding of this limitation in my research project. By relying on snowball sampling to recruit a more ethnically diverse sample, I overlooked "other markers of identity" (Kalathil 2013, 128) because I placed a particular and perhaps quite heavy focus on the 'psychiatric survivor' identity. The relevance of Kalathil's (2013) observation becomes even starker upon examination of my efforts to recruit from Asian communities. I had contacted a potential participant from an Asian ethnic background who attended the event on the Future of Advance Decisions. At the event, he suggested that I should get in touch when I was ready to recruit participants for my research as he had links with an informal local support group for people with experiences of mental health distress from Asian communities. I did so but, eventually, I was informed that the members of the community appreciated the premise of my research but were not interested in participating because my research did not focus specifically on the differences in cultural experiences. In hindsight, this was a missed opportunity for me to rethink my recruitment strategy because my narrative and photo-elicitation methods could have been successfully used and re-shaped to explore those cultural differences to enrich the examination of the desirability and potential of advance consent to mental health treatment. At the same time, to account for the cultural differences in a meaningful way, I argue that it is necessary to take this factor into account from the start of the project design stage, and it should not be an 'add on' consideration. Additionally, the total number of participants was relatively small which added further constraints to recruiting participants representing diverse backgrounds. In addition to Kalathil's observations (2009; 2013), I argue that relatability is another aspect or factor for successful recruitment. Throughout the course of this empirical research, I learned that relatability is key to building rapport, openness and trust. I reflect on the relatability aspect more in ‘Reflexive Remarks’ towards the end of this chapter.

Notwithstanding the general acceptance that snowball recruitment techniques do not meet the gold standard of probability sampling (Noy 2008; Sadler et al. 2010), this method of a self-selecting, strategic, opportunistic snowball tactic allowed me to enrich my data with participants who had varied experiences of mental health treatment in different parts of the country. In addition, this particular sampling technique is the preferred or even desired recruitment method for methodologies concerned with storytelling and narratives because this sampling method fits with the material and constructionist paradigm that focuses on specific experiences of marginalised groups (Noy 2008; Woodley and Lockard 2016).

##### *3.3.1.2. Participants and Recruitment: Language and Diagnosis.*

One of the first challenges encountered by researchers in any aspect of mental health research (Kalathil 2009), and as highlighted by the previous section, is finding participants that identify within the desired population. It is therefore important to consider the language used in the recruitment and research processes, in particular, the language of mental ill-health and diagnosis because language can result in perpetuating mental health stigma (e.g. Price 2022). In this section, I begin by examining the language of mental ill-health. I then move on to explore the reasons behind my choice not to focus on a specific mental health diagnosis/ diagnoses.

In more recent legal scholarship, the language of mental disability and psychosocial disability has been largely adopted and reflects developments in human rights approaches to mental health law.[87] Moreover, the language of mental disability recognises the social, environmental, and relational aspects of mental health.[88] Stavert and McGreggor (2018, 71) argue that adopting an understanding of mental health “in its widest sense of not simply encompassing mental illness or disease” would lead to a more meaningful implementation of relevant human rights that “can actually support human flourishing”, and I suggest that the same applies to the development and implementation of national mental health laws. Therefore, I initially intended to adopt the language of human rights or disability law scholarship. Nonetheless, I was mindful of research in other disciplines suggesting that people might not identify with their disability or illness or might identify with one or the other or both (e.g. Thomas 2007).

I was first met with such a situation when I presented my research project at the SureSearch meeting. In my presentation, I used the language of mental illness and disability interchangeably. In the discussion with participants afterwards, it became clear that the language was contested. Some people emphasised that they do not have a ‘disability’ and instead they are ‘ill’, whereas a couple of participants highlighted the disabling effect of their condition. Thus, it was clear that if I chose to use the language of mental disability or mental illness in my recruitment materials, I might not be able to reach people who do not consider their mental health experience as denoting disability or illness. Instead, in my recruitment materials, I focused on finding people with ‘experiences of mental health treatment’[89] to avoid the contested use of the terms ‘illness’ or ‘disability’ during the recruitment stage. In the empirical chapters of this thesis, I use a variety of terms as I decided to mirror the language used by my participants. It is worth noting that participants of this research were asked the

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[87] This is particularly visible in research focusing on mental health and human rights and in the context of the UN Convention on the Rights of People with Disabilities; e.g. Stavert (2021; 2022).

[88] Social model of disability and biomedical model.

[89] See Appendix 2 for recruitment materials.

question: “Do you consider yourself to have a disability?”.[90] Only Edward identified the diagnosis of PTSD as disability, and Eliza considered herself to have “internalised disability due to forced treatment experiences”. In Chapter 1 I explained the rationale for the expression ‘psychiatric survivor’, which was also adopted to avoid the use of the term ‘service users’. Participants who attended my presentation at the SureSearch meeting were also critical of this phrase. I consider the language of ‘psychiatric survivors’ it to be a useful umbrella term for people (who self-identify as such) who have had experiences of receiving mental health treatment for whatever if any, diagnosis whilst remaining mindful of the general critique of ‘survivor’ language.[91] The term also implies that I was seeking people with some prior experience in receiving mental health treatment.

It was also imperative to capture the diversity of experiences with different diagnoses because the majority of research on psychiatric advance decisions focuses on the context of episodic mental illness.[92] This is true whether we consider empirical studies (e.g. Gergel and Owen 2015) or theoretical explorations (e.g. Howell, Diamond and Wikler 1982; Bielby 2014). The benefit of psychiatric advance decisions is often contextualised through examples of anorexia nervosa (e.g. Davidson and Birmingham 2003; Coggon 2013; Johnston 2014, schizophrenia (e.g. Winston et al. 1982) and bipolar disorder or borderline personality disorder (e.g. Gergel and Owen 2015).[93] The justification for this focus is often that these examples serve as ‘hard cases’ where fluctuating capacity might be an issue because of distinctive symptoms specific to any of the mentioned disorders (e.g. Gergel and Owen 2015). Perhaps the benefit of advance consent is most ‘obvious’ in episodic mental illness. For instance, one

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[90] See Appendix 1 and Table 3.1.

[91] For instance, see Creswell’s (2005) exploration of this.

[92] Episodic Mental Illness refers to illnesses characterised by appearance of symptoms in brief periods or ‘episodes’. Examples typically include mood disorders such as bipolar disorder or psychotic disorders such as schizophrenia.

[93] Likewise, other studies who argue against psychiatric advance decisions also focus on specific diagnoses, see Lundahl, Helgesson and Juth (2020).

of the most common reasons for studying advance consent in schizophrenia is the presence of psychosis. Psychosis means that people might refuse treatment, not willingly, but rather because their voices/delusions instruct them to. Mental capacity might be fluctuating but the presence of psychosis rarely means capacity is absent (Gergel and Owen 2015). It might therefore be more compelling to make advance consent arguments in the context of schizophrenia.

However, I argue that this single-diagnosis approach to studying advance consent has only limited value in socio-legal analysis or legal implementation. The law on mental health has developed to be inclusive of all conditions. Developing a socio-legal analysis approach to one specific diagnosis is not legally meaningful and generalising from one 'set' of experiences does not capture the diversity of mental health treatment that may need to be requested in advance of relapse or incapacitation. Additionally, focusing on one specific diagnosis is not pragmatic because a) similar symptoms can be present in different disorders and people will often have multiple diagnoses and b) improper or changing diagnosis is characteristic in psychiatry (Markova 2005, 115; Bipolar UK 2022). Misdiagnoses could also lead to missed opportunities for seeking appropriate treatment. It takes, on average, nine-and-a-half years of symptoms and six misdiagnoses to receive a diagnosis of bipolar disorder in the UK (Bipolar UK 2022). Thus, to explore advance consent for a specific type of mental illness is problematic and carries a high risk of excluding people who could benefit from this instrument and whose diagnosis might change in the future. The majority of participants in this study spoke of a range of diagnoses they had received in the lifespan of their mental health treatment. Thus, recruitment was focused on people who had experience of receiving mental health treatment, rather than those with a specific diagnosis. The presence or absence of diagnosis was indicated in the demographic information sheet[94] where participants wished to do so, but whether or not that diagnosis was correct was not important – what was important was that diverse stories of treatment and care were obtained to inform the examination of advance consent mechanisms.

### 3.3.2. Methods: Narrative Interview and Follow-up Photo-Elicitation Interview.

#### *3.3.2.1. Rationale for Two-stage Interview and the Role of Photographs.*

Mental health researchers, such as Erdner et al. (2002) and Erdner and Magnusson (2011) have established that people with experiences of mental health distress struggle to candidly articulate those occurrences and associated processes, like their encounters with treatment. Experiences of stigma and trauma might mean that participants tend to be uncertain of new people, may lack confidence in their views and question their own memory because, for instance, episodes they recall could have taken place in a heavily medicated state (e.g., Erder et al. 2002; Erdner et al. 2009; Sandhu et al. 2013). In addition, they may manifest mistrust in the research process (Sandhu et al. 2013). Consequently, participants in verbal interviews tend to adopt a "wait and see approach" and passively await guidance or assistance from the researcher on answering questions (Erdner and Magnusson 2011, 145). Erdner and Magnusson (2011, 147) argue that unstructured, individual (rather than group) and verbal interviews are one the most appropriate methods for research with participants who suffer from mental distress. Taking these insights into consideration – along with coming from an angle of a researcher who has an appreciation of secondary rather than primary experiences of mental ill-health –attracted me to the idea of an unstructured or in-depth interview for several reasons as such methods of interviewing

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[94] See Appendix 1.

balance participant–researcher power relations. By limiting the number of questions, I would be able to ensure that participants were in control of articulating their own experiences without me – the researcher – imposing a certain order in which the stories would be told. Simultaneously, in this approach participants are able themselves to decide which aspects of their stories are given greater or particular meaning.

Additionally, scholars (Erdner and Magnusson 2011; Cabassa, Nicasio and Whitley 2013; Sandhu et al. 2013) encourage plural forms of methods in the context of mental health experiences. Moreover, some form of an unstructured interview with the use of visuals and designed around building rapport between interviewee and interviewer is thought to be of a particular benefit in this context. Studies which have followed this guide for research design, especially with the use of visuals, have demonstrated an improvement in rapport in the qualitative interview and help with memory triggering, plus facilitating time for reflection and opportunities for greater openness (Erdner 2002; Sandhu 2013). Despite this evidence, photo-elicitation remains a unique method for research with participants who suffer with mental distress (Erdner and Magnusson 2011) and in qualitative paradigms more generally (Close 2007; Prosser and Loxley 2008; Erdner and Magnusson 2011; Glaw et al. 2017).[95] Despite the emerging use of visual methods in law (e.g. Goodrich 1991; Moran 2009; Mulcahy 2017) the use of photo-elicitation for socio-legal research into mental health law is a novel approach. Therefore, the significance of this thesis also lies in the use of this unique method and provides an account of this technique which may be further developed in future studies.

Not all photo-elicitation methods are equal, and approaches to this method may vary. For instance, photo-elicitation may use researcher-created visual data (e.g. Rieger 1996; Posser and

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[95] See Prosser and Loxley (2008) for an overview of the history of visual research methods across art, humanities, social sciences and physical sciences.

Loxley 2008) or respondent-generated visual data (e.g. Sandhu et.al. 2013). I used the latter approach in this project as discussed in section 3.3.2.2. below. I also viewed photographs as ‘performative’. The rationale for using respondent-generated visual data was for the photographs to perform the role of eliciting stories that were not told during the narrative interview or to complement the story already told. They worked as a stimulus for eliciting stories and for the additional data that emerged around the images. They were acting as forms of support for the verbal interview, and so in this sense they might be said to be performative in their function. Consequently, photographs were not intended as a form of data in their own right.

Throughout this chapter, I emphasise that the rationale for using empirical inquiry to the study of advance consent is not only to address gaps in current knowledge and to provide empirically grounded answers to important questions relevant to the law on advance consent but also to include the authentic voices of those at the heart of the issue. One of the main goals of the narrative inquiry and narrative itself is to explore how participants create meanings based on their experiences. The approach of using a narrative interview complemented by a follow-up photo-elicitation gave me a close insight into the journeys of people with experiences of mental health treatment within the practical limitations of doctoral research. My method’s aim was to elicit stories of mental health treatment under the current legal regime to provide an understanding of advance consent’s potential in English law.

#### *3.3.2.2. Narrative Interview and Photo-Elicitation Interview: Conduct.*

The design of the narrative interview drew on the work of scholars who use biographic narrative methods (Wengraf 2001; Czarniawska 2004; Ward 2009; 2012) to encourage storytelling about a participant's own life and experiences. All interviews were conducted face to face between September 2019 and February 2020. The time between narrative and photo-elicitation interview varied between two to eight weeks depending on participants' and my availability.

The narrative interview was divided into four parts.[96] The first part consisted of an explanation of the interview process. I would tell participants that my research is focused on advance consent and that hearing about any experiences of mental health and mental health treatment would be very helpful. I would emphasise that the story is theirs and they should share whatever they wish to and omit any parts they wish to keep private.

The second part of the interview would begin by me asking participants a broad question, such as "How did you come to have experiences of mental health treatment? Tell me your story", to signal the beginning of their narrative interview. The opening question always followed the same general wording for each participant and was designed to encourage the telling of their mental health story without setting too many boundaries to the responses participants might give. Throughout the narrative field notes were taken on key topics or points. All participants chose to tell their story by recalling the event or series of events that led to them becoming unwell.

Once the narrative section was finished, in the third part of the interview, I would ask any clarifying questions (only where necessary and when for instance I was not clear on any parts of the story) and then I would conclude the interview by thanking the participants for their time and their invaluable insights.

At the end of the narrative interview, I talked to each participant about the photo-elicitation interview. I would explain that the primary aim of using photographs is to elicit

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[96] See Appendix 5: Narrative Interview Schedule.

stories that tell something about their experiences of mental health. Participants were encouraged to use photographs taken specifically for the interview or ones they already owned. I also reassured participants that they could take part in the follow-up interview even if they chose not to use any photographs. The reason for this was to ensure that any photos chosen or taken by participants were acting as stimuli for narrative data which emerged around images. The potential of participant-generated photographs rests upon the implication that they are likely to be particularly representative and significant for the participants (Walker and Weidel 1985, 143).

I found that participants were generally keen to take part in the second interview, and, consequently, nine out of twelve participants attended a follow-up session as per Table 3.1. Helen chose not to take part in the follow-up interview and Millie and Katie were willing to do so at first. However, they were both going through life changes that included moving to different parts of the country and eventually momentum was lost and the follow-up interviews did not materialise. All but two participants (Michael and Albert) produced between 2 to 30 photographs for the interview. Each photo-elicitation interview began with participants showing their photographs while telling their narratives. I was taking brief notes while participants were speaking of any aspects which I wanted to ask more questions about. It was important that I did not interrupt their narratives or spontaneous accounts told about their photographs. These photographs seemed to capture more spontaneous storytelling. People also told new stories which did not emerge during the previous narrative interview. They have expanded on their stories with new details. In general, the photographs were approached with a great deal of enthusiasm and openness. To my surprise, several participants prepared objects for the interview that they then wanted me to photograph while they were talking about what the items represented.

For instance, Lucy brought with her the diaries she wrote whilst going through a psychotic breakdown and asked me to photograph some of the pages to show how her handwriting was changing depending on the severity of her symptoms and how her entries differed from when she started the treatment to when she was ready to withdraw from it.[97] Another example was Eve, who showed me a ceramic box she had made which represents the trauma she had been through that resulted in a severe decline in mental health. She took the photographs herself during the interview. Examples of those photographs are below.

**Figure 3.1. Box representing a person who keeps 'pretty' and 'happy' exterior – Eve.**

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[97] Please refer to 'Ethical Considerations' in Part 3.6 of this Chapter where I discuss this in detail.

**Figure 3.2. 'Inside of the person' – complex and dark experiences that result in mental breakdown – Eve.**

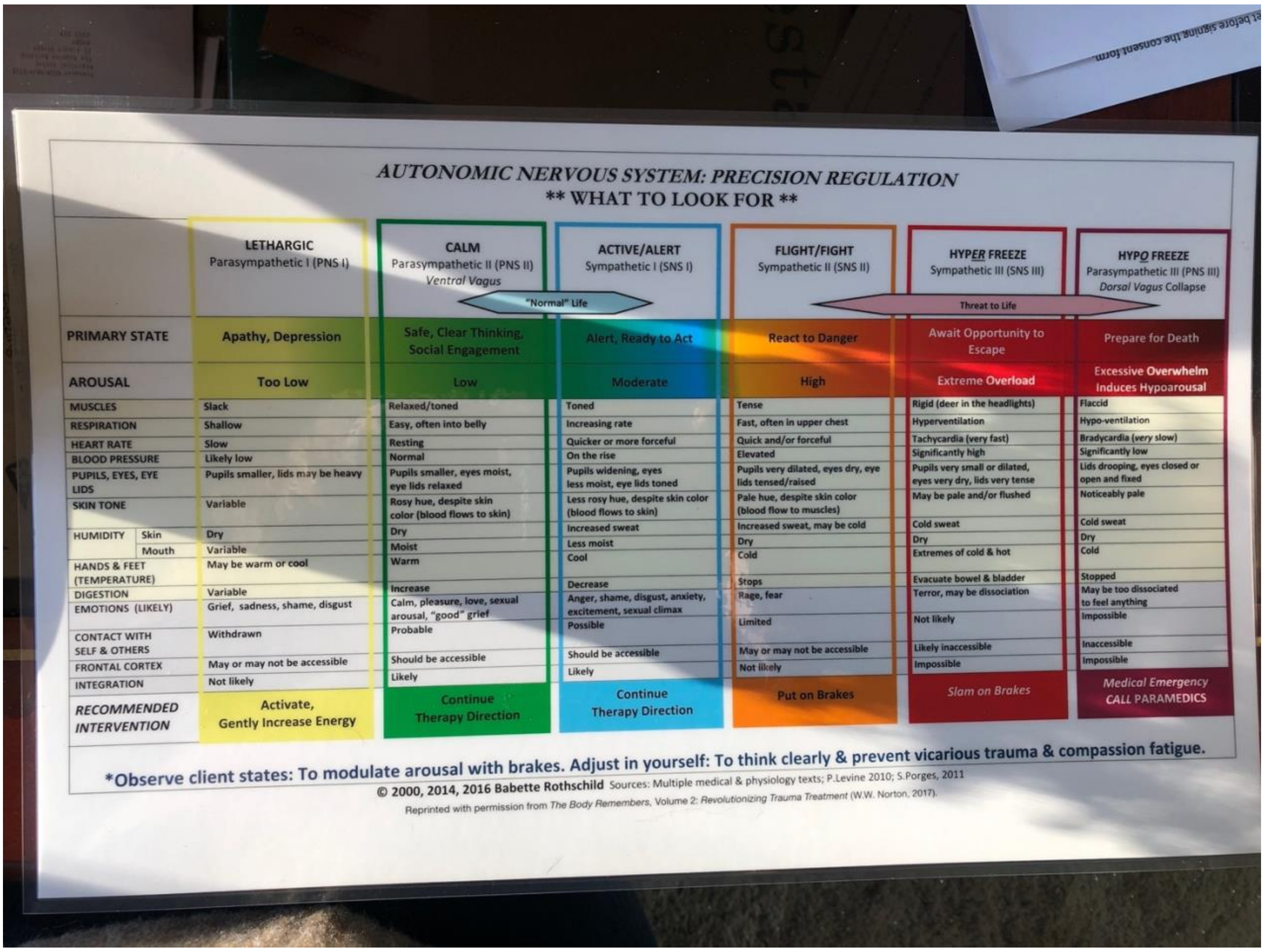
**Figure 3.3. Distressing external forces that limit recovery. (Eve)**

The first picture (Fig. 3.1) represents Eve who kept a pretty and happy exterior to cope with everyday reality which masked the other reality of mental breakdown for as long as possible to avoid stigma. The larger box contained many smaller boxes. The smaller boxes (Fig. 3.2.) depict that each person is made of complex experiences that might in later life trigger episodic mental illness. The third picture (Fig. 3.3.) represents additional forces in one's life that further inhibit freedom and wellbeing. These pictures are just examples of how photos helped Eve to tell her story in more depth, reflect on the experiences and events she shared during the first interview and highlight various values and events.

Other participants, like Sophie, shared photographs that told the direct story of mental health treatment. The picture below (Fig. 3.4.) was titled ‘A Road to Recovery’ by Sophie. She said that she took that photo after receiving mental health treatment for the first time. However, her ‘road to recovery’ later required a completely different cocktail of medication and support from a clinical psychologist. Thus, Sophie told a story about how recovery requires change based on one’s experience with mental health treatment. The only constant for Sophie in her recovery was the cup of tea as depicted below. Photographs symbolising recovery treatment were also common among some other participants. For instance, Eliza showed a photograph of the ‘Autonomic Nervous System’ (Fig. 3.5.) which she used to evaluate her feelings and mental wellbeing at the time of distress.

**Figure 3.4. ‘A Road to Recovery’ – Sophie.**

**Figure 3.5. ‘Autonomic Nervous System’ – Eliza.**



*AUTONOMIC NERVOUS SYSTEM: PRECISION REGULATION*
** WHAT TO LOOK FOR **

| | | LETHARGIC<br>Parasympathetic I (PNS I) | CALM<br>Parasympathetic II (PNS II)<br>*Ventral Vagus* | ACTIVE/ALERT<br>Sympathetic I (SNS I) | FLIGHT/FIGHT<br>Sympathetic II (SNS II) | HYP*ER* FREEZE<br>Sympathetic III (SNS III) | HYP*O* FREEZE<br>Parasympathetic III (PNS III)<br>*Dorsal Vagus* Collapse |
|---|---|---|---|---|---|---|---|
| | | | “Normal” Life | | | Threat to Life | |
| PRIMARY STATE | | Apathy, Depression | Safe, Clear Thinking, Social Engagement | Alert, Ready to Act | React to Danger | Await Opportunity to Escape | Prepare for Death |
| AROUSAL | | Too Low | Low | Moderate | High | Extreme Overload | Excessive Overwhelm Induces Hypoarousal |
| MUSCLES | | Slack | Relaxed/toned | Toned | Tense | Rigid (deer in the headlights) | Flaccid |
| RESPIRATION | | Shallow | Easy, often into belly | Increasing rate | Fast, often in upper chest | Hyperventilation | Hypo-ventilation |
| HEART RATE | | Slow | Resting | Quicker or more forceful | Quick and/or forceful | Tachycardia (very fast) | Bradycardia (*very* slow) |
| BLOOD PRESSURE | | Likely low | Normal | On the rise | Elevated | Significantly high | Significantly low |
| PUPILS, EYES, EYE LIDS | | Pupils smaller, lids may be heavy | Pupils smaller, eyes moist, eye lids relaxed | Pupils widening, eyes less moist, eye lids toned | Pupils very dilated, eyes dry, eye lids tensed/raised | Pupils very small or dilated, eyes very dry, lids very tense | Lids drooping, eyes closed or open and fixed |
| SKIN TONE | | Variable | Rosy hue, despite skin color (blood flows to skin) | Less rosy hue, despite skin color (blood flows to skin) | Pale hue, despite skin color (blood flow to muscles) | May be pale and/or flushed | Noticeably pale |
| HUMIDITY | Skin | Dry | Dry | Increased sweat | Increased sweat, may be cold | Cold sweat | Cold sweat |
| | Mouth | Variable | Moist | Less moist | Dry | Dry | Dry |
| HANDS & FEET (TEMPERATURE) | | May be warm or cool | Warm | Cool | Cold | Extremes of cold & hot | Cold |
| DIGESTION | | Variable | Increase | Decrease | Stops | Evacuate bowel & bladder | Stopped |
| EMOTIONS (LIKELY) | | Grief, sadness, shame, disgust | Calm, pleasure, love, sexual arousal, “good” grief | Anger, shame, disgust, anxiety, excitement, sexual climax | Rage, fear | Terror, may be dissociation | May be too dissociated to feel anything |
| CONTACT WITH SELF & OTHERS | | Withdrawn | Probable | Possible | Limited | Not likely | Impossible |
| FRONTAL CORTEX | | May or may not be accessible | Should be accessible | Should be accessible | May or may not be accessible | Likely inaccessible | Inaccessible |
| INTEGRATION | | Not likely | Likely | Likely | Not likely | Impossible | Impossible |
| *RECOMMENDED INTERVENTION* | | Activate, Gently Increase Energy | Continue Therapy Direction | Continue Therapy Direction | Put on Brakes | *Slam on Brakes* | *Medical Emergency*<br>*CALL* PARAMEDICS |

*Observe client states: To modulate arousal with brakes. Adjust in yourself: To think clearly & prevent vicarious trauma & compassion fatigue.

© 2000, 2014, 2016 Babette Rothschild Sources: Multiple medical & physiology texts; P.Levine 2010; S.Porges, 2011

Reprinted with permission from *The Body Remembers, Volume 2: Revolutionizing Trauma Treatment* (W.W. Norton, 2017).

Once participants finished sharing their photographs and telling stories about them I would begin the questioning phase by drawing on a photograph and their story. I would then ask questions about anything that came up specifically that was relevant to the broad themes of the interview[98] or directly relevant to the earlier narrative interview. I would then make links wherever possible to advance consent to elicit the opinions and attitudes of participants more generally, about relationships with doctors, safeguarding, experiences of forced treatment or instances of requesting a treatment in advance and then later on changing one’s mind about undergoing the treatment. However, these questions were dependent on the direction of the

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[98] See Appendix 6: Photo Elicitation Interview Schedule.

interview, set by the interviewee, and were constructed out of their stories. Although, the focus of the interview was clearly steered by me, both in terms of the chosen topic and the design of the opening question, within these parameters participants were free to set the agenda and designate their own comfort levels in terms of what information they chose to share.

Here, it is important to reiterate that I do not include any other photographs in this thesis. As emphasised previously, the photographs were performative in eliciting important stories. They were used to build rapport and to gain a greater insight into individual and subjective experiences and to complement the narratives told in the first interview. The vast majority of photographs were incredibly private and depicted important people in psychiatric survivors' lives or they depicted themselves. Some photographs were of various personal documents. To blur out faces or identifying information in order to anonymise those pictures and include those photographs in this thesis would lose the meaning that participants assigned to them. Additionally, from the start of this project, the rationale for using photographs was to elicit stories and that was reiterated to participants: the photographs were never intended to be used as data in their own right that would be analysed. It is the stories around the photographs, not the images themselves, that form part of the data used for my empirical chapters.

#### *3.3.2.3. Narrative and Photo-Elicitation Interviews Conduct: Final Remarks.*

A narrative interview followed by a photo-elicitation interview proved to be a useful strategy for this doctoral study in eliciting important stories about mental health. There are a couple of final reflections that are noteworthy. The first refers to the risk of distress to participants. Mental health researchers who have adopted plural methods of some form of in-depth interviewing and photo-elicitation interviews suggest that photo-elicitation interviews carry a greater potential for triggering upsetting or difficult memories as well as distressing emotions and that this risk is heightened in photo-elicitation interviews (e.g. Sandhu et al. 2013; Erdner and Magnusson 2011). However, there is no evidence that participant-generated photographs pose this higher risk and, in fact, it has been shown that, through the process of choosing photographs and preparing for the next interview, participants have the time to become familiar with those and learn to manage any emotions these might trigger (Erdner and Magnusson 2011). Nonetheless, the risk of distress is assumed to be greater in a photo-elicitation interview compared to a verbal interview.

I have found the opposite to be true. It seemed that narrative interviews were more triggering and upsetting for my participants. This is unsurprising when one considers that the majority of participants reflected after the interview that it was the first time they had had the opportunity, time and space to tell their entire story and had perhaps surprised themselves with new thoughts that had occurred and memories that came back whilst recalling their experiences. When and if a participant was becoming visibly distressed, I would suggest a break or offer to stop the interview. Only one participant wanted to stop the interview. The majority of my participants expressed the view that the process of giving a narrative was ‘cathartic’ and they appreciated the rare opportunity to be able to tell their stories. Again, this is not unusual as studies have shown that people with mental health problems do not talk about their experiences with family and friends and so they lack opportunities in everyday life to recount their experiences from their own point of view (Erdner and Magnusson 2011; Sandhu 2013).

Tinkler (2013) urges researchers to ask themselves whether their project will benefit from using photographs. The unquestionable benefit to my design was that this approach allowed me to continue to balance power relations and the level of participation that psychiatric survivors were comfortable with. It balanced these power relations by choosing to do research ‘with’ psychiatric survivors rather than ‘on’ psychiatric survivors. In this way, I viewed my participants as ‘experts by experience’. In addition, participants seemed more relaxed in the second interview: the rapport between myself and the interviewee had already been clearly established and it appeared that the power was distributed more evenly. The interview design most importantly gave space for participants to tell their story in their own words which, based on participants’ informal feedback, was the most valuable aspect of the interview/s.

## 3.4. Analysis: Thematic and Narrative Approach.

> … every time the person tells their story, they tell it in a different way, every time they tell it, the words are never the same. Some of the words will not be there next time. Every time they tell their story, there’s a danger of the person they are talking to damaging their story. The people not understanding it, saying the wrong things, being dismissive and then next time, part of their story falls away and they don’t tell the people, that’s why. The story changes every time, falls away and sometimes it falls away because it is not necessary next time because they’ve told it once but in the end all the bits that fall away, it gets left with a fixed part of the story. There’s a part of the story that you tell every time because that’s the part that’s left after it’s all been chipped off by other people’s misunderstanding, being dismissive, not listening, saying harsh or unkind things and that’s […] that’s why you have to keep some bits safe.
> (Eve, photo-elicitation interview)

Lawler (2002) suggests that participants who construct narratives engage themselves in an interpretative process. This process involves the interpretation of events and the participant’s own identity to construct a narrative. The above quote comes from one of my participants, Eve. She said it when discussing photographs that she has chosen in order to enhance and further tell her story of mental health. This quote is important when considering how narrative and follow-up interviews can be analysed so that the ‘fixed part of the story’ is preserved whilst nuances are emphasised. In this part of the chapter, I discuss the analytical approach adopted.

### 3.4.1. Thematic Analysis.

Riessman (1993, 30) has suggested that thematic analysis is one of the most appropriate approaches to the analysis of narrative data, indicating that it is particularly helpful to compare plot lines between participants’ stories, examining causal and material sequences, emerging key themes, patterns and turning points that signal “the break between ideal and real”. In this approach, plot lines are understood as twists or events that might point to the differences between participants and nuances to the understanding of the narrative (Ward 2012). To begin my analysis, I transcribed narrative and follow-up photo-elicitation interviews verbatim and analysed them thematically (Braun and Clarke 2021), first by hand and then using NVivo. In addition, narrative interviews were also preliminarily analysed for themes and topics for discussion in preparation for the photo-elicitation interview. All transcripts were examined for key themes and patterns in relation to socio-legal aspects of mental health and advance consent, such as stigma, experiences of treatment, doctor–patient relationships, the role of law in improving experiences, changes of mind, and safeguards. For each statement that was deemed as representative of one of those themes a note was made on the transcript in NVivo, and a note was made to link the excerpts to relevant research or law where appropriate. In addition, I highlighted ‘plot twists’ in each story. These are unique experiences or events which are crucial to the contextualisation of any particular experience. By doing so, I ensured that excerpts from thematic analysis would not be separated from the context of an individual experience.

The thematic approach was chosen for a variety of reasons. Firstly, thematic analysis caters for theoretical freedom (Nowell et al. 2017) which allowed me to analyse complex, rich and detailed data in a meaningful and systematic way that was consistent with my material-narrative and feminist methodological approach. The theoretical freedom in this way of analysing narrative is characterised by the discovery of both deductive and inductive codes generating anticipated and unanticipated results (King 2004). For instance, an unanticipated result that was coded related to the clinical notion of ‘insight’ which I explore in Chapter 5. Secondly, using narrative and photo-elicitation interviews which can be described as in-depth methods, I collected large amounts of data which meant that thematic analysis provided me with a rigorous way to effectively summarise findings. Finally, thematic analysis is consistent with my methodological approach because it begins a process of interpretation of data and prepared that data for narrative analysis (Strauss 1959; Czarniawska 2004; Ward 2009; 2012)

### 3.4.2. Narrative Analysis.

Narrative research attempts to acknowledge the diversity of individual stories, needs, values and behaviours located within the context of patterns and social disparity (Czarniawska 2004, 7). This approach allowed me to ensure that social structures which shape and contextualise experiences were not omitted in the analysis, and the context of the findings as well as the interplay between the narrative, law and society, have all been appreciated and accounted for throughout the empirical chapters. This is important as stories do not exist in the abstract (Plummer 1995; Czarniawska 2004).

Traditionally, a model of narrative analysis developed by Labov and Walezky in 1967 and later refined (1997) was considered to be the standard for narrative analysis. Here, the focus was on evaluating narratives in connection with time or temporality, space and situation. In this account of narrative, sequential clauses contextualised in time and space are necessary as they link the plots and storylines of narratives and are used to explore important events in people’s lives. Nowadays, due to the variety of epistemological and ontological approaches that underpin a narrative inquiry, approaches to narrative analysis are no longer monolithic. For instance, Riessman (1993; 2008) encourages the use of thematic analysis alongside structural analysis (to examine structures which underpin particular experiences) to give narratives meaning, whereas McAlpine (2016) encourages a chronological analysis of events and experiences to preserve the purity of the story, “to keep it intact” and to focus on a literary approach to the language used.

My approach to narrative analysis was influenced by the work of Strauss (1959), Czarniawska (2004), Nussbaum (2011) and Ward (2012). Czarniawska’s (2004) approach suggests that each narrative is constructed around equilibrium, action, and complication. Equilibrium is the life or part of the narrative that is undisturbed. Then, a complicating event occurs which disturbs the equilibrium and so action is then taken to restore the equilibrium. I adopted this approach so as to include looking at the central list of capabilities (Nussbaum 2011) and was therefore able to evaluate not only the reasons behind actions and complications but also the development of the disruption of capabilities that support crucial functionings.

This approach was crucial in identifying which capabilities psychiatric survivors value and have a reason to value. The freedom provided by the thematic approach and the rigour of my narrative analytical approach meant that I also developed a new capability outside of Nussbaum’s (2011) list: namely, the capability for safety. This approach was especially useful when examining the relationships between the participant’s capabilities, the mental health system at large and advance consent to mental health treatment. Here, the evaluative part of capabilities analysis included elements of thick description (Geertz 2008). I focused on the micro, meso and macro structures, relationships, institutions, and laws that shaped various experiences of mental health treatment. Each of those experiences was then evaluated in terms of how it enabled or hampered a specific capability/capabilities and what it meant in relation to justice (including agency). There, I included a thick description analysis to describe the realities and complexities of mental health lived experiences through the lens of capabilities. A thick description is considered to be a mode of capabilities analysis (Robeyns 2017, 134) and has been successfully used by scholars to analyse narrative data (Unterhalter 2003; Conradie 2013). In this thesis, thick description was used to ensure that context and meaning accompany the empirical claims I am making and to describe the feelings and actions of participants in a way that gave them meaning. Through evaluation and thick description the capabilities analysis provided a better understanding of advance consent as a legal phenomenon for achieving social justice for psychiatric survivors.

Although I adopted Czarniawska's (2004) approach outlined above, instead of looking at actions to restore equilibrium, I used Strauss's (1959) notion of turning points, with the overall approach being influenced by Ward (2009; 2012). Turning points are critical events/situations in people's stories which lead to a period of reflection and re-evaluation of an individual's life, values, beliefs and attitudes. For Denzin (1989, 2), narratives are built around significant "turning point moments or epiphanies" in the story that might change who people are. Turning points are particularly pertinent in the context of this research and are often presented as relapse, experiences of treatment, psychiatric appointments, decision-making and social relations post-diagnosis. Turning points mean that people try to realign themselves with their new reality following a mental health crisis. Turning points in the narrative tended to signal a new event that warranted relevance to advance consent, capabilities, decision-making or realignment/re-evaluation of values. The key turning points within the stories told by psychiatric survivors were characterised and flagged by the use of language in psychiatric survivors' narratives: for example, "And then what happened was …", "this led to great suffering, which in turn impacted on …", "just when you think it couldn't get any worse".

When exploring turning points in narratives, there was a clear need to examine what informs participants' choices in relation to treatment and support; how they make decisions; and how they adjust their lives in response to the complicating action. Each narrative was examined and three categories were used to identify analytic sections of narrative unit: life before and leading towards mental breakdown, psychotic episode or mental health crisis and responses to it. Psychiatric survivors' stories were often told in a disordered way with memories triggering memories and these triggering narratives about particular episodes, situations, relationships. This became especially apparent in the follow-up photo-elicitation interviews where participants often added to their narratives by saying 'oh I only remembered to tell you this after you left …', 'this reminds me actually …', 'wait, no, I now remember what happened'. This demonstrates that the stories told were not rehearsed and showed that the narrator was "an entity that thinks and feels, acts and interacts, reflects and evaluates its actions and interactions" (Tappan 1997, 381). With this in mind, I did not consider it necessary to ensure that the stories were told and analysed in chronological order.

### 3.4.3. Concluding Summary.

The thematic analysis combined with the interpretative thrust of Czarniawska's (2004) and Ward's (2009; 2012) work was an important analytical starting point for understanding the main themes, events and turning points that characterised each and all narratives. The capabilities informed evaluative analysis with elements of thick description that gave each narrative a meaning. It allowed me to evaluate micro, meso and macro structures, relationships and laws that are discussed in the empirical chapters of this thesis – Chapters 4 to 7 – to inform the understanding of the desirability and potential of advance consent. Participants have also received a lay summary of findings of indicated that they wished to.[99]

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[99] See Appendix 7.

## 3.5. Ethical Considerations.

This project has received the approval of the University of Birmingham's central Humanities and Social Sciences ethics committee (number ERN_19_0504) As is common with other qualitative research, I took care to ensure that results are reported with anonymity. I have developed a strategy for removing all of the personal details that may reveal identity: names were replaced by pseudonyms, names of persons such as children or spouses were removed and replaced with 'my child', 'my spouse' etc. I have also used broader geographical locations rather than counties and cities. If the participant mentioned, for instance, a city in the West Midlands area, the name of the city was removed in favour of the wider geographical location. This is particularly important in narrative research as any report of chronological events in one's life over a number of years might make recognition somewhat possible. Participants, where requested, had an opportunity to read and redact their transcripts though none of the participants requested to do so. Informed consent was obtained from each participant[100] and all participants had the capacity to consent to research. There was an ethical concern to ensure that participants were also well enough to take part in the research. As such, participants were self-selecting, recruitment advertisements specified that the project sought people with previous experiences of treatment, and the ethical documentation specified that participants needed to be "in control of their symptoms".[101]

Notwithstanding the more obvious and widely considered ethical and legal issues when researching human subjects and especially psychiatric survivors, the use of images raised additional concerns. The issue of informed consent to the use of visuals was of paramount

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[100] See Appendix 8: Consent Form (Narrative Interview) and Appendix 9: Consent Form (Photo-Elicitation Interview). Participants were provided with Participant Information Sheet for each interview, see Appendix 10: Participant Information Sheet – Narrative Interview and Appendix 11: Participant Information Sheet – Photo-Elicitation Interview

[101] If I thought it was necessary, participants were provided with Support Information Sheet, see Appendix 12.

importance. It is advocated that researchers should have an open conversation with participants about the purpose and the possible uses of visuals (Tinkler 2013). Prior to the follow-up interview, I explained to participants the reasons for using photographs and that their aim was mainly to aid storytelling. Participants were told that if sharing photographs was not something they were comfortable with we could just meet for a follow-up verbal interview. However, all participants but one produced photographs during the photo-elicitation interview. The standard consent form was obtained prior to the start of the follow-up interview. At the end of the interview, an individual consent for each photograph was negotiated.[102] Participants were given the choice whether they would like to leave their photographs with me and whether they agreed to different forms of publication etc. The ownership of photographs was also considered in detail (Tinkler 2013).

Anonymity and the right to privacy in relation to others who were in photographs was carefully considered. Initially, I planned to blur out any faces (Prosser and Schwartz 1998). However, due to worries about anonymity, I discussed with participants that I would not be taking copies of any photographs with people in them. Any photographs with identifying information (names and places) were also removed or excluded from use outside of the interview. The removal of identifying information was discussed with the participant. Ethical issues that arose in this research will be discussed in the reflexive conclusion below.

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[102] See Appendix 13: Consent for Individual Photographs.

## 3.6. Reflexive Remarks.

In this thesis, my goal was to make more transparent the thinking, processes and procedures involved in experiences of mental health treatment and decision-making. I have employed narrative methodology to examine mental illness and mental health treatment or care as flexible concepts best understood as situated within the context of psychiatric survivors' broader life experiences and relevant capabilities. To employ any other technique in examining those experiences would put me in danger of categorising those experiences within the medical model by focusing exclusively on treatment experiences. The narrative allowed me to examine a spectrum of experiences to emerge within the context of the person's story. The results are not victory narratives of those who survived mental illness but they are tales of triumph over adversity. At the same time, these accounts do not simply talk of failures. Instead, a complicated set of stories emerged that were unexpected and even influential in changing the nature of the research. This in turn helped me shed light on some of the most difficult questions asked in law about advance consent.

An interview is not an exchange of views (Kvale 1996). Czarniawska (2004, 50), therefore, contends that a more appropriate term would be interrogation or inquisition. Interviews are a collection of opinions and attitudes about something that is researched. If the point of the enquiry was not present in a research interview, it would not be research (Czarniawska 2004, 50). The question I asked myself before embarking on the choice of methods was whether I believed that an interview should be an exchange of views. Kvale (1996) claims that conversations are the main practice for knowledge production. Semantically speaking, knowledge production explained this way seems to be more of a dialogue and less of an interview. The disadvantage of interviews is therefore a clear asymmetry of power between the interviewer and the interviewee. It became increasingly clear to me that I had to give as much power back to the participants as possible. The narrative interview with a follow-up photo-elicitation appealed to me because in this method the participant was the only expert on the subject of their personal experience. In exchange, what I had to offer was not my views but respectful, non-judgemental, and interested attention. The importance of this approach has been emphasised by the feedback I received from one of the interviewees following Eve's photo-elicitation interview:

> it was great to talk to you and you are a lovely listener. Just to say that it is unusual to have someone who is able to listen without knocking some of the words off with careless responses and a lack of understanding. So, thanks for that.

The above feedback might be a testament to the narrative method rather than a credit to me. At the same time, it brings me to consider my position as a researcher interested in the experiences of psychiatric survivors whilst not having suffered from mental illness myself. My experience of mental distress is that of an informal carer which also meant that I have biases and preconceptions about the experiences examined for this thesis. I was able to mitigate any bias by the use of the narrative method. Throughout the interviews and the analysis, I was becoming consistently surprised by findings that did not match my pre-conceived expectations. This research has therefore challenged my own views and opinions.

It has also been important for me to carefully construct cameos and choose excerpts for reporting findings since the lengthiness, the richness of findings and the practical constraints of a doctoral thesis have forced me to leave out much of the data. In addition, I did not want to add meaning that was not in the original narrative as I blended the diverse experiences to derive common stories and themes. This is crucial as, over the course of two interviews and several hours spent with each participant, I developed a privileged intimate knowledge of each individual. For instance, one of the interviewees during the first interview questioned me about whether I should interview people who are currently in the midst of psychosis to see whether their perspectives on treatment are very different from those who are reflecting on past experiences. After explaining the practical and ethical complications of such an approach, the participant decided to gift me with the journals she wrote over the 18-month episode of severe psychosis. She had communicated with her psychiatrist, herself and her family only through her entries as ‘voices’ did not allow her to speak out. She insisted I take photographs from original handwritten entries and gave me a typed-up version of her journals. For her, the journals are part of her narrative and had been so imperative to her recovery that she insisted that her experience could be only contextualised with insight into the diary. Her journals revealed something unique – the consistency between her recall of her experiences with those experiences as they were occurring. Her thoughts on treatment, her willingness and unwillingness to undergo treatment appeared similar in her current narrative and her past narrative. However, those conclusions about the complementary nature of her journals are evident from the recording itself and the conversation around her journals. At first, the participant wanted me to take her handwritten journals with me and use them for the purpose of this thesis. I refused to do so, explaining to her that the personal nature of the documents and the fact that they were her original copies could raise some serious ethical questions. I decided to take photographs of some of the pages she was quoting from but decided not to use the photographs in this thesis. In order to use them for analysis, it would have required me to apply for an amendment to my ethical approval and, after re-listening to the interview, it did not seem to me that the benefit of analysis of the diaries would be greater than what had already been discussed in the interview.

## 3.7. Conclusion.

This chapter has offered an account of my novel methodological approach to socio-legal examination of advance consent to mental health treatment. I have discussed the underpinnings and reasons for choosing a feminist material-narrative framework. In my choice of methods, I have contributed to socio-legal knowledge by offering a new way of studying lived experiences of mental health law through the combination of narrative and photo-elicitation approaches. Additionally, I have provided a unique account of my analytical approach underpinned by the capabilities analysis.

The next chapter is the first empirical chapter of this thesis, where I draw on the data collected and in which the analysis is conducted. That chapter is a meta-narrative of lived experiences that I categorise into three different relationships and explore the main sources of unfreedom found in people's narratives.

# CHAPTER 4: REPAIRING RELATIONSHIPS: METANARRATIVE ON PSYCHIATRIC SURVIVORS' COMPLEX EXPERIENCES OF MENTAL HEALTH TREATMENT

## 4.1. Introduction

This chapter is a metanarrative of psychiatric survivors' experiences of mental health treatment. A metanarrative should be understood as an overarching account and interpretation of people's narratives associated with their experiences of mental health treatment as told in narrative interviews, unprompted by any questions. To construct the metanarrative I have used the analytical frame of turning points.[103] Turning points are significant aspects of the story and include experiences of mental health treatment, decision-making and relationships. Accordingly, this paints a picture of what it means to be a psychiatric survivor and demonstrates how taking the capabilities approach to those experiences gives them meaning.

By using the capabilities approach I have been able to conceptualise three types of relationships that both underpin and structure this overarching story. This chapter begins with psychiatric survivors' personal relationship with themselves and their values. It is a relationship that attempts to preserve agency by staving off a mental breakdown until a survivor reaches the tipping point. I argue that psychiatric survivors delay seeking treatment because they value their life pursuits and life roles, like building a successful career or being a parent, more than good mental health. Moreover, at this point in the story, psychiatric survivors perceive mental health treatment as something that might hinder the pursuits that they value so much.

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[103] Please see section 3.4. of Chapter 3 for details on the analysis of 'turning points'.

The story then moves on to examine the complex relationship between mental health treatment and the professionals who facilitate it, as well as exploring the value of planning for future mental ill health. This relationship with professionals comes after the tipping point has been reached. Here, I explore the value of relational continuity of care and argue that a doctor–patient relationship must be built on mutual trust, respect and understanding of an individual's values, needs and experiences. Using the capabilities notion of unfreedom, I conceptualise how experiences of treatment and the doctor–patient relationships can be perceived as sources of unfreedom and how moving towards relational continuity of care can strengthen and repair those relationships and bring about a shift towards greater agency in mental health care and treatment. I then go on to argue that achieving agency freedom requires opportunities for planning for the future.

Finally, I explore the third relationship that forms the final part of this metanarrative: namely, the relationship between psychiatric survivors and society. I argue that this relationship is characterised by stigma which is an example of structural violence. I contend that the relationship needs to be reimagined to promote the full inclusion of psychiatric survivors in their communities, following experiences of treatment. I then conclude that capabilities thinking about agency provides practical solutions through which justice can be achieved.

## 4.2. The micro-level relationship between psychiatric survivors and their life roles, pursuits and values: valuing things other than treatment

As discussed in Chapter 3, the psychiatric survivors involved in this study were not required to tell their stories in any particular way. However, each story recounted in this research began with psychiatric survivors providing a brief background of their life stories to contextualise the first episode of mental distress, or a breakdown, in the words of psychiatric survivors. Those life stories were communicated briefly and can be described as traumatic, exhausting, or stressful. For instance, Sophie suggested that her problems with mental ill health could be traced back to her childhood and becoming a subject of her mother's Munchausen-by-proxy syndrome:[104]

> My mum has a Munchausen-by-Proxy, and she would hold my face under a boiling kettle to hurt me and then get attention from the doctors, and I can talk about all these horrendous things that happened to me, but why?
> (Sophie, narrative interview)

In her brief account of inflicted injuries and traumas during her childhood, Sophie mentioned that she had spent most of that childhood and her early adulthood in abusive relationships. Eve also experienced abuse and neglect in her early years. In contrast, other psychiatric survivors recalled happy childhoods filled with love and familial support. For example, Lucy and Helen remembered having had happy and fortunate lives growing up. However, Lucy suggested that she may have exhibited her first psychotic symptoms when she was as young as eight years old. Though, she was perceived as a child with a luxuriant imagination and Lucy herself was not able to recognise at that age that her experiences were perhaps a symptom of mental ill health. At that stage, the symptoms were mild and not particularly disturbing, hence going unnoticed. Lucy told a story of her first "floridly psychotic" episode resulting from increasing pressure due to the demands of her new job and her ambition. She confessed that her life up until her first "mental breakdown" was "normal and quiet, nothing out of ordinary". Helen's decline in mental health was triggered by a relationship breakdown. While, similarly to Lucy, Robert associated his mental health problems with losing his job at the height of his career

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[104] Munchausen-by-proxy refers to what is now known as Factitious Disorder Imposed on Another. This is a form of child abuse which involves a parent or a carer fabricating or inducing illness on a child. The reasons behind this disorder are not well-understood. See NHS' Overview of the Fabricated or Induced Illness here https://www.nhs.uk/mental-health/conditions/fabricated-or-induced-illness/overview/ or WHO (2019/2021) ICD-11 section 6D51.

because prior to that he had lived an "ordinary and happy life". Meanwhile, Edward's experiences were the result of his career as a soldier and then losing his beloved wife, and both Fred and Michael recalled the struggles of coming to terms with their sexuality as the main factor contributing to the decline of their mental health. Nonetheless, in all cases the psychiatric survivors had encountered both good and bad experiences with mental health treatment.

The majority of life stories before a 'mental breakdown' can be described as ordinary. These are stories of people who are living their lives, pursuing their goals and ambitions. They are people who are facing everyday life disappointments and people with a variety of human and everyday experiences. However, what makes this metanarrative extraordinary is the awareness developed by psychiatric survivors which informs them that their mental health is deteriorating and that this deterioration is likely to reach its culmination at some point. In this part of the chapter, I refer to such a situation as 'holding off a breakdown', which is characterised by a delay in seeking treatment. I argue that this delay is closely connected to what people value like personal relationships, family life and career development.

The story progresses to what I describe as the 'tipping point'. Tipping points are an example of turning points in the metanarrative whereby psychiatric survivors experience an event leading up to their first experience of mental health treatment. This is a significant event in which psychiatric survivors begin to lose control over their lives, at least to some extent. However, reaching the tipping point also means that psychiatric survivors began to re-evaluate their values in pursuit of agency freedom.

### 4.2.1. Holding off a breakdown and the tipping point: metanarrative

Holding off a breakdown is taxing in many ways. It can have a variety of impacts upon an individual's life and is often accompanied by disturbing symptoms of mental distress:

> I've always felt that I was holding off a breakdown of some sort and that at some point I would go 'bang' […] but you hold off 'going bang', you don't want to 'go bang'. So, I had times in the past when I felt depressed and suicidal. I have never told anyone at the time.
> (Eve, narrative interview)

> I remember thinking in January 2007 "I'm going to have a breakdown". I distinctly remember that […] The best way I can describe it is that I felt like a coiled spring. Like someone was winding me inside, tighter and tighter and tighter. My head just physically began to hurt. The other thing was that I was hearing a voice at the time. Not as frequently as once I had a breakdown, but it was definitely building. The tension I was carrying made me want to self-harm.
> (Lucy, narrative interview)

> I was so choked up with emotion […] I'd hidden it from so many people for so long.
> (Helen, narrative interview)

The above accounts of holding off a breakdown are not unique in that most of the psychiatric survivors described similar feelings and behaviours. Holding off a breakdown is a demanding task because the symptoms of the illness begin to seep in and the task of "holding it together" (Robert) becomes harder with time, often because symptoms of mental illness become more pronounced. Accordingly, based on the various descriptions of holding off a breakdown, it does not have a set time or longevity. It can last for the majority of one's life, like in Eve's or Sophie's examples, or it may last a few months, as in Lucy's case, and anything in between – namely, two years for Robert and five years for Eliza. As a consequence, holding off a breakdown results in a delay in seeking treatment or support, but there are important reasons why people choose to do this:

> [The] reason why I was pushing it off [breakdown] was because I suppose I set my career goal high. I was going to be the first non-teaching head of a school, that was what I wanted to do and I was on my way to doing that. I've made that assistant head of year group for three years and I thought to myself "gosh I could really do this. If I work really, really hard then I could do this, it's possible".

> (Lucy, narrative interview)
>
> I had a bit of a breakdown, but I held off seeking help when I was 29. I left my first teaching job. I joined my husband who was working about 80 miles away. It was a bit of a life crisis for me. I got married and I had two beautiful children. Being a mum and a homemaker was more important. At that point, I carried on pretending everything was okay.
> (Eliza, narrative interview)

In this metanarrative, at the time during which they were holding off a breakdown, psychiatric survivors were doing so because they valued specific life pursuits or life roles more than seeking help for their deteriorating mental health. In addition, seeking treatment or help was perceived as potentially at odds with those pursuits. Eliza recalls that having a family had a drastic impact on her priorities. She had left her career to care for her successful husband and her young children. Thus, her decision to delay treatment was made in consideration of her responsibilities as a mother and a wife. Lucy recalls holding off her breakdown and disregarding her symptoms in a desperate attempt to reach her career goal. She had always been an ambitious person and, at that point in time, her career took priority. She explained this was more valuable to her because of the work she had done and because of life compromises she made to “get there”. She also reflected that successes related to her career were what had always given her a true sense of happiness and there was a sense that seeking help would disrupt that happiness. For Helen, it was also imperative to preserve her family life as one undisturbed by her illness. Meanwhile, Eve wanted to enjoy her new romantic relationship whilst Robert did not want his family to experience any financial hardship should he be hospitalised. Mavandadi et al. (2018) and Pavlova and Berkers (2022) found that people are more likely to seek help or treatment for mental ill health when it is perceived or framed in terms of benefits rather than risks. Consequently, people are more inclined to seek help if it is associated with positive change (Pavlova and Berkers 2022, 639). In this metanarrative of holding off a breakdown, there is a clear conflict between people’s values and pursuits and what mental health treatment can offer. At this point in time, the treatment was not viewed as something that could bring about a positive change. Moreover, it also points to the deeply internalised public stigma of receiving such treatment as something disabling to one's life (e.g. Mavandadi et al. 2018).

Psychiatric studies suggest that the delay in seeking treatment is a symptom of a mental disorder in itself because at this stage patients do indeed have relevant insight[105] to recognise their deteriorating mental state (e.g. David 1990; Thompson et al. 2001; Ramu 2019). Perspectives from sociology and health sciences suggest that this delay is rooted in the stigma and fear of psychiatry itself (e.g. Rickwood et al. 2007), but my analysis suggests this actually comes later in the experience of mental distress, usually following the initial treatment or an inpatient hospital stay. Instead, psychiatric survivors hold off a breakdown because they are 'just people'; people who prioritise other pursuits such as family life or a career over their mental wellbeing whilst being aware that their mental health is in decline.

Nonetheless, the treatment can only be delayed to a point, otherwise, it could be inferred that psychiatric survivors have complete control over the development of their mental illness which would therefore transfer the full responsibility for what is happening on to them. Instead, the choice of psychiatric survivors' language is indicative of knowing that the breakdown is coming. It can be held off, but it cannot be stopped. For most psychiatric survivors there was an identifiable event, 'the tipping point' at which experiences of mental health treatment began, see Table 4.1 below:

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[105] Note that I discuss the notion of 'insight' and its relevance to this research throughout the entirety of Chapter 5. Insight in the above context means awareness of one's mental illness.

Table 4.1. Metanarrative excerpts on the tipping point - narrative interviews.

In 2007 my dad died in a very extreme way. He was lost at sea. Never had his body back or anything like that. That was kind of like the tipping point. And the way I look at my life is in two halves.
(Sophie)

The next thing I knew it was a Monday, 14th May is when I had a breakdown, my actual breakdown. I was in the office. A child didn't knock on the door and just barged in and I just lost it. I'm grateful to say, thankfully, I didn't lay a finger on him but I wanted to shake him and say "why didn't you knock?". I remember just sort of my manager looking at me and saying, "you need to go home and you need to go to the doctor" and I thought, "yes, I probably do".
(Lucy)

My husband and I were mixing concentre and putting up a fence in the garden. I don't know, something snapped, something snapped. My mind started to race. […] and I tried to fight [the breakdown] off […] something snapped.
(Helen)

I was also working at Tesco's which I hated. One day, I just I don't know what it was, I went to put some bread out of the way, right? Broke down and I said, I can't do this anymore. I'm going to the doctor.
(Michael)

I was driving in [the city] one day and I pull over and I start crying. I said to my wife 'I went mad'. Suddenly, it started coming back. Flashbacks. The experience of living through it again. The pain and everything else like that. I thought I need to sort it out and my wife said "you need to go see the doctor".
(Edward)

Here, Sophie was able to pinpoint a specific event, her father's death, as the tipping point. The event forms a crucial part of Sophie's story and is defined by grief, sadness, anger and undeniable pain. It is not difficult to understand why a tragic event might trigger a breakdown and the inability to hold it off. However, tipping points are not always triggered by an objectively tragic event. In Lucy's story, the tipping point can be characterised as a culmination of symptoms that were tipped over by a seemingly insignificant event. Without the context, the event seems trivial, and Lucy's reaction exaggerated. However, by understanding that Lucy's symptoms had been amplifying for five months and that she started to feel “crippled by it” to the point she could not function, it is not difficult to recognise that the event was ‘the straw that broke the camel’s back’. Helen, Michael and Edward also became overwhelmed and tipped over by their emotions during routine daily tasks which speak to Lucy’s eloquent description of the emotional burden experienced by holding off a breakdown:

> [Holding off] was an ongoing struggle, I guess. The one that builds up. If you imagine wearing a rucksack and you know, stress was a brick block and you were just adding, adding, and adding to the point when you just feel crippled by it, you can’t function.
> (Lucy, narrative interview)

These stories of the tipping points are also turning points in people’s metanarrative on mental health treatment. For most, reaching the tipping point resulted in seeking help. This comes at the point where the breakdown cannot be held off or doing so would potentially result in more devastating consequences on those important life pursuits or life roles. However, not everyone sought treatment at the tipping point. Eve and Eliza were both subjected to compulsory treatment, which forms part of the focus of Chapter 5.

### 4.2.2. Discussion: preserving agency freedom

The main concepts of the capabilities approach are ‘functionings’ and ‘capabilities’. Functionings are doings or ways of being (e.g. Sen 2002, 383–384), such as being illness-free or being treatment-free or holding off a breakdown. Capabilities are the genuine opportunities individuals can achieve, but only if they choose to do so, for particular functionings (e.g. Sen 2002, 384; Robeyns 2017, 39). In order to achieve these functionings, capabilities are needed which are shaped by interactions between individuals and their environments, including their social relationships and their values. Likewise, functionings, such as being illness-free, are often more environmentally and socially shaped rather than being acquired by an individual (Venkatapuram 2011). Therefore, the basic principle of capabilities thinking is that what makes for a good life is having capabilities and freedom to achieve valued functionings to enhance human flourishing/development. Thus, the evaluative focus is on the extent to which people are free and able to be and do what they have reason to value being and doing (Sen 1985, 203). This refers to the idea of agency freedom:

> A person's 'agency freedom' refers to what the person is free to do and achieve in pursuit of whatever goals or values she regards as important. A person's agency aspect cannot be understood without taking note of his or her aims, objectives, allegiances, obligations […] Agency freedom is the freedom to achieve whatever the person as a responsible agent, decides he or she should achieve. (Sen 1985, 203–204)

These features of the capabilities approach are useful for conceptualising reasons behind holding off a breakdown, thus delaying seeking care and only choosing help at the tipping point. The basic interpretation behind this metanarrative is that for as long as symptoms of mental distress are somewhat manageable (can be held off) people value things other than their mental wellbeing. At the tipping point, they might still value things other than their mental wellbeing but they can no longer actively pursue or enjoy those life pursuits or life roles. This beginning part of their story sheds light on the agency exercised by those in mental distress. I argue that people delay treatment because at the stage of 'holding off a breakdown' they are valuing their functionings (what can be achieved at that moment in time) over capabilities (what opportunities they have for the pursuit of mental wellbeing that will later result in valued functionings). By doing so, they exercise agency freedom (e.g. Sen 1985; Sen 1999; Sen 2002). What follows is a clear need to develop support frameworks around treatment decisions that consider the particularity of individuals' experiences and the importance they assign to relationships at micro-level (like everyday roles and pursuits), meso level (like the one they have with their own mental health care) and help-seeking and macro relationships with larger structures, such as laws, medicine and society, that shape and influence their agency freedom because people are only as free as their environments allow them to be (Sen 2002, 37).

Some psychiatric survivors stated that, with hindsight, the delay in seeking treatment was good for the preservation of their life ‘as it was’, but it was detrimental to their future lives and pursuits, or in capabilities lexicon – the alternatives to the life as it is which could improve freedom and social justice. For Lucy, seeking mental health treatment and striving to be an assistant head of school appeared mutually exclusive. Yet, Lucy later reflected that the delay in seeking treatment was a contributing factor to her eventually changing career. For Robert, seeking treatment and providing for his family were at first mutually exclusive actions. However, on reflection, a vast majority of psychiatric survivors stated that they would not have delayed treatment had there been a way to ensure that they were listened to and that their life concerns were accounted for when treatment decisions were being made. In the psychiatric survivors’ metanarrative, the presence of mental illness in itself does not inhibit their valued functionings (being a parent, a spouse or being career-focused) but there is a strong perception that encountering mental health services will hamper those functionings. At the tipping point, however, they begin to place value on capabilities which encourage seeking help, in the hope that they can still continue enjoying their valued functionings and preserve their agency freedom.

Individuals differ in the value they place on particular functionings, which means that focusing on capabilities to achieve functionings, rather than functionings themselves, avoids imposing particular ideals on everyone, such as arguing that being a spouse or being career-focused ‘is’ a valued functioning for every psychiatric survivor. Nonetheless, agency is a common functioning that participants value. The guiding idea and argument arising from this part of the metanarrative is that psychiatric survivors must be treated as individuals, whole persons (not just medical patients) and their subjective experiences, values and life projects must be at the forefront of health-related decision-making in a broadly conceived mental healthcare.

## 4.3. Complex relationships with mental health treatment and the value of planning: sources of unfreedom/freedom, option freedoms and agency freedom

In their narrative interviews, psychiatric survivors paid significant and scrupulous attention to recounting their experiences of mental health treatment. The majority of participants referred to their life as ‘before’ and ‘after’ treatment rather than before and after mental illness or diagnosis, indicating the significance they attached to their experiences of mental health treatment. In this section, I argue that the relationship between the patient and the mental health (or medical) professional is crucial in conceptualising whether these treatment experiences are either a source of freedom or a source of unfreedom (Sen 1999; Sen 2009). I then move on to examine the role of planning for future mental health crises and argue that an ability to plan for the future is an ‘option freedom’ (Pettit 2003; Robeyns 2017) which is a sub-category of agency freedom.

### 4.3.1. The complexity of mental health treatment and relationships that lead to freedoms

Participants’ narratives of seeking mental health treatment can be characterised by a series of disappointing, unhelpful, harmful and sometimes life-altering treatments, as well as treatments that are effective, helpful and even lifesaving. Consequently, finding the right treatment is often a journey that may take months or even years. In addition, not every clinically effective treatment is experienced as a ‘good’ treatment. Instead, a good treatment can be described as a treatment that is not just clinically effective but is individualised and facilitated by a professional who is sensitive to people’s values and needs, a relationship which therefore facilitates the achievement of the capability for bodily integrity, enhances agency freedom and prevents the treatment from being experienced as unfreedom. The complexity of mental health treatment and the doctor–patient relationship was well depicted in Lucy’s long narrative excerpt in Table 4.2 below.

Table 4.2. Long narrative interview excerpt – Lucy.

[Experience of Early Intervention Treatment lasting three years]

About a week and a half in probably… since first going to the GP, the early intervention service got involved and I have to say, out of all the different treatments and out of all the different people and professionals I’ve encountered, they were outstanding. They were amazing. They were just what I needed. I kept journals when I was ill, so when I felt like I couldn’t talk to the psychiatrist about what was going on because the voices would be sort of saying “if you tell the psychiatrist you are going to die or your family or whatever it might be”. So that was happening often and when it was happening, I would just give my journals to the psychiatrist and be like “can you just read it?” and I found that really, useful. Initially, I wasn’t sure how they are going to take it, are they going to be like “we need to hear it from your mouth” etc. But, the psychiatrist was amazing about it all, he was just like “yep, if that’s how we’re going to communicate about it all, that’s how we’re going to communicate, whatever works for you”, which was so lovely […]

My psychiatrist was consistent, though and that was amazing. That really helped. My psychologist was consistent and it was great.

[Discharge from Early Intervention Treatment and assigned a new psychiatrist].

The first time I met my psychiatrist she said “well, you’ve got a schizoaffective disorder” […] It wasn’t a bombshell in a sense it confirmed what I felt and what I thought but the way I was told was not the best. She went on to say “which means statistically, your life expectancy will be reduced by 15 years” and I was like “Oh My God” and this is what I mean about the polar opposites. I was going from the lovely nurturing environment […] to “right, you’re probably going to die 15 years earlier, you’ve got this and by the way people don’t recover from it, it’s genetic blah blah blah”. So, I left the first meeting with my psychiatrist being like “I hate her, I absolutely hate her”. […]

[After five years] I felt like I was more living in the side effects of too much medication. I started to develop parkinsonian side effects. I was even referred to a neuro-psychiatry team and I remember thinking “I think, I need to come off my antipsychotics” and then thinking […] “that means I need to tell my psychiatrist, whose clearly not in favour of anything I suggest”, but I thought “right this is what I want to do, no decision about me without me, I thought I’m going to quote all the Trust’s slogan, I’m going to quote them back at her.” […]

“So, I’ve made a decision to come off the medication, will you help me?” and she went “no, I think you’re making the wrong choice”. So, I said “aha” and she goes “it is your decision but if you do it I would not recommend that at all and you’re on your own”. So, I said “can you recommend how I do this at all?” and of course I’ve done my research […] and she said “I’m not prepared to offer you any advice and I just expect to see you in a week or two back to how you were” and I was like “right, okay”.

[…]

So, over the next three months I weaned myself off of the medication and then I had an outpatient appointment after 12 weeks. And I remember going to see her and her being so completely different to how she was before and she said “wow, you’ve done it and you look well”, and I said “well I am well, I feel better than I did in a very long time” and she actually apologized which was the start of our relationship becoming a really good one, now we have a great relationship. You know I tell it like it is and she tells it like it is […] I am so happy I was able to do this by myself but it makes you think, if someone doesn’t have the capacity or the capability to absorb that information or perhaps English isn’t their first language, what do they do? Like how do they make an informed choice about their medication because if they don’t know all this then the medication and treatment will be pushed on them.

For the first three years of treatment, Lucy was under the care of an Early Intervention team[106] and her experiences with the team were nothing short of exceptional, helpful or even “nurturing”, in Lucy’s words. Throughout the interview, she emphasised several times that the psychiatrist and a clinical psychologist she was seeing were consistent. They understood her unique communication needs, i.e. communicating through journals, and they made her appointments only as long as necessary because Lucy experienced intense trepidation about her sessions with a psychiatrist which lessened with time because the most disturbing symptom she was experiencing, ‘a voice’, became infrequent and she knew her psychiatrist was willing to work with her to meet her individual needs. This importance in the continuity of care or

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[106] Early Intervention treatment teams were first introduced across the UK in 1999. Patients referred for the service are those who present with the first episode of psychosis. The treatment lasts up to three years. Neale and Kinnair (2017, 370) explain that treatment includes: “standard pharmacological antipsychotic therapy, alongside psychological, social, occupational, and educational interventions. EI teams aim to improve short- and long-term outcomes by reducing the duration of untreated psychosis, protecting social support networks, involving families in care, and providing prompt and intensive pharmacological and psychological treatment.”

seeing the same person was emphasised by many participants, but there was also a strong sense of frustration among participants who did not share this experience. For instance, Albert found it frustrating that he was unable to see the same psychiatrist, highlighting how not having to repeat his ‘story’ at every appointment would increase the likelihood of him continuing to seek care:

> They sent me to another hospital to see a psychiatrist and a psychologist. So, I was seeing both of them. It seemed fine but the one thing I didn’t enjoy was that even though they were taking notes every time I went there, I was seeing different people every time and it was upsetting me more because I had to go over the same thing over and over again. I asked the doctor why can’t I see just one person so that I don’t have to repeat myself all the time? Even the psychologist, I used to come out of their office suicidal basically. It didn’t work so then I stopped going. I’d keep going if I didn’t have to repeat myself, it was painful. You can’t have a relationship with a doctor like that.
> (Albert, narrative interview)

Similarly, a discouraging effect was experienced by Michael:

> I was always passed on from one GP to another which wasn’t very helpful. […] Trying to get a GP appointment is difficult and trying to get a specific one is even more difficult, there’s nothing for like 3–4 weeks. That’s no good when I need something sooner.
> (Michael, narrative interview)

Interestingly, both Albert and Michael described how they had trusted medical professionals and mental health professionals, and found pharmacological treatment for depression effective. Yet, there is a disconnect between how they tell their stories of seeking and receiving treatment. Both Michael and Albert experienced frustration and upset about their inability to rely on having the same professional continuously looking after them. Michael explained that when he experiences depression it can be incredibly difficult to muster the energy necessary to make an appointment with the doctor and so having to think about needing to speak to someone different every time added additional challenges on top of an already difficult task. Albert and Michael’s experiences suggest that forming positive doctor–patient relationships would not only result in them seeking treatment sooner but would also improve their overall experiences of treatment. Those who had experiences of continuity of care, as Lucy did, described the comfort it brought to them, especially in times of crisis, and also explained how it facilitated trust:

> The only person I trusted in my mental health care was my GP. He understood what I was going through because he knew me. Everyone else was a bore, getting their books out, […] asking the same questions. I would just end up being very angry.
> (Robert, narrative okay)

> My GP […] took such an interest in me that we've built a very strong relationship, to the point that […] it made me feel like I could be trusted. All I wanted to do is to be well, a functioning member of society and be a good mother to my daughter.
> (Sophie, narrative interview)

For my participants, being able to see the same professionals meant that they were able to build a relationship that was based on mutual understanding and, most importantly, trust. A doctor–patient relationship that is based on mutual trust, understanding and availability is sometimes described in psychiatric research as a therapeutic alliance (e.g. Ljungberg, Denhov and Topor 2015). This therapeutic alliance transgresses the boundaries of "traditional professionalism" and is facilitated by the professional relationship that exists with interpersonal relationships (Ljungberg, Denhov and Topor 2015, 472). Green et al. (2008) describe this relationship as a relational continuity of care for the development of which a long-term doctor–patient relationship was seen as helpful and key to achieving wellbeing. A variety of studies report that mutual trust is the very fundament of such a relationship (Green et al. 2008; Denhov and Topor 2012; Ljungberg, Denhov and Topor 2015).

Green et al. (2008) also found that the relational continuity of care has profound effects, not only in fostering good practice around illness and medication management but also through having a positive effect on patients' everyday lives and the quality of those lives. Green et al. (2008) argued that building such a fruitful relationship takes significant time, and is likely to develop over at least two years or even longer. This finding is consistent with the stories told in this research. The relationship between Sophie and her GP was built over four years, for Robert and his GP it was two years, and for Lucy and her first psychiatrist it was three years. However, first encounters were also important in treatment experiences. Sophie stated that her GP took an interest in her from the start which resulted in Sophie developing a relationship of trust with the doctor from the very beginning meaning that this first encounter had a crucial influence on how the relationship developed from there. However, when Lucy was discharged from the Early Intervention team and placed under the care of a new psychiatrist, her relationship with her psychiatrist was hampered by that person's cold and clinical communication style, along with distrust, dismissal of Lucy's request for help with medication withdrawal and ignorance regarding Lucy's experiences of side effects. Nonetheless, this continuity of care eventually translated into a therapeutic alliance facilitated by the psychiatrist apologising for ignoring Lucy's wishes and beginning to transform and repair the relationship.

All participants told stories about the side effects[107] of the different treatments they received. Lucy did not stop her treatment because it was ineffective, but rather because she spent five years on that particular medication and, although she was no longer experiencing disturbing symptoms, the side effects became all too prominent. Nonetheless, Lucy stated that:

> If I relapse, I'd absolutely want that treatment again because it did make my symptoms go away and the symptoms are worse than the side effects. I just don't want to take them long-term if I can help it.
> (Lucy, narrative interview)

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[107] See Bartlett (2011) particularly pp. 530-535. Bartlett, here, provides a useful overview on the usefulness and problems associated with psychiatric treatment and how this relates to mental health law and especially the idea of "appropriate treatment" within the meaning of the mental health legislation and what this means in practice.

Lucy’s story of withdrawing from medication can be sharply contrasted with Sophie’s, see Table 4.3 below.

| Table 4.3. Long narrative interview excerpt – Sophie. |
|---|
| She [psychiatrist] gave me Lamotrigine and it completely turned my life around. The reason we chose that was because I didn’t want to put any more weight on, like I don’t need any help in that department. She said that a lot of mood stabilisers do lower your metabolism and make you hungry promoting weight gain. I said I didn’t want anything that has weight gain as a side effect. She said the only one is Lamotrigine.<br>It was really really good. She also put me on Depakote and Quetiapine but I didn’t like that. After three days it turned me into a zombie. The fog was so intense I just couldn’t deal with it. Again, I didn’t like it because it was making me ravenous, so hungry. My happiest state was when I was on Lithium and Lamotrigine. The reason I stopped taking lithium is because it levels you out really well, but it stops you feeling any excessive happiness.<br>So, for instance, at Christmas, what’s there not to be happy about? It’s glitter and stuff but with Lithium you’ll be like “oh yeah.” It made some everyday things really hard like disciplining children. How can you have proper reactions like “this child is making me angry, or is pissing me off” you need some level of fluctuations but I didn’t have that. Then I was on Benperidol or whatever it’s called for a short time, but eventually at that point, Lamotrigine is what did it.<br>[…]<br>At this point my mental health services had discharged me because I was doing so well. They would just prescribe me my medication if I needed it but said they were discharging me because they didn’t need to see me anymore. It was a long process, but […] I went to Dr D [GP] and said I wanted to reduce my medication. He was very nervous at that time, but we did it very slowly, 25mg at the time, really slowly.<br>Then colours started to come back. So, throughout 2015 I was coming off my medication, I was detoxing through that whole year. I thought that as soon as I feel wonky, I will stop this detox. But I just continued to feel fine. |

Sophie experienced this therapeutic alliance and relational continuity of care from the first interaction with both her new GP and her psychiatrist. This was not Sophie’s first experience of mental health treatment as prior to that she sought assistance from a number of psychiatrists and GPs, but the approach of Dr D and Dr K resulted in Sophie gaining control of her symptoms. What is striking in Sophie's narrative is that both her psychiatrist and her GP were always thoughtful about choosing treatments suitable for Sophie's needs: from selecting a medication that did not cause weight gain to helping her withdraw from an effective treatment so that she was able to feel "extreme emotions" and that "the colours would come back", and this level of support also meant that she could fully participate in her everyday roles as a mother, spouse,  friend and member of society.

Another striking difference between Lucy's and Sophie's accounts is that Lucy would often speak about her wishes and the wishes of her psychiatrist as disconnected and even colliding. Conversely, Sophie uses the term 'we' throughout her narrative whenever speaking about her treatment, "the reason we chose that" or "we did it very slowly". Consequently, this illustrates that Sophie felt that she was actively participating in the treatment decision-making process. Decisions were shared between Sophie and her psychiatrist or Sophie and her GP. This shared decision-making facilitated a relationship of trust, mutual respect and understanding of Sophie's unique life story and her individual needs which were always taken into account even when it made her doctor "very nervous". Lucy described her relationship with her psychiatrist "now" as one of trust, mutual understanding and respect. However, it took several years for this relationship to flourish and to get to this point where decisions about Lucy were not taken without her – "nothing about me without me", to use Lucy's words. Nonetheless, Lucy and Sophie, and also Robert, who all report very positive relationships with their GPs, were only able to have or develop this positive doctor–patient relationship because of what Green et. al. (2008, 9) describe as relational continuity of care. It is a care that is based on shared values, on patients being able to see the same professional over a number of years and on patient-directed decisions.

### 4.3.2. Planning for treatment: the role of mental health professionals

The previous section emphasised that finding an effective treatment can take a long time and that how treatment is facilitated by professionals shapes those experiences. The side effects experienced by psychiatric survivors can result in unwillingness to take even the most effective medication long-term. However, the majority of participants, with the exception of Edward, Helen and Eliza, stated that they would go back to taking the medication if necessary, for example if they started to experience symptoms again (e.g., see Sophie’s narrative in Table 4.3. or Lucy’s in Table 4.2.) or if they underwent another mental health crisis. This is because they were able to understand the treatment’s effectiveness for their illness, despite the presence of side effects. The initial experience of mental health care resulted in participants expressing the importance of planning for the future as expressed by Lucy:

Table 4.4. Planning for the future narrative interview excerpt - Lucy.

> The Early Intervention Team just launched an intervention where you’d create your own crisis plan. I was, sort of, in the first cohort of people trying to create that really. I found the crisis planning, really helpful. Basically, I was encouraged to write a list of early, middle, and late warning signs and then sort of counter that with what do I put in the early, middle and later. So, for instance, if I was to say to my mom “I feel like a coiled spring” that was one of my early warning signs. So, then I would go into my paper and be like, right I need to go and see my CPN. And it ranged from different things like speaking to somebody through to going and having a medication review, seeing someone, or seeking hospitalization.
>
> I think one of the key things the Early Intervention service had done for me is that they told me that recovery was possible, where I never thought that before. And that you can plan your recovery. They would kind of say “you know, when things start working and you get better then you might want to think about what you gonna do and want”, and they were sort of very forward looking and encouraged planning. At the time, I was like “yeah, sure, whatever, we’ll see about that”. But I think it actually really helped. […]

> So, well, yeah, that’s where I am now really, I’m on the higher than maintenance dose but I’m on the highest dose of antidepressant and it seems to be working. I see it as a tool in my toolbox. […] [I] recognise what works.
>
> I think I’m very aware now of how I feel and symptoms but that’s come with time with over 10 years of symptoms and treatment. I’ve always been a fairly insightful person but the main thing that helped were journals, because I have written evidence of how I felt when I was taking the medication.

In Lucy’s account, two different methods of planning can be distinguished. Firstly, Lucy planned for her mental health care and treatment by writing journals.[108] Journals acted as evidence of how the medication made Lucy feel, consequently providing invaluable information to her psychiatrist. The journals proved to be especially helpful in situations where symptoms of Lucy’s schizoaffective disorder made her unable to communicate effectively. Without those, she would likely have refused the treatment being offered in order to appease the voice she was hearing. This could have resulted in involuntary detention. However, Lucy wrote twelve journals over the first three years of mental health treatment, allowing her to plan for appointments with psychiatrists which she tended to “dread” because the sessions were especially unwelcome to the voices. Lucy has continued to keep her journals over the years because they serve as important evidence of what she needs when in a mental health crisis and still allow her to plan the next steps.

The second way of planning for future care highlighted by Lucy was the crisis plan which the Early Intervention service had helped her to design. This included a list of triggers specific to Lucy and the action she might need to take in response. In her narrative, Lucy highlights the normative importance of planning as something that is an expression of the possibility of

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[108] See Table 4.2 for relevant excerpt.

recovery from a mental health crisis. It was an articulation of her wishes because she was encouraged to think about what she might want in the future. It provided Lucy with hope for that future and a sense of control over the illness. Sophie, too, found this way of planning helpful:

> I was always a big one for writing things up and so she wrote down lots of trigger things specific to me. I finished therapy with her and it was quite brutal because you don't get told that you'll be arriving at your last session. She said "right, this is the last time we're meeting". At that point, I was shocked but anyway. [..] I had those triggers written down, etc.
> (Sophie)

Sophie, similarly to Lucy, found it helpful to get ideas down on paper that would enable her to plan for the future. For both women, it was also an important aspect of being discharged from psychiatric care because it provided them with a certain level of safety and control over their mental health and possible future instances of relapse. It also made them more willing and confident to seek help in the future and to seek it at an earlier juncture, which meant that holding off a breakdown was no longer necessary in order to pursue the things in life that they really valued. Lucy admitted that she felt nervous that her new psychiatrist would refuse to communicate through journals, but nonetheless both the journals and the crisis plan gave her the confidence to reach out and assert her needs. For Sophie, it meant that she felt able to go and see her GP as soon as she sensed that some of the symptoms were returning, and she also knew what treatment she would need for them:

> We've built a very strong relationship, to the point that I could go in when I was struggling with anxiety, and I could just walk in and say "can I get a prescription for 15 diazepams?" And he would go "yeah, no problem". He knew I wouldn't abuse it or become dependent on it.
> (Sophie, narrative interview)

The plans that Sophie and Lucy were able to create were informal but valuable. However, most importantly they were a result of a relational continuity of care built on trust and mutual respect. Other participants who did not experience this continuity of care were unable to grasp opportunities for planning for their future needs. Nonetheless, they did comment that being able to do so could be especially helpful for times when they might be unable to see the same professional when seeking mental health treatment:

> There’s no follow-up or check-up in that regard. Some people go on crash diets. You lose all the weight. It’s trying to keep it off that’s the problem. The same with mental health treatment. You almost need like a plan or something so you can rely on this when you need it but don’t have the energy to start the process again.
> (Michael, narrative interview)
>
> I didn’t wanna get up and shower and I don’t want to eat. So to be proactive, make a doctor’s appointment… Wait two weeks or more for the doctor appointment and then talk about it all. It would be valuable to just have, like, a little bit of a quicker way. […] like a document someone could handle for you, it would just make it easier. I think it would make it easier. [..] I’d choose antidepressants.
> (Millie, narrative interview)

Here, participants emphasised the difficulty of accessing treatment when unwell. This difficulty is two-fold: it stems from resources outside of their control (i.e. doctors’ availability) and the symptoms of depression which make seeking treatment a burdensome task. Michael and Millie both thought that finding a quicker way of receiving such treatment would benefit them, especially as they were unable to see the same professional every time they needed help. This resonates with Albert’s frustration, discussed earlier, whereby he found it upsetting to have seen new doctors each time and to have had to repeat and relay all the same information once again.

Molyneaux et al. (2019) suggest that psychiatry as a discipline lacks robust and strong evidence for which particular interventions help to reduce compulsory treatment. However, in their systematic review of available evidence from randomised controlled trials, they concluded that planned emergency interventions like advance decision-making or joint crisis-planning did reduce those rates, especially when compared to care that did not include these elements. Farrelly et al. (2015) argue that crisis-planning or planning for future care improves the therapeutic relationship between the doctor and the mental health patient and is a good predictor for positive outcomes on one's mental health. These studies are based on the idea of joint crisis-planning, which does not have legal footing but has been studied as a psychiatric therapeutic element and is seen as a "middle ground between professionally-led plans and advance directives" (Atkinson 2007, 183). There are various definitions of the concept, but they essentially involve a process of negotiation between the patient and the mental health professional (Flood et al. 2006, 729), and sometimes others whom the patient wishes to involve, to draw up a plan of care for times of crisis and are usually designed for those with psychotic or mood disorders (Atkinson 2007, 183). A version of this was also used by Lucy's Early Intervention service team.

However. even though they have been reported as helpful (e.g. Henderson 2004; Farrelly et al. 2015), they suffer from a number of shortcomings. Firstly, joint crisis plans are not designed to accommodate the needs of those who do not have frequent contact with mental health services or those who have not experienced a relational continuity of care. Therefore, Michael or Millie would not be able to use such a plan for their future requests to receive antidepressants without having to wait for appointments with doctors or referrals. Secondly, joint crisis-planning is only successful for those who have experienced continued therapeutic relationships with a specific clinical team (Farrelly et al. 2015). So, for Albert, who used to see a different professional each time he went for his psychiatric appointment (and others in the same situation), there would be no point in drawing up a joint crisis plan between him and a doctor he is meeting for the first time. Furthermore, such a plan could not accommodate psychiatric survivors wishing for their decisions to be independent with little or no input from the doctor/psychiatrist. Finally, there is no way of guaranteeing that joint crisis plans will be followed or considered by professionals in the future when the need for invoking the plan arises (e.g. Henderson 2004; Flood et al. 2006; Atkinson 2007; Farrelly et al. 2015). Nonetheless, the data and the research in this area suggest that relational continuity of care facilitates helpful planning for future mental health crises in some people. Likewise, the lack of relational continuity of care increases the need for planning in others to ensure that their wishes will be met and their access to treatment not hindered by lack of resources, distrust or an emotional burden that might be experienced when seeking help.

### 4.3.3. Discussion: relational continuity of care, agency and bodily integrity

Green et al. (2008, 22) argue that this relational continuity of care is key to a successful recovery from mental illness and that the relationship between the mental health patient and their psychiatrist and other professionals involved in their care must not be underestimated, criticising psychiatry for ignoring or not paying enough attention to how this relationship is a key factor in recovery. My data analysis in this part of the chapter suggests that the quality of the doctor–patient relationship can facilitate or hamper justice for psychiatric survivors. This is because the relationship is key to whether the treatment is undergone as a source of unfreedom, thus hindering the capability for bodily integrity, or experienced as agency freedom, leading to the development of the capability for bodily integrity. Sen (1992, 31) suggests a way to judge an individual’s agency freedom or freedom by examining their social relationships:

> A person’s position in a social arrangement can be judged in two different perspectives, viz. (1) the actual achievement, and (2) the freedom to achieve. Achievement is concerned with what we manage to accomplish and freedom with the real opportunity that we have to accomplish what we value.

By applying Sen's evaluation of freedoms to psychiatric survivors' experiences of treatment, it is clear that judging such encounters through the first perspective, 'the actual achievement', is inadequate. This is because, even when psychiatric survivors find effective treatment, and so experience the actual achievement – effective treatment – the achievement does not necessarily equal agency when it is underpinned by sources of unfreedom like an unsupportive doctor–patient relationship. In my participants' accounts of their treatment and the doctor–patient relationship, effective treatment was experienced as unfreedom when it was facilitated by professionals who did not take into account their patients' wishes, needs and values. The cold and clinical approach of Lucy's second psychiatrist made Lucy fear her appointments, even though the treatment continued to be successful in managing her symptoms. And, even when Albert or Michael found treatments to be working, the lack of meaningful doctor–patient relationships and relational continuity of care meant that their treatments also became a source of unfreedom. It resulted in frustration and upset caused by the need to repeat one's story and the effort that was attached to doing so. Finally, side effects of even the most successful treatments can be viewed as sources of unfreedom when they interfere with everyday life's functions, pursuits and values. This suggests that what participants value is better explained by Sen's second perspective – the freedom to achieve. In his later works Sen suggests the reasons why freedom to achieve is important:

> Freedom is valuable for at least two distinct reasons. First, more freedom gives us more *opportunity* to achieve those things we value, and have a reason to value. This aspect of freedom is primarily concerned with our ability to achieve, rather than with the process through which that achievement comes about. Second, the process through which things happen may also be of importance in assessing freedom. For example, it may be thought, reasonably enough, that the procedure of free decision by the person himself (no matter how successful the person is in getting what he would like to achieve) is an important requirement of freedom. There is, thus, an important distinction between the 'opportunity aspect' and the 'process aspect' of freedom. The recognition of this distinction does not, however, rule out the existence of overlaps between the two aspects. [emphasis as in the original] (Sen 2002, 585)

In the metanarrative of psychiatric survivors, it is clear that it is the freedom to achieve that is important, along with both the opportunity aspect and the prospect aspect of the process. This is because psychiatric survivors value achieving good mental health through considerate and sometimes shared decision-making rather than through the treatment merely being delivered to them by a doctor without taking into account their individual needs. This means that "the *prospect aspect* of freedom will have a direct bearing on the *opportunity aspect* as well" [emphasis as in the original] (Sen 2002, 586). This further highlights the importance of the ways in which treatment is provided and the role that the doctor–patient relationship plays in this.

On this note, Robeyns (2017, 104–105) applied Petitt's (2003, 394–395) notion of 'option freedom' to the capabilities approach. Pettit (2003, 389) argues that option freedoms are the alternatives that people can choose from in order to achieve the desired level of agency freedom, and so agency freedom is measured by examining the access the person has to those alternatives. Robeyns (2017, 105) used this notion to argue that the notion of option freedom is "indeed the access that a person has to a wide range of valuable alternative options" and further suggests that the development of capabilities and agency freedom requires a provision of many different options and alternatives for people to access in order to achieve capabilities like bodily integrity or functionings like agency freedom. Robeyns (2017) therefore complements Sen's idea about what freedom is, why it is important and how it should be implemented. This application resonates with participants' stories because it highlights that mental health care must be designed to offer access to various alternatives to different treatments for psychiatric survivors in order for them to achieve the capability for bodily integrity, namely by being able to choose treatments the side effects of which are acceptable for the patient's understanding of their own bodily integrity and which enhance the patient's agency by providing options to choose from.

This requirement of responsiveness toward an individual’s life story and significant capabilities when providing mental health care is closely aligned with the concept of agency in the capabilities approach and the relational underpinnings of autonomy (e.g. Mackenzie and Stoljar 2000; Harding 2017b; Lindsey and Harding 2021). The individual autonomy in the capabilities approach is broadly consistent with relational understandings which recognises who people as individual persons are able to be, and how much people can contribute to that themselves, depending on their social contexts, relationships and environments, as well as wider societal structures (Sen 1999; 2002; Mackenzie and Stoljar 2000; Smith and Seward 2009).

Following on from the above discussion, it is clear that agency requires shared decision-making at the very least and more opportunities for independent decision-making. Shared decision-making in psychiatry is the process of enabling patients to participate actively and meaningfully in their treatment by providing them with accessible medical information and medical choices. There are ethical, clinical and economic arguments for shared decision-making (Drake and Deegan 2009). I emphasise ‘medical’ in the notion of shared decision-making to highlight its focus and limitations. Shared decision-making concentrates on the development of the skills and practices of clinicians that enable them to share treatment decision-making with patients (Joseph-Williams et al. 2017).

In the context of health, shared decision-making has been widely applied in the UK National Health Service (Joseph-Williams et al. 2017). From a clinical perspective, there has been mounting evidence suggesting that involving patients in decision-making processes reduces unnecessary treatment, results in shorter delays in seeking treatment and improves treatment outcomes (Clever et al. 2006; Veroff et al. 2013). From the stories told by psychiatric survivors, shared decision-making in psychiatry is rare, superficial or insufficient. But shared decision-making is an important steppingstone in psychiatric practice for bestowing much-desired choice and sufficient information around treatment choices. This type of decision-making provides space for evidence-based medicine, but it also promotes a high level of disclosure about treatment choices which, as my data highlights, would be a welcome development with the potential for improving the doctor–patient relationship and addressing people’s distrust of the psychiatric profession.

Psychiatric survivors’ own views of what is good for them and what they value should never be neglected in practice. As emphasis here is on encouraging capabilities for agency, this approach does not advocate simply mandating patient choice-making in the name of absolute individual autonomy. Instead, it requires the merging of personal preferences with safe medical advice, support and choice. If a patient wants to withdraw from medication, then capabilities-informed shared decision-making for cultivating capabilities for agency would encourage the psychiatrist to discuss potential risks, support medically safe withdrawal and consider what might happen if particular difficulties arise. This approach promotes a supportive doctor–patient relationship that helps psychiatric survivors to identify, check and perhaps refine and pursue their own particular valued interests and functionings. In turn, this would promote some health-related goals without undermining patients’ development of capabilities for agency. Accordingly, people do not necessarily want treatment long term, but they do want long-term relationships with mental health professionals.

Finally, opportunities for planning for the future are crucial and must extend beyond shared decision-making. Being able to prepare for eventualities is a matter of both agency and bodily integrity. The experiences of treatment planning in this metanarrative are limited to occasions of informal planning in a clinical setting. Those experiences of planning or, indeed, reports of the lack of opportunity for planning could, respectively, have been achieved or avoided through the use of advance statements. Clearly, participants appeared unaware of this possibility, and their professionals used clinical models for crisis-planning rather than advance statements which could have accommodated the wishes of many psychiatric survivors. At the same time, advance statements in England do not have a legal footing, they are simply mandated in the Code of Practice of the Mental Health Act 1983 (Department of Health 2015, 9.1), therefore they do not guarantee that patients' wishes will be followed. The perceived legal ineffectiveness of advance statements has been noted by scholars (e.g. Stavert 2013; 2021) and I explore this issue further in Chapter 6. However, advance statements could have had an advantage over clinical plans in that they would allow those psychiatric survivors who wish to receive less involvement from clinicians (Stavert 2021) or those who did not experience relational continuity of care a chance to plan for their own future treatment.

## 4.4. Psychiatric survivor versus society: the relationship with stigma

### 4.4.1. Stigma: a source of unfreedom

In the previous section of this chapter, I discussed the complex experiences of mental health treatment. These experiences suggest that the nature of treatment is challenging and requires psychiatric survivors to be given opportunities to develop meaningful relationships with professionals. Edward is the only one of the psychiatric survivors who has not found any of the treatments or therapies he was offered to be helpful. He has, however, learned to manage his symptoms and has been discharged from mental health care. Lucy has also been discharged from mental health services following the successful withdrawal of antipsychotic medication in 2012 and has not suffered a relapse since. Sophie also withdrew from her antipsychotic medication in 2015 and has not needed it since. Both Lucy and Sophie remain on other mental health medications like antidepressants and antianxiety medication. Eliza has stopped her medication and finds hypnotherapy extremely effective in managing any symptoms that creep in from time to time. Katie continues her therapy. Fred, Albert, Robert, Michael and Millie are well and all on low doses of medication to manage their symptoms. Eve has not needed mental health services in the last 20 years. Apart from Helen and Edward, who were not able to find suitable treatments, all other psychiatric survivors report that, after years of searching for the right cocktail of medication, the right therapy and the right mental health professional, they have been able to recover to the point where they feel fulfilled with their lives and remain largely undisturbed by their symptoms. Their success in recovery can be attributed to finding mental health professionals who were more attuned to their needs, changes in diagnoses and consequently changes in treatment, and years of knowledge acquired through their lived experience.

Their stories could end here as survivors of mental breakdowns, misdiagnoses, relapses and psychosis. However, it was only after the psychiatric survivors regained their mental wellbeing that they were faced with stigma, which led to experiences of unfreedom, oppression and structural violence. Even though psychiatric survivors have stopped stigmatising treatment, their communities have not:

> It is only when you leave your bubble of treatment and just being focused on getting better you realise this is not over, your life is affected forever and even though you can manage that in your personal life, the massive stigma that's everywhere never lets you forget.
> (Sophie, narrative interview)

Sophie's reflection raises several points about her life as a psychiatric survivor. Firstly, psychiatric survivors have been through years of self-focused searching for wellbeing and there is a sense in their stories that this focus on treatment has meant that parts of their personal lives were put on hold – such as jobs and relationships – and as such they were not prepared for the stigma they faced when 'resuming' their lives' pursuits.

One particular aspect in which stigma has been experienced by several psychiatric survivors is within the different local communities to which they belong: see Table 4.5.

Table 4.5 Experiences of stigma – narrative interviews' excerpts.

I'm a Christian so I go to Church. But the Church I used to go to, to which I don't go to anywhere was not helpful. Members of the congregation would come up to me and say "did they inject you? What's it like?" and stuff like that.

The more I am starting to work in the third sector with those organisations the more I'm starting to find that faith communities are not well educated on how to help people with mental health conditions and quite often they over-spiritualise everything. I had people come up to me and say "well we need to pray that the demons come out". So this has been very difficult, balancing my faith alongside all that. I don't see any part of my illness as spiritual and it is difficult when others so clearly do.

[…] Stigma unfortunately is still there, people think that once you're mentally ill you're always going to be mentally ill, you won't be able to live 'normal life' whatever that is. Sad, but it's the way of the world.

People would go through the person that was with me like I wasn't there. For instance, I would be standing next to my mum and people would go "how is Lucy? Oh it must be so awful to have your daughter in such a state" and I would think "hello I am right here. I've got a mental illness, but I am not deaf or invisible." It was like I was this unknown quantity that people didn't know how to behave around.
(Lucy)

Very few people are capable of showing no judgement when you discuss your mental health with them. Everyone is so incredibly judgemental, and they all say the wrong thing.
(Eve)

I wouldn't talk to people I hang out with about my experiences because of the massive stigma, even when people say "I don't have stigma". The classic way of establishing whether they do is when you tell them you're down and need to see the GP and they go "to the doctors? What for? Oh you don't need to do that". The same if you tell them you take antidepressants and they say "oh no, that's not for me, but I don't have stigma about anyone else doing it". I'm sure they wouldn't say "it's not for me" if a GP prescribed them treatment for a physical health condition?
(Sophie)

I'm part of this club for war veterans. Blokes are the worst. They just laugh it off and tell you to get a grip.

(Edward)

The above experiences of stigma are those encountered in everyday life relationships, within communities that are important to psychiatric survivors. Unfortunately, this means that psychiatric survivors have learned not to talk freely about their mental health. As a result, some of their social needs and the needs they have in relationships cannot be met. The continuous experience of judgement, misunderstanding and lack of awareness in society means that psychiatric survivors remain an oppressed group within the context of social interaction. All psychiatric survivors have confided that I was the first person to whom they have told their story (beside recounting parts to a psychiatrist) and that the experience of being able to do so was cathartic. This is suggestive that the stigma of mental illness is capable of silencing the needs of those with lived experience. Similarly, Pavlova and Berkers (2022) found that the growing awareness of mental health among the public is, in fact, superficial and lacks depth, meaning that it can actually trivialise experiences of mental ill health, diagnosis and treatment. Psychiatric survivors in this research experience stigma on a deeply emotional level, often leaving them unable to communicate their mental health stories and needs in everyday life.

Another sphere in which psychiatric survivors experience stigma is at an institutional level. Sophie shares her frustration about being unable to obtain life insurance because of having a diagnosis of bipolar:

> I've been stable since 2015 and have not taken any medication since then, but because my medical notes state 'bipolar and suicidal thoughts' they just look at that and put a blanket over it. Can you not invent a life insurance policy that don't cover me for suicide but cover me for cancer?
> (Sophie, narrative interview)

Lucy has left her job because responsibilities were taken away from her when she came back from her voluntary inpatient stay. Sophie has also left her employment because her boss was worried about promoting her to a managerial role because of distrusting Sophie following her new diagnosis of bipolar disorder. Eve has left her town altogether to start a new life in a place where nobody knew she was “that woman with psychosis”, which illustrates the impact that stigma has on peoples’ lives.

### 4.4.2. Discussion: stigma as structural violence

The literature on stigma and mental health is vast (e.g. Fink and Tasman 1992; Wallcraft 2005; Thornicroft 2006; Pilgrim and McCranie 2013; Mavandadi et al. 2018; Pavlova and Berkers 2022). This part of the metanarrative is used to highlight that even successful recovery will lead to stigmatising experiences in various communities. Stigma seeps into all aspects of everyday life: from one’s religious communities to insurance cover. Within the conceptualisation of the capabilities approach, stigma is more than a source of unfreedom: it is an example of structural violence. Stigma deprives people of opportunities to develop capabilities and to engage in functionings that are valued by them. The capabilities approach provides scope for addressing factors relevant to mental health and wellbeing at both individual and societal levels.

Stigma can have a critical impact on the agency and development of capabilities for psychiatric survivors. The term ‘structural violence’ has been used in the capabilities approach to capture the way in which social structures and/or institutions harm people by suppressing the possibility of their needs being met (White, Imperiale and Perera 2016, 6). The stories of stigma in this thesis cause harm, and oppression and may prevent the achievement of capabilities necessary for justice. Farmer et al. (2006) claim that there has been a tendency to de-socialise difficulties that people experience, such as mental illness symptoms, and ignore how de-socialisation can lead to negative outcomes and the framing of mental health issues in terms of risks (Mavandadi et al. 2018). The capabilities approach fosters opportunities to highlight stigma and associated inequalities as forms of unfreedom and structural violence and promotes re-socialisation of mental illness. This approach enables an understanding that mental disability can be recognised as capabilities deprivation because it interferes with a person's ability to make valued choices and participate fully in society. Addressing stigma is, therefore, necessary because it is social judgements that largely determine how life post-treatment is experienced by psychiatric survivors.

Psychiatric survivors need to experience full inclusion in the community to realise their capabilities. Psychiatric survivors ought to be approached in all aspects of life as having the status of people who matter. This is not the type of achievement that can be reached by psychiatric survivors themselves. Psychiatric treatment is still something that is seen as 'outside' of the social norm, leading to the experiences of structural violence encountered in the everyday life of a psychiatric survivor.

## 4.5. Conclusion

In this chapter, I have created a metanarrative on the lived experience of mental health treatment. The aim of the metanarrative is not to give an in-depth account of survivors' daily lives, but rather to paint a picture of psychiatric survivors' encounters with treatment and use the capabilities approach to give those episodes meaning. This provides an invaluable context for the remainder of the empirical chapters.

In this chapter, I have argued that psychiatric survivors delay seeking treatment because they perceive such treatment as being at odds with what they value, their life pursuits and life stories. Therefore, psychiatric survivors hold off a breakdown to preserve their agency freedom at least until they reach the tipping point where the breakdown occurs. It is at this point that the vast majority of psychiatric survivors come to have their first contact with health/mental health professionals. It is not possible, based on those narratives, to ascertain whether some clinicians, like GPs for example, are better than others, for instance psychiatrists, psychologists, or nurses. This is because, for every story which depicts a helpful psychiatrist, there is another portraying psychiatrists as unhelpful; the same applies to other professionals. However, examining doctor–patient relationships in this metanarrative illustrates that helpful clinicians are those who provide relational continuity of care. In turn, this cultivates important capabilities (i.e. for bodily integrity) and functionings (like agency) because such relationships are built on trust and the art of attunement to an individual's life story and values. I have also highlighted here how meaningful relationships can cultivate and facilitate opportunities for planning for the future which form an important aspect of peoples' metanarrative. Finally, I have argued that stigma fosters experiences of structural violence and that full inclusion of psychiatric survivors in the community is required for the achievement of capabilities and, thus, social justice. The application of the capabilities approach has allowed me to conceptualise these experiences as sources of unfreedom, therefore hampering social justice, or as expressions of agency freedom, thus increasing the likelihood of justice achievement.

In the following chapter, I explore the premise of advance consent, its practical benefit and its potential barriers. I also examine the role of the clinical concept of insight and mental capacity in relation to advance consent and argue that both act as barriers to fulfilling the empowering premise of advance consent understood through its practical benefits and support for bodily integrity.

# CHAPTER 5: THE PRACTICAL BENEFITS OF ADVANCE CONSENT AND ITS BARRIERS: BODILY INTEGRITY, INSIGHT AND MENTAL CAPACITY

## 5.1. Introduction

In the previous chapter, I examined psychiatric survivors' relationships with their own mental health and mental health treatment in general by creating a metanarrative of three relationships between psychiatric survivors and themselves, their mental health treatment (including a relationship with clinicians), and their relationship with society. In this chapter, grounded in data from both narrative and photo-elicitation interviews, I examine the premise of advance consent understood through three major benefits:

- firstly, advance consent as an asset because of its potential to minimise the need for coercion;
- secondly, advance consent as a real opportunity for giving informed consent; and
- finally, the major benefit of advance consent – its perceived ability in enabling people to access and receive treatment promptly.

The concept that permeates this chapter is a clinical notion of 'insight' which is experienced by psychiatric survivors as a source of unfreedom hampering their achievement of social justice and, in particular, the development of capabilities for bodily integrity. I, therefore, begin this chapter by defining insight. To do so, I draw on my original data and relevant psychiatric literature. Throughout this chapter, I suggest that insight is a barrier to each of the identified benefits of advance consent before suggesting that insight could become a serious challenge for the desired implementation of advance consent.

In addition, I maintain that insight is used as an extra-legislative criterion for involuntary detention. However, by minimising the need for coercion, advance consent has the potential to also minimise the reliance on insight in psychiatric settings which would then be replaced with the actual wishes of psychiatric survivors. I then move on to argue that advance consent offers a meaningful opportunity to obtain informed consent that satisfies the level of information required for an individual to give what is perceived as valid consent. Finally, I suggest that the major benefit of advance consent is the prompt provision of and access to treatment. Here, both insight and mental capacity are interrelated barriers to the achievement of this benefit. Therefore, I argue that advance consent should not be invoked on lack of capacity. Finally, I conclude that advance consent has the potential to improve people's experiences of mental health treatment by providing them with an opportunity to achieve bodily integrity, a component of social justice. For this to be achieved, the law on advance consent must regard both insight and mental capacity to be detrimental to its premise.

## 5.2. Insight as a source of unfreedom and a barrier to the empowering premise of advance consent

### 5.2.1. Defining insight

Insight has been deemed one of the most important and troubling concepts in psychiatry since the nineteenth century (Markova 2005, 3-32) and "the absence of a consistent definition of insight and means by which it is assessed" became a dominant aspect of its problematic status (Markova 2005, 66–67) along with questions concerning insight's scientific validity (e.g. Perkins and Moodley 1993). Case (2016, 366) established that Lewis's (1934) definition of insight appears particularly influential in its development and understanding. According to

Lewis (1934, 333), insight is a “correct attitude toward a morbid change of self”. The strong emphasis on the ‘correctness’ of psychiatric patients’ perceptions of their illness suggests that “disagreement with the psychiatric diagnosis and treatment would require ‘correction’” (Case, 2016, 366–367), giving way to a lazy justification for coercive and paternalistic intervention in an individual’s mental health care.

However, Markova (2005, 71) contends that it is David’s (1990) definition that has had the most influence on contemporary psychiatry. It comprises three characteristics indicative of the presence of insight in a mental health patient, including the recognition of own mental illness, compliance with treatment and the ability to relabel unusual mental events (like delusions and hallucinations) as pathological (David 1990). More recently, David and Ariyo (2021, 186) have encouraged researchers and practitioners to view insight as “self-knowledge” and recognise that acknowledgement of illness and the need for help is “necessary for living an authentic life”. However, as David (2020) admits himself, his efforts to refine the meaning of insight in psychiatry have not impacted his original definition in practice. In defence of the concept, David (2020, 522) further argues that the concept of insight has been rigorously applied in research over the last two decades, but this has not translated to better clinical practice and, in fact, there may be a difference between psychiatrists in academia and those in practice when it comes to understanding, assessing, and applying insight in research versus clinical practice. In the subjective opinions of psychiatric survivors, this appears to be true as their experiences and understandings of insight mirror David’s (1990) definition, as demonstrated by the following excerpts:

> Either you think you are ill, so that means you aren’t too ill really …
> So, he said “if you take this medication, you will show me insight, and this means you are getting better”.
> (Eliza, narrative interview)

> They want you to say, “I’m mentally ill, that was a hallucination and oh I suddenly realised that was a delusion, I’ve been mentally ill, and I have to take medication.” They have a very fixed definition of what insight is and insight is agreeing with them, with their belief systems. –
> (Eve, narrative interview)

The excerpt from Eliza embodies two elements of David’s (1990) definition. Firstly, by acknowledging her own illness, Eliza would show that she has an ability to recognise her own condition, which would be indicative of insight being present. Eliza also recalls being told directly that compliance with medication is not just a sign that her mental health is improving but that she has insight. Eve’s understanding of what she refers to as “a fixed definition of insight” – acknowledging the illness, complying with medication and showing an ability to recognise unusual mental events like delusions and hallucinations as pathological – meets all three characteristics of David’s (1990) definition.

The quotes also resonate with prominent literature in this area. Eve refers to insight as something that has a fixed definition. This reflects a critique of insight presented by Perkins and Moodley (1993, 7), suggesting that the rigidity in the definition is not a product of a scientifically valid concept but rather of “arrogance, professional imperialism and sheer ignorance for cultural sensitivity”. To illustrate this particular critique, it is worth considering Eve’s story in some detail.

Eve was an Anglican nun for a number of years before deciding to leave the convent despite the fact that this left her homeless and struggling. Eve stated that even though she was no longer a nun, parts of her faith remained with her, providing her with a sense of comfort. Additionally, she stated that she had spent years of her life praying every day, and so it was not something she was able to give up immediately after leaving the convent, yet, in Eve’s account, her praying was misconstrued:

> A religious delusional mania! Now bearing in mind, just come out of the convent. So, if I had religious mania, actually who would want to leave [the convent] then? Yeah, so I would kneel down by my bed to pray. They said that was religious delusions and mania. […]
>
> Another thing that happened was that I had arranged, I'd managed to arrange some Christian counselling at some kind of place, for a couple of months' time for when I go out. But the consultant said they weren't gonna let me off my section until I cancelled that. Because I shouldn't be having Christian counselling because that would feed on my religious delusions. So, I didn't cancel it, but I pretended that I cancelled it. But they said "we will not let you off your section till you accept the medication and you drop everything religious."
> (Eve, narrative interview)

Eve explained that her praying in the hospital was not a part of her delusions or hallucinations but her ordinary religious practice at the time. Eventually, when Eve started to recuperate in terms of her mental health, she was informed that she might soon be discharged. She thought that receiving some counselling might help her upon release and that the Church community might help her build her life again through its networks. However, she was promptly warned that doing so would mean that she lacked insight and needed to stay in the hospital longer. Eve criticised her care as not being able to recognise the cultural and religious needs of patients, which were typical aspects of Western medicine. This mirrors the criticism of insight by Perkins and Moodley (1993, 7) as being ignorant of the various cultural needs of psychiatric patients and reflects the general critique of insight as being Eurocentric (e.g. Saravanan et al. 2004) and incapable of separating genuine cultural and religious factors/beliefs from a lack of insight (e.g. Tranulis et al. 2008), thus attracting substantial criticism from cross-cultural psychiatry (e.g. Kirov et al. 1998).

As a result, many participants adopted an attitude well expressed by Lucy in her narrative interview with the slogan "if you can't fight them, join them". This assumes that the only way for a psychiatric survivor's voice to be taken into consideration is for them to 'perform insight'. For instance, when Eliza was released from the hospital, she lied to her mental health team about taking prescribed medications that she did not want to take because of their disabling side effects. After two weeks of daily check-ins, the team reduced their contact, stating that Eliza was showing very good insight because she was complying with the medication and therefore becoming visibly well. Thus, by performing insight, Eliza managed to avoid forced treatment. Furthermore, Robert, claims to have performed insight on every occasion when seeing a community treatment team. Robert said he used to prepare for those appointments by ensuring he was dressed well, presented well and always appeared compliant, knowing that this would prevent him from being sectioned. In reality, Robert's symptoms were poorly managed, resulting in rapid devastation to his family and work life. Reflecting on those situations, Robert expressed disbelief in how easy it was to mislead healthcare professionals when, in hindsight, he had thought he would meet the criteria for detention. By performing insight, psychiatric survivors highlight the futility of this concept, which in their hands becomes both a tool and a barrier to bodily integrity.

### 5.2.2. Insight and bodily integrity

Bodily integrity forms part of Nussbaum's (2011, 33) list of central capabilities, and its definition includes the following non-exhaustive (Nussbaum 2011, 35) components:

> being able to move freely from place to place; to be secure against violent assault … having opportunities for sexual satisfaction and for choice in matters of reproduction.

By complying with medications, psychiatric survivors were able to preserve parts of their bodily integrity in the sense that treatments were not physically forced upon them. Having insight or performing insight meant that Eve was able to 'move freely' again by avoiding prolonged detention and the same tactic also allowed Eliza to avoid yet another section, which she had previously experienced as abusive and coercive, as will be shown in section three of this chapter. In Eliza's case, insight was used as a tool for the preservation of bodily integrity, but, because it is experienced as a source of unfreedom, it cannot actually become one of the components of bodily integrity. Accordingly, by performing insight, psychiatric survivors were compromising their bodily integrity by complying with medications or treatment they did not agree with. Sources of unfreedom are human constructions and designed to control the level of agency and opportunities, namely the capabilities available to an individual. In a subtle way, insight masks experiences of coercion, making those experiences invisible to the law. However, the law here is as much to blame for the negative experiences of insight as is psychiatry. This is because experiences of insight remain largely unexamined in and by the law and gaps between how the law is written in statute and applied in practice effectively mean that the law allows the concept of insight to permeate mental health law in practice. Thus, the influence of law deserves to be scrutinised as much as that of psychiatry.

## 5.3. Experiences of formal legal and extra-legal coercion: psychiatric detention and the role of the clinical concept of insight: minimising coercion through advance consent

### 5.3.1. Non-consensual psychiatric treatment: the law

For a patient to come within the remit of the Mental Health Act 1983, they must be suffering from a mental disorder, defined in the Act as "any disability or disorder of the mind".[109] The length of each detention is determined by the clinician's reliance on specific provisions of the

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[109] Mental Health Act 1983, s.1(2); note that under s1.(2A) mental disorder does not include a person with learning disability unless 'unless that disability is associated with abnormally aggressive or seriously irresponsible conduct on his part.' S.1(2A)(b).

Mental Health Act 1983. For instance, patients detained under section 2 are detained for 28 days for assessment and six months for treatment, with a possibility of this being renewed under section 3 of the Act. For these two admissions, an application must be made by the nearest relative or by an approved mental health professional.[110] Conversely, under section 11(4)(b) an approved mental health professional should consult the nearest relative unless this would not be "reasonably practicable or would involve unreasonable delay". Detaining patients under sections 2 and 3 allows doctors to treat them without their consent under section 63 of the Act.[111]

There are two important justifications for formal legal coercion in the psychiatric context. The first one is the notion of 'dangerousness' whereby a patient poses a danger to themselves or others.[112] This ground has survived the test of time despite overwhelming and growing evidence that mental illness is a poor predictor of violence towards others and may be no greater than among the general population; the risk of violence is much greater towards oneself than others, and the risk towards others is unlikely to be a result of mental illness and is more commonly a result of substance abuse (e.g. Monahan 1988; Peay 2007; Large et al. 2008; Langan 2010; Taylor, Corteen and Morley 2014). Therefore, it has been argued that focusing on dangerousness perpetuates the stigmatisation of people with mental illness (Farid 2021). Nonetheless, the consequence of this justification is that, impliedly, the role of coercion validated through the prevention of violence includes some form of social control and so this ground has been met with scepticism among mental health professionals (Eldergill 2002; Bartlett and Sandland 2014; Gojkovich and Rivardo 2021).

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[110] Approved Mental Health Professionals, commonly known as 'AMPS'.

[112] Mental Health Act 1983, s. 2(a).

The second legal justification for legitimate coercion is the need for care and treatment due to the degree of mental disorder that an individual is suffering[113] and that appropriate medical treatment is available to that patient.[114] Contrary to the first ground, this notion of the need for care and treatment suggests that formal legal coercion is there for the alleviation of suffering and the provision of treatment rather than for social control. However, the notion of 'appropriate treatment' introduced by the Mental Health Act 2007 is problematic. Appropriate treatment does not need to be a treatment that is successful, but only that is considered by clinicians as appropriate, "which is for the purpose of alleviating or preventing a worsening of the patient's mental disorder or its symptoms or manifestations".[115] This raises the question of whether 'manifestations' could include posing the risk of violence towards others, which means that appropriate treatment could potentially be applied as a means of social control (Bartlett 2011).[116]

Whatever the ground, involuntary detention under sections 2 and 3 has two main distinct effects. Firstly, an individual cannot leave the psychiatric hospital without the permission, and patients can now be treated without their consent under section 63 of the 1983 Act.[117] The treatment must be medical, which is defined as "nursing, psychological interventions, and specialist mental health habitation, rehabilitation and care",[118] the purpose must be for alleviation or worsening of symptoms,[119] and it must be provided to those who are suffering from mental disorders. There is an important safeguard under section 58, which limits the non-consensual treatment with medication for three months after the initial detention. After

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[113] Mental Health Act 1983, s. 2(a)

[114] Mental Health Act 1983, s. 3(2)(d) as amended by the Mental Health Act 2007.

[115] Mental Health Act Code of Practice 2015, para.6.8.

[116] Relevant literature also suggests that the standard might be at odds with human rights standards, see Bartlett (2011) for analysis.

[117] Section 63 does not apply to treatments under sections 57 like psychosurgery or hormonal therapy and section 58A, electro-convulsive therapy.

[118] S.145(1)

[119] S.145(4)

this time has elapsed, the patient can only be treated with medication on their valid consent,[120] or if a Second Opinion Appointed Doctor (SOAD) confirms that the patient lacks capacity under the MCA 2005, or, if the patient has refused treatment, then the treatment can be given if the SOAD deems it to be appropriate.[121] Thus, despite its safeguards, section 58 still allows for Second Opinion Appointed Doctors to override capacitous refusals of treatment with medication. Notwithstanding these rules, treatment may always be provided without consent in cases of emergency, as the doctrine of necessity applies to mental health treatment.[122] It is worth noting that the SOAD system is generally regarded to be the most important procedural safeguard under the MHA 1983 for those patients who are involuntary but scholars have questioned its efficacy for a long time (e.g. Fennell 1996; 1998) as well as following the MHA 2007 (Bartlett 2011).

Patients may also be voluntarily detained; this is known as ‘informal detention’ under section 131(1) of the Act. This means that, under the law, the patients may leave the hospital whenever they wish to do so, and they may refuse any treatment. Hale et al. (2017, 15) suggest this is a theoretical position and, in practice, two types of voluntary patients can be observed. First, there are those who are regarded as “truly voluntary”. These patients agree with doctors’ advice and comply with all treatment. The second type of voluntary patient is a patient who refuses treatment or wishes to leave the hospital. In those situations, patients may be “persuaded” to stay or to take medication because otherwise they will be sectioned under sections 2 or 3 of the Act so that the treatment in question can be provided without consent (Hale et al. 2017, 15). In addition to preventing patients from leaving the hospital, section 5 may be applied which allows

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[120] S.58(3)(a)

[121] S.58(3)

[122] *Re T (Consent to Medical Treatment) (Adult Patient)* [1993] Fam 95; see analysis of the doctrine of necessity in the context of mental health and human rights in Bartlett (2011).

voluntary patients to be sectioned for up to 72 hours. However, section 63 (non-consensual treatment) would not apply in this situation.

This brief but necessary overview of the law on hospitalisation under the Mental Health Act 1983 demonstrates that coercion in mental health care is used for both alleviation of symptoms and also for the protection of the public, resulting in laws that continually survive the test of time and are rarely examined in the courts. It is therefore even more important to interrogate how they are experienced in practice.

### 5.3.2. Psychiatric survivors' experiences of in-patient mental health treatment and insight as the extra-legal criterion for involuntary treatment

#### *5.3.2.1. Involuntary detention: 'Catch 22'*

Eliza was involuntarily detained 17 times, each time for a period no longer than 28 days, which would suggest she was most likely sectioned for assessment under section 2 of the Mental Health Act 1983. However, she did not appear able to justify why each of her hospitalisations lasted precisely 28 days but thought that this was because the psychiatrist who was seeing her would only be able to see each patient once a month. Even though section 132 of the Mental Health Act 1983 requires that a patient be informed of their section, Eliza's experience suggests that she was not informed of her legal rights nor of the legalities surrounding her section. The two legal justifications which would trigger detention under section 2 – dangerousness or need for treatment – are not obvious decisive factors for deciding whether Eliza should have been sectioned or become an informal patient. Instead, the perceived lack of insight acted as the reason for involuntary detention. In recalling the first time she was sectioned, Eliza stated the following:

> The psychiatrist came following the police and she said ‘it’s like this. Either you think you are ill, so that means you aren’t too ill really. You think you’re ill and you need to be in the hospital, that means you’re not too ill and you don’t need to be in the hospital but we will take you there, to be on the safe side, or you think you’re just ill and don’t need the hospital which means you are ill and we need to take you to the hospital’. So, it was a complete Catch 22. I explained I knew I was ill and wanted help but did not want to go to the hospital because I had two small children. So, I got sectioned.
>
> On my way there I had a panic attack, I was so worried about my children. So, the next thing I knew I was being carried by about three men. They got me onto this bed, face down, holding me down, pulled my dress up, pulled my pants down and injected me. I sat up and said, “that was very rude” and passed out.
>
> Then following morning, I woke up naked with a sheet over me on a flat mattress on the floor in a small room with white walls and a small window that was barred. That was a lot and that’s how I woke up on my 40th birthday.
> (Eliza, narrative interview)

Eliza’s first experience of mental health services was terrifying and traumatising. It was filled with worry for her children, a sense of injustice and a feeling of impediment to her bodily integrity. Applying the capabilities approach to Eliza’s experience requires an evaluation of the extent to which she was able to be and do what she values. What Eliza describes as a ‘Catch 22’ was essentially a choice given by a psychiatrist between voluntary and involuntary admission. This choice was dependent on the presence of insight and Eliza’s unwillingness to show it by not agreeing to hospital admission effectively resulted in involuntary detention. In her story, Eliza contends that her reason for not wanting to go to the hospital – because of her worry about her two small children – was disregarded and her non-compliance was seen as a lack of insight. The Wessey Review (2018, 37) found that “people’s experiences, knowledge and reasoning are often overlooked by mental health professionals and mislabelled as lack of insight or an aspect of their disorder”. In Eliza’s story, it appears that insight was also used as an extra-legislative proxy for involuntary detention. The finding is consistent with the wider literature on insight and the law across many jurisdictions. Radovic et al. (2020) found that insight is frequently used in Swedish mental health proceedings but remains legally undefined. In addition, it exists in Swedish law as an “extra-legislative catch-all argument” used to justify involuntary detention. Dawson and Mullen (2009) derived a legal definition of insight based on the case law in New Zealand to be understood as compliance with treatment. Similar to Radovic’s et al.’s (2020) findings, the lack of insight was the most significant factor in justifying involuntary treatment decisions. Diesfield and Stojstrom (2007) also found that in Victoria, Australia, the concept of insight dominated mental health review proceedings.

Insight, in the current case, meant that Eliza was not able to act in accordance with her chosen goals and values, namely looking after her children, meaning that her agency freedom was severely limited. A capabilities-informed approach to such a situation would place a legal requirement on the clinician to consider the personal values and circumstances of an individual who meets the requirements for involuntary commitment. The importance of individual values and life roles was emphasised in the previous chapter.

While in detention, Eliza experienced a series of treatments that were forced on to her in the form of particular medications and sedatives. The process through which treatment was initially provided to her, as highlighted in the excerpt above, left Eliza feeling violated. At this point, she was not only taken away from her children but she was now being stripped down, injected with medication and left naked in the hospital room until she woke up.

Eliza’s experience can be readily contrasted with Sophie’s whose concern for her young child meant that she avoided involuntary detention. In the midst of a psychotic episode, a psychiatrist informed Sophie that the best course of action would be involuntary detention. Petrified by that option, Sophie explained that this did not align with her responsibilities as a single mother. The psychiatrist asked Sophie to explain *how* she was taking care of her daughter despite an intense psychotic episode. It became clear that looking after her child meant that Sophie had a sense of purpose and a structure to her day that she managed to maintain. Considering Sophie's personal circumstances, the psychiatrist decided not to detain Sophie but to offer a cocktail of medications to control her symptoms, warning Sophie that it was necessary for her to comply with treatment in order to avoid hospitalisation. Similarly to Eliza's psychiatrist, Sophie's psychiatrist used the lack of insight, understood as non-compliance with treatment, as an extra-legislative criterion for involuntary detention, of which Sophie was directly informed.

Nonetheless, Sophie's story serves as a potential example of what capabilities-informed decision-making regarding treatment might look like if the reliance of insight is taken out of the equation. It requires an appreciation of extra-medical aspects of the individual's life and a more nuanced understanding of their values and pursuits as emphasised in Chapter 4 of this thesis. This example reiterates the importance associated with the facilitation of treatment. The different processes that were used to achieve the same outcome are significant when viewed through the capabilities lens. Sen (2002) highlights that the process through which an outcome is obtained is more important than the outcome itself. This means that an individual who is forced into detention to receive treatment, which they would have accepted under different, less coercive circumstances, is no longer a free agent because of the "violation of the process aspect of [their freedom], since an action is being forced on [them] even though it is an action they would have chosen freely" (Sen 2002, 331) under different circumstances. The process is deemed more important than the outcome because, if the process does not allow an individual to act in accordance with their values and choices, the "good" outcome could be offset entirely by the negative experiences of compulsion, which is apparent in Eliza's example. Eliza's choice would be to undergo treatment which would not prevent her from looking after her children. Despite the fact that Eliza was coerced into detention, it was the lack of insight that appears to be the main, or final, reason for coercion, meaning that her supposed lack of insight was experienced as a major source of unfreedom.

It appears that, in this account, the psychiatrist believed that Eliza probably had a serious need for care or treatment, but it was the insight or lack thereof that would be the ultimate determiner as to whether that need could be fulfilled with formal coercion or voluntary detention, which makes insight an extra-legislative justification for coercion. Ostensibly, the need for treatment and care was sufficient to involuntarily detain Eliza. Insight added an extra layer of gatekeeping where its presence would result in 'the least restrictive' form of detention being used. Arguably, Eliza did show insight by admitting she needed help and that she was not well. It was her lack of compliance with the suggested treatment (detention) that ultimately meant she lacked insight in the opinion of her psychiatrist. This might suggest that compliance with treatment is the strongest predictor of the presence of insight which is consistent with the clinical literature (e.g. Kemp and David 1996) as well as with the legal literature examining how the concept of insight features in law (e.g. Case 2016; O'Keeffe 2022).

#### *5.3.2.2. Voluntary detention*

Informal patients, under section 131 of the Mental Health Act 1983, can only be treated on their valid consent. But the absence of formal legal coercion in such a situation does not necessarily mean that admission is voluntary in the sense of being freely chosen (Hale et al. 2017, 15). Similarly, to Eliza, Lucy had been given a choice between a section or voluntary detention for treatment. Lucy had chosen to become an informal patient, unlike Eliza, and, although she felt this was truly her choice, the treatment that was administered during an informal stay was still experienced as coercion because it was not consensual:

> I didn't refuse treatment in the hospital, but I saw people who did, and it terrified me. And so, I was very much like "no, thank you very much, I will take my tablets even though they made me feel awful". So, I was never restrained in the hospital which I am very grateful for. My treatment wasn't consensual, I feel … I can remember the doctor sort of saying "you need this, you need this right now" and me being like "oh okay"

> and then not remembering anything until the next day. I don't remember ever being asked if I would like a medication. That was never asked of me. It was never a question, it wasn't like "we can give you some antipsychotics, or you can choose not to have them, this is what they do and this is what they are" they would just go "we are going to start you on clozapine".
>
> It felt very invasive and abusive … I felt like my choice was to take the medication and not question it or die.
> (Lucy, photo-elicitation interview)

Lucy's excerpt demonstrates that the experiences of informal patients might be more complex than previously discussed in Hale et.al.'s (2017) typology of voluntary patients. Lucy's hospital stay was truly voluntary as she emphasised on a number of occasions throughout her narrative and photo-elicitation interviews. However, despite 'agreeing' to treatment, her consent was an illusion. To preserve her bodily integrity by avoiding physical force and restraint, Lucy obeyed all treatment that was given to her. Additionally, Lucy's treatment did not just lack consent but lacked any participation by Lucy herself in the decision-making process about the treatment, thus blurring the lines between formal legal coercion and what was supposed to be a voluntary treatment plan.

### 5.3.3. Advance consent for minimisation of coercion

The examination of legal coercion in law through the lived experiences of psychiatric survivors indicates that law is encountered as obstructing the development of bodily integrity, an important capability. Moreover, the involuntary detention and hospitalisation of informal patients are both facilitated by mental health professionals, meaning that how these provisions are implemented in practice remains largely invisible to the law and is rarely contested in the courts. This indirectly gives way for clinical concepts to seep into the application of laws that are intended to function in everyday life, largely outside of typical legal settings or scrutiny.

From the accounts of psychiatric survivors, it appears that they have little control over what happens to them. Researchers have argued that the legal classifications of involuntary and voluntary hospitalisations do not capture fundamental distinctions between those who are and who are not coerced (Lidz and Hodge 1993; Saks 2002; 2004). Through the analysis of lived experience, it is clear that voluntary admission, or choosing voluntary detention when given that choice, does not protect individuals from treatments they do not consent to. In order to preserve some of their bodily integrity (i.e. avoiding the use of force, such as restraint), it is necessary to comply with doctor's directions or to perform insight. Therefore, it is unsurprising that one of the highlighted benefits of advance consent was its potential to minimise the need for coercion and hospital stays:

> It could replace the need for compulsory treatment. That's right. So, they would have to treat you in accordance with your wishes. … [not] holding me down, injecting me and eventually I realised I would never get home to my children if I didn't do what they wanted me to do. There was no belief in it in my heart, I was simply doing as I was told because I had no choice. ... So, [advance consent] is an excellent plan, a humane plan.
> (Eliza, photo-elicitation interview)
>
> I could have made that [advance consent] after my section I think, because, if I had to go through that again, all that treatment, trials etc, I would kill myself. It was so terrible that I tried to kill myself.
> (Eve, photo-elicitation interview)

Here, advance consent was seen as minimising or replacing coercion that had been experienced both physically and emotionally by Eliza and Eve. In turn, Eliza would therefore be treated in accordance with her wishes. Finally, by minimising the need for coercion, Eliza would be likely to fulfil her valued life role as a mother. This view that advance consent can reduce instances of coercion is consistent with research into broadly conceived psychiatric advance directives. For instance, Henderson et al. (2004) found that joint crisis plans halved the rate of involuntary detentions in England. Similarly, Swanson et al. (2008), using a randomised controlled trial, demonstrated that psychiatric advance directives, in general, significantly reduce the number of coercive interventions required for a patient. Szmukler (2008, 232) blames psychiatry for its “lack of attention to the underlying ethics” which translates to an unwillingness to accept measures like legally enforceable advance directives which effectively address the issue of coercion in psychiatry.

Capabilities-informed mental health law might require the removal of involuntary detention and replacing it with capabilities-enhancing alternatives wherever possible – but these alternatives cannot be imposed on individuals, they must be freely chosen. However, the capabilities approach might be more helpful in facilitating change in the law as it occurs in everyday life rather than in statute, by bridging the gap between the law and the treatment in practice. This is because it encourages professionals to step away from the assessment of insight and consider the possibility of other, more everyday reasons why an individual might not wish to be detained but still wish to be treated. The decision-making processes around treatment would instead be encouraged to focus not simply on medical outcomes but also on the consequences of treatment decisions on personal circumstances, values and bodily integrity. The capabilities lens, therefore, encourages the use of processes that are the least restrictive on individuals’ ability to pursue their capabilities while also enhancing agency freedom.

## 5.4. Provision for advance consent as an expression of informed consent

### 5.4.1. Experiences of insufficiently informed consent

In this research, psychiatric survivors expressed a general disappointment with how little information they received regarding a particular treatment. This was perceived as an imposition on their bodily integrity especially when accompanied by bothersome and unexpected side effects, as explicated in Table 5.1. below:

Table 5.1. Excerpts - informed consent

She said to me “you probably won’t get pregnant because you’ve been on medical castration medication for so long and on such a high dose that you’re probably infertile. Anyway, being pregnant whilst suffering with schizoaffective disorder would not be good for your mental health. You might find it all very hard.”
(Lucy, narrative interview)

They would say “this is your medication, yes you may experience some side effects when you first start taking it, like for instance people on olanzapine put on a little bit of weight, a little bit of weight”. Well, a little bit was an understatement. ... I went from size 8 to size 18. I was like a slug. I couldn’t move, I had to roll myself out of bed just to wake myself up enough so I could go to the toilet. Like I would sit and dribble in the corner, I couldn’t keep my eyes open, I would fall asleep on the toilet, on the phone, anything. On Abilify [aripiprazole], after taking the maximum BNF dose for 5 years I was then informed by my psychiatrist “don’t expect to ever having children because you’re properly actually infertile”, well, thanks for that.

So, informed choice to me is a bit of a joke. It’s like “I’ll inform you why you need this and I’ll explain a little bit how you’re going to feel when you start and I’ll explain a little bit and we will deal with other long term things later because if I tell you that now you’re not going to take it and I need you to take it because I need to manage you.” It’s very much managing system I feel like you know, “oh she’s alright now, we don’t have to worry about her now because she’s on her meds, she’s managing”. It wasn’t like “oh we don’t have to worry about her because she’s got all this input from all these different things and she starting to recover, how exciting is that”. Well, it wasn’t like that. It was very much like “how are you finding the medication?” when you see a psychiatrist you don’t dare saying how you’re finding it and when I piped down and said “well, I hate it, I feel like I cannot function on it, I want to come off it” it was like “well if you do, you know, I’ll probably see you here in a few weeks and don’t expect any help”.
(Lucy, photo-elicitation interview)

They just give you the tablets and they don’t explain to you the side effects. Instead of treating me in according to my needs, including social needs and just life needs, they gave me the tablets and said “take that, it will help you”. I have learned about the side effects from my own experience and not the psychiatrist. They just tell you that it is normal to experience some side effects, but they do not tell you what they are and these side effects can really

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| mess up other areas of your life. I feel like suing the NHS because my consent was not informed, so it was not consent – really.<br>(Albert, photo-elicitation interview)<br><br>So for me, it worked. But what if you’re someone else that either has problems or has huge weight gain with the kind of medicine? Because with me, I gained around 12 pounds but for me, it's fine. But think about someone that already had eating disorders and is forced to be on that kind of medication like the person would not continue with that. So and I do know about that because I'm very close to people that already had eating disorders, and I know how hard it can be. So, in my case, I just stop being able to use some of my shirts! But for other people who have, it would have more like harder to get accustomed to.<br>(Fred, photo-elicitation interview) |

The excerpts contained in Table 5.1. suggest that the information psychiatric survivors receive about their treatment, and in particular about medications, is insufficient, but this does not appear to be of equal importance to all psychiatric survivors. For instance, Fred was not informed about weight gain as a possible side effect and, even though this side effect was actually realised, it was not of much importance to Fred, but, importantly, he notes that this information could be crucial for others. However, weight gain appeared to be an important side effect for Lucy and she was left feeling that the information given was downplayed to increase her compliance, thus insight. Yet, the biggest infringement on Lucy’s bodily integrity was the lack of information regarding her treatment’s relationship with her reproductive health.

After five years of effective mental health treatment, Lucy decided that she would like to have a child but became worried about possible side effects that the medications she was taking would have on her potential pregnancy and so decided to discuss this with her psychiatrist. Lucy pinpointed this memory as a stark realisation that she had been on a potentially life-altering treatment without her consent. The psychiatrist explained that certain side effects had not been disclosed to her because they could have severely impacted her “insight”, and it had been more important at that time to alleviate the severity of her symptoms and reduce the possibility of relapse through use of that particular medication. Clinical research has shown that adherence to psychiatric medications, especially antipsychotic medication, is poor outside of hospital settings where the treatment can be administered with force if needed (Corrigan et al. 2008). It has been suggested that compliance with medication and the associated presence of insight is closely related to the information that the patient has about the perceived risks and benefits (i.e. presence of insight) of any given treatment (Corrigan et al. 2008). Thus, current psychiatric practice encourages practitioners to only disclose important side effects proportionately to the risk that the patient presents (Weiden 2007; Corrigan et al. 2008). Kane, Kishimoto and Corell (2013, 221) also found that psychiatric patients suffer from "the lack of information as to what to expect from treatment in terms of side effects and the risk of specific side effects" and suggest, in line with other studies (e.g. Lacro et al. 2002), that adherence to medication should be achieved through meaningful trusting relationships between the psychiatrist and the patient where there is a mutual discussion about side effects and perceived benefits. Lack of disclosure or the provision of insufficient information have been associated with concerns over insight, not just in the stories told here but also acknowledged in other research (Owen et al. 2009a; Tessier et al. 2017).

Here, it might be worth considering how the misguided focus on insight, in the guise of compliance with medication, and the need for greater information disclosure could be remedied by the law. The aforementioned clinical studies do not discuss the need for doctors to adhere to relevant legal provisions on the disclosure of relevant information. Some studies report that in many jurisdictions psychiatrists' knowledge of mental health legislation and associated relevant laws may be patchy and poor, emphasising the lack of sufficient legal training in psychiatry (e.g. Humphreys 1998; Wilder et al. 2012). Prior to 2015, consent did not have to be as informed[123] in terms of its risks and benefits. However, in *Montgomery v Lanarkshire Health Board (General Medical Council intervening)*, the Supreme Court held that:

> an adult person of sound mind is entitled to decide, which if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken. The doctor, therefore, has a duty to take reasonable care to ensure that patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatment. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should be aware that the particular patient would be likely to attach significance to it. [124]

Hale et al (2017, 211) state that "by sound of mind the Supreme Court meant a patient with the capacity to decide their own medical treatment". This is problematic because it is not clearly inferred from the judgment that this is what the Supreme Court did actually mean. Therefore, it does not necessarily follow that this is how *Montgomery* is or will be applied in practice.[125] Instead, it is possible that by "sound of mind" psychiatrists might infer someone who does not suffer a mental illness and that those who do might not be afforded the privilege of sufficient information given about their treatment, as promised by this landmark case law. I discuss the issue of mental capacity in greater depth in the following section of this Chapter, but it is worth noting here that, based on psychiatric survivors' experiences, mental capacity is underused in practice and instead insight might be being used more often to assess the soundness of mind or judgement of an individual.

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[123] For instance, the information threshold for battery is low and requires that the patient understand only the broad nature of the treatment and the threshold would be satisfied whether the patient obtained that information from the doctor or sought that information themselves from elsewhere (*Chatterton v Gerson* [1981] 1 Q.B. 432 at 443). Information standard in negligence was previously governed by the *Bolam* test (*Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582) or 'a reasonable doctor test' which was repealed by the 'reasonable patient test' (*Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871).

[124] *Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11, 87 (Lord Kerr and Lord Reed)

[125] For literature discussing the impact or potential impact of this judgment see Montgomery and Montgomery (2016); Mchale 2017; Laing (2017) Harrison et al. (2018); Turton (2019); Carver (2020); Ward et al. (2020).

Looking back on Lucy's story, it is unlikely that she lacked the capacity to decide whether or not to undergo the treatment because it was given to her during a routine appointment following a weight gain from her previous medication. Lucy also appeared to have a good understanding of the mental capacity assessment and stated that she did not think she has ever lost her functional capacity to make decisions. It is therefore difficult to imagine a situation in which a doctor prescribing treatment for a young woman knowing that it carries the risk of chemical sterilisation does not consider this to be relevant information and a material risk pertinent to disclosure. Lucy's story, however, is one of devastating symptoms that caused serious danger to her life and health and the lives of others. If knowledgeable about the information disclosure law, the psychiatrist could potentially rely on the exceptions created by the Supreme Court in *Montgomery*. These include the provision of urgent treatment to patients who are unconscious or unable to decide, or where the doctor reasonably believes that the disclosure of the risks would be seriously detrimental to the patient's health,[126] with the second exception being more likely applicable in Lucy's situation given the severity of her symptoms prior to receiving psychiatric treatment. However, this exception should not be abused because the doctor might be liable for making a decision that was not considered to be in the patient's best interest.[127]

The standard created by the Supreme Court in *Montgomery* also requires that the doctor informs the patient of suitable alternatives.[128] It is also unclear whether there was an alternative medication that Lucy could have been given, and it is also entirely possible that Lucy's story is a prime example of bad practice. Another participant, Sophie, specifically recalls being asked

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[126] *Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11, 88 (Lord Kerr and Lord Reed)

[127] *Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11, 91 (Lord Kerr and Lord Reed)

[128] *Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11, 89 (Lord Kerr and Lord Reed)

if she was planning to have any more children in the future, because the psychiatrist needed to know whether a medication that can cause fertility issues should be avoided. Nonetheless, the outcome of Lucy's experience was that she considered informed consent in psychiatry to be "a bit of a joke" and, similarly, Albert's excerpt in Table 5.1. suggests that his consent was not informed and that this left him with a sense of injustice.

### 5.4.2. Advance consent as a means for informed consent and the capability for bodily integrity

The analysis of the importance of informed consent in psychiatric treatment highlights that the real culprit in preventing meaningful consent in psychiatry is the lack of or insufficient information about the proposed treatment. The Supreme Court in *Montgomery* recognised that any risks to which a patient is likely to attach a significance should be disclosed. This view was mirrored in my data and highlighted by Fred's excerpt and the stories which suggest that different people will attach significance to different risks. Providing treatment was equated in *Montgomery* with interference with bodily integrity,[129] but, in the view of psychiatric survivors, it is insufficient information that is strongly interfering with their capability for bodily integrity. The interference with the capability for bodily integrity is especially striking in Lucy's story. Nussbaum (2011, 33) considers reproductive health and choice within that to be central to this capability, and in Lucy's story that part of bodily integrity was hampered not directly by the medication but by the lack of information. Here, impeding on bodily integrity means impeding on agency freedom too.

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[129] *Montgomery v Lanarkshire Health Board (General Medical Council intervening)* [2015] UKSC 11, 87 (Lord Kerr and Lord Reed)

The capabilities approach is concerned with providing people with the minimum threshold of capabilities, but the minimum threshold remains undefined in the approach. It is, however, suggested that the threshold should be enough to accommodate people's opportunity for developing relevant capabilities like bodily integrity that support associated functionings like agency freedom. The psychiatric survivors highlighted that side effects should be disclosed in accordance with individuals' needs, and therefore the standard created by *Montgomery* appears to be compatible with the development of capability for bodily integrity in the psychiatric context. However, for this capability to be supported it would need to be sufficiently applied in clinical practice. This again highlights the difficulty of requiring psychiatric professionals to apply new and quite complex laws in their psychiatric practice. Consequently, psychiatrists rely on clinical concepts like insight to aid adherence and consent to treatment by patients.

The capabilities approach applied to this data suggests that it is not necessary that there is full disclosure of all information but only that there is sufficient disclosure of information that is relevant to a particular psychiatric survivor. However, for mental health professionals to have the knowledge allowing them to distinguish which information is important to any patient and which is not requires what I discussed in Chapter 4 as an attunement to people's values and unique life stories and might even require a relational continuity of care. However, advance consent to mental health treatment presents an opportunity for developing bodily integrity through the provision of informed consent for future treatment. Robert suggests the following:

> The only answer to that [informed consent] is by looking at your information and seeing traditionally looking in history what worked best and then try to start with that.
> (Robert, photo-elicitation interview)

It is not difficult to understand how advance consent can facilitate informed consent to psychiatric treatment. By choosing to self-bind to a particular treatment that they have previously experienced, psychiatric survivors have intimate information about how the said treatment affects their bodily integrity. Of course, some side effects may need to be discussed regardless, such as the impact of antipsychotics on fertility, but, overall, advance consent here was seen as increasing agency and cultivating bodily integrity. I return to this issue in more depth in Chapter Seven, where I discuss appropriate safeguards for and restrictions on advance consent which includes limiting it to treatments that have been previously experienced by psychiatric survivors. Nonetheless, the perceived benefit of advance consent was that it was seen as an opportunity for informed consent and, in turn, the capability for bodily integrity.

## 5.5. Provision of speedy treatment and the notion of mental capacity as a barrier to advance consent

### 5.5.1. Advance consent as improving access to treatment.

Advance consent to mental health treatment was also seen as a significant opportunity for improving access to treatment and reducing the time in which relevant treatment can be provided. This benefit appeared to be particularly enthusiastically articulated by psychiatric survivors, which can be observed in Table 5.2. below:

| Table 5.2. Excerpts - advance consent as improving access and time in receiving care |
|---|
| I’ve been thinking about this and logically to me, that is the way forward. … You can produce something to then say “actually, this worked before, let’s do this in that order”. That makes complete sense to me. … If it’s worked before why reinvent the wheel? It takes a long time to find a cocktail of medication that’s gonna work. For me, it took a number of years of trial and error with different antipsychotics and antidepressants and that type of thing. So, I think if after all that time I come out with what really suits your body why would you want to go through this trial and error again. … The wide impact of it [advance consent] is phenomenal, especially in terms of resources. This would save the NHS so much time … |

But also, the amount of stress of the trial and error and actually the scope of it is really amazing. … The consultations with psychiatrists are tiring especially to have to tell your story over and over again.
(Lucy, photo-elicitation interview)

I think that'd be really helpful because the last thing you want when you sort of relapse is to be told you've got another six-month wait for CBT [cognitive behavioural therapy]. Especially like me for example. … if somebody does relapse or has a bad episode you can go to them and they can then pick up the file and say okay well this is how we'll work through it rather than that six-month wait because in that six-month wait you're just in limbo and you don't know what's going on.
(Michael, photo-elicitation interview)

I find it very frustrating the thought of having to go back through a system, I think in terms of the NHS and the struggles that the NHS is under … . If even if it was just a portion a fifth or sixth, a tiny percentage of people that had some kind of fast track like advance consent that would almost bin them out of the system completely because they just they wouldn't have to see the doctors and the CPNs and have all the initial thingies.

When you don't have to go through the consultations where you have to go back all over your family history. I mean, I don't want to come from my family history again.
(Sophie, photo-elicitation interview)

Absolutely fantastic. If that if that if that existed or does exist and that would be, I think that would, it would be amazing. … That's one of the reasons that people play the system they get fed up because they know that they're just going through this.
(Robert, photo-elicitation interview)

In the excerpts contained in Table 5.2. there is a strong emphasis on advance consent allowing psychiatric survivors to access treatment more promptly. However, there are several criteria which need to be fulfilled for this access to materialise. Firstly, the benefit of advance consent is dependent on the presence of effective treatment. As Lucy notes, finding the right "cocktail of medication" can take several years, so to be able to request this for a future relapse (should relapse occur) was associated by Lucy with a sense of relief. For this to work, psychiatric survivors must have a specific treatment in mind which has been previously effective in helping them during the times of mental distress. Lucy and Sophie both stressed what Albert emphasised earlier,[130] that telling your story of mental ill-health and family history, and having to go through a number of consultations is exhausting and is especially taxing in times of mental health crisis. Michael saw a clear benefit of advance consent used for requesting cognitive behavioural therapy for his depression as reducing waiting times and consultations. There was also a sentiment that advance consent would have a far-reaching benefit by saving the resources of the NHS in that it would eliminate the number of people who require a variety of appointments in order to access their desired treatment.

In Chapter 4, I suggested that people hold off their initial 'mental breakdown' because at that stage mental health treatment is perceived as oppressive and disabling to the pursuit of an individual's values, life roles and life projects. However, as their stories progressed, psychiatric survivors associated successful treatment with the preservation of agency that would enable them once again to resume and pursue what they really value. Accordingly, advance consent was seen as bridging the gap between undesired treatment or treatment provided in an undesirable way and the devastating consequences that relapse can have on someone's life:

> The mixed state[131] is the highest risk because when you're manic and I can vouch for this, everything is great, I spent thousands of pounds in minutes, everything you touch is great, everyone you meet is great, it's like being on cocaine and ecstasy and it doesn't go away for weeks, sometimes.
> (Sophie, narrative interview)

Here, Sophie reflects on her behaviours when experiencing a particular state of bipolar disorder, where she recalls spending over £10,000 in minutes and even thinking about marrying

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[130] See Chapter 4, section 4.3

[131] The mixed state in the bipolar disorder refers to the presence of high and low symptoms at the same time. This term is now considered outdated. See Malhi (2013).

a newly met man. Sophie reflected that those decisions could have had a devastating impact on her life and having advance consent in the future would reduce the time for finding effective treatment and minimise these socio-economic and very real consequences that a relapse would have on her life. Those consequences are also vastly reported in the literature (e.g. Saks 2002).

Finally, the promptness of receiving treatment was related to advance consent's ability to minimise coercion, a benefit discussed earlier in this chapter and reiterated by Eve:

> Maybe if people had advance consent, they would seek treatment because they knew they wouldn't be treated badly, they would be treated in accordance with it. What's interesting is that it is so great it could happen.
> (Eve, photo-elicitation interview)

In Eve's excerpt, she encompasses something that has been noted in clinical literature. Srebnik (2004) reports on the findings of a study in which advance directives (including consent to treatment) were trialled on patients and which found that advance consent resulted in prompt treatment and in patients willingly coming forward in times of crisis knowing that their advance wishes would be applied. In reporting a story of one of their participants, Brenda, Srebnik (2004, 71) writes:

> Brenda made a psychiatric advance directive (PAD) to utilize her voice in treatment decisions. ... She reported, "I was extremely psychotic and suicidal and needed help directing treatment and telling people what I wanted. The PAD was extremely helpful for getting the right treatment, coordinating my care, and getting what I needed. I felt people listened to me. Treatment was speedier, organized, and involved everyone necessary. I had more control over the situation, and I was being heard." Today, Brenda is actively participating in her treatment and has expressed renewed faith in herself and in the mental health system.

Srebnik (2004) reports that, overall, the use of advance directives reduces the waiting time for receiving treatment. Brenda, in this study, is an example of the perceived benefit of advance consent being realised in practice. Winick (1996) argued that patients who are actively involved in decision-making about their mental health are much more likely to seek the treatment significantly earlier, and Maylea et al. (2018) found this to be true for patients who have experience of using advance statements in Victoria, Australia.

Conceptualised through the capabilities approach, the promptness in receiving treatment and improved access to the desired treatment has inherent value in improving both the agency and the bodily integrity of psychiatric survivors. Nussbaum (2011, 33) defined bodily integrity as including choice in reproductive matters. Accordingly, this was particularly visible in Lucy's story of non-consensual treatment with medications that had the potential to impact her fertility. However, Nussbaum's definition of bodily integrity should be expanded to include having opportunities for mental well-being and for choice in matters of mental health. Well-being here should be understood in its ordinary sense. Well-being can be achieved through the use of advance consent in times during which the mental distress impedes psychiatric survivors' bodily integrity. Consequently, advance consent is a partial measure through which bodily integrity can be restored or achieved.

### 5.5.2. Mental capacity as a barrier to advance consent

For an advance consent to aid the achievement of bodily integrity in the way captured by psychiatric survivors, its perceived benefit/s are inextricable from the question of its invocation. Defining the precise time at which advance consent should apply is not an easy task. Following the English law on advance refusals, it might be intuitive to suggest that advance consent applies when the psychiatric survivor has lost their mental capacity to make decisions about their health. The MCA 2005 has created a legal framework which is obsessed with decision-making processes being based on this notion in relation to people who are perceived as too vulnerable to make these decisions for themselves.[132] I argue, however, that blindly following this line of legal thinking in the context of advance consent to mental health treatment would gravely undermine the empowering premise of this mechanism as well as its benefits.

The notion of mental capacity came up organically in several interviews, usually when I prompted participants to explain what they mean when they say "sound of mind". In general, they had some awareness of the mental capacity test and expressed opinions on its application in the psychiatric context. As Lucy had experienced several informal hospital stays, I asked her directly if her capacity was ever assessed. When asked about her experiences of mental capacity assessments, Lucy said she did not realise they were relevant to mental health settings and that she does not think her capacity was ever assessed. She stated that she had read all her medical notes, and she had not come across any information about her capacity status. However, as an informal patient, Lucy could only have been treated on her valid consent, which means that her capacity should have been assessed, at least in theory. Instead, Lucy said that her medical notes presented plentiful information about the presence or absence of insight when notes were made about her adherence to rather than her consent to medication. Similarly, other participants stated that they did not remember having had their mental capacity assessed and that decision-making appeared always to have been dependent on the presence of insight.

Insight is a weaselly term that does not map onto statutory criteria or legal terminology in any obvious manner. As it is a clinical concept, its definition is absent from the legal lexicon. Previous academic attempts by legal scholars to define insight in English common law have proven unsuccessful (Case 2016; Gurbai, Fitton and Martin 2020) despite it being the most

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[132] See Chapter 1, 1.5.1. for outline on the mental capacity assessment and context.

cited concept in mental health law proceedings and used as a clear aid for capacity assessments when psychiatrists are called in as expert witnesses; "insight trump[s] the statutory criteria for capacity assessments" (Case 2016, 360). It is not clear whether judicial silence on this concept has resulted from its perceived understanding and implied 'relevance' to mental health patients, something that is simply a part of expert witness testimony. In 2021, a counsel used the term 'insight' in legal proceedings in Ireland, arguing that the pregnant woman concerned had been diagnosed with mental health illness, meaning that she lacked insight and capacity to consent to a suggested C-section (O'Faolain, 2021). This example demonstrates that insight is used in various legal proceedings despite not having a clear definition derived from law. This relationship between capacity and insight is very problematic (e.g. O'Keffee 2022), considering that lack of insight was found to be the most significant predictor of incapacity in psychiatric care in England and Wales (Owen et al. 2009a).

Lived experiences of mental health care in this research reveal little reliance on the concept of mental capacity. Brown et al. (2013) found that only 9.8% of capacity assessments were documented in almost 18,000 admissions to a psychiatric hospital in England. Within those, only 14.7% relied on the Mental Capacity Act criteria for assessing capacity and other criteria used were described as arbitrary (Brown et al. 2013, 122). Yet, assessments based on insight appear common and, as shown in this chapter, the presence of insight comes with certain privileges. If, as suggested by this data and other medico-legal research, psychiatrists conduct capacity assessments arbitrarily or rely on the concept of insight in capacity assessments, it is worrying to note that psychiatrists make up over 50% of mental capacity expert witnesses in the Court of Protection (Case 2016). It is not clear why psychiatrists are so often called for their perceived expertise in capacity assessments, but Case (2016) suggests this is linked to the perception that, as psychiatrists 'cure' minds, there might be an impression that they are also well placed to assess capacity. Also, this might or might not be related to the history of the development of mental capacity law. In *Re C (Refusal of Medical Treatment),* Thorpe J found helpful a forensic psychiatrist's analysis of the decision-making process broken down into three stages: comprehending and retaining treatment information; believing it; and, finally, weighing it in the balance to arrive at a choice.[133] This suggests that mental capacity is not purely a legal concept, and its legal development has been influenced by the discipline of psychiatry (Ruck-Keene et al. 2015). This interrelatedness between mental capacity and insight provides an explanation as to why insight so easily seeps into capacity assessments conducted by psychiatrists. This further explains why, for instance, expert witnesses in the Court of Protection commonly use medicalised approaches to assess capacity (Ruck Keene et al. 2015: Lindsey 2020), as Lindsey and Harding (2021, 19) point out:

> this is arguably because capacity is often considered to be a clinical question, which can be assessed through cognitive tests or other quasi-objective measurements used by psychiatrists to aid diagnosis.

However, other studies suggest simply that mental capacity is a complex legal concept and professionals require more training to fully understand it (Jayes, Palmer and Enderby 2017). In 2018, the National Institute of Health and Care Excellence (NICE 2018, para 1.4.24.) released guidelines on assessing mental capacity in practice, stating that:

> Practitioners should be aware that a person may have decision-making capacity even if they are described as lacking 'insight' into their condition. Capacity and insight are 2 distinct concepts. If a practitioner believes a person's insight/lack of insight is relevant to their assessment of the person's capacity, they must clearly record what they mean by insight/lack of insight in this context and how they believe it affects/does not affect the person's capacity.

The guideline highlights that 'capacity' and 'insight' are distinct and not interchangeable concepts. Nonetheless, it still permits the use of insight in capacity assessments providing that the reasons for its relevance are clearly recorded. But using insight in this context is using

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[133] *Re C (Refusal of Medical Treatment)* [1994] 1 F.L.R. 31, 295 (Thorpe J)

extra-legislative criteria which might result in the denial of rights for those who, in fact, have the capacity.

It is clear that the mental capacity test may be severely underused or misused in practice, and, when it is applied, it tends to be invisible to the law. I am therefore hesitant to argue that there should be a greater reliance on the concept of mental capacity in psychiatric practice or that applying advance consent should be dependent on mental capacity status. Psychiatric survivors in this research appeared equally sceptical about the usefulness of the notion of mental capacity in this context, questioning whether waiting for the loss of capacity would undermine the benefit of receiving treatment promptly:

> About the mental capacity thing … You shouldn't have to get to the point where there is no mental capacity. You cannot wait for a person to be incapacitated because it hardly really happens, ever.
> (Eve, photo-elicitation interview)

Eve was familiar with the mental capacity test because she had a Lasting Power of Attorney for her mother and recalled the assessment being carried out. Eve suggested that, even though people are clearly affected by the symptoms of their mental health, the vast majority would be capable of making treatment-related decisions in consideration of all the relevant information. Hale et al. (2017, 74) suggest that, when capacity assessment is applied in accordance with the law, then it is in fact a rare situation for a mental health patient to actually lack capacity in the legal sense. These assumptions are evidenced by a number of studies which assessed capacity of psychiatric patients to make treatment-related decisions. Okai et al. (2007) found that mental capacity can be reliably assessed in those settings and that a majority of patients have capacity, despite the severity of symptoms.

Finally, participants questioned the validity of mental capacity and its wider application in the psychiatric context:

> I think mental capacity is hard to think about. I swear different professionals assess it differently. Isn't there a unified training? I don't know it is potentially creating a dangerous situation. […] I don't think I ever lost capacity. […] Risk assessments are better because I genuinely posed a risk to my own life and my mum's, but I am sure I could appear as someone who could still have capacity. Risk is real, this capacity test is not. I don't think your capacity is assessed much in mental health settings, maybe they do it and don't tell us? This might be another concept that ends up being abused by most professionals.
> (Lucy, photo-elicitation interview)
>
> On the flip side, what if I have capacity, don't get sectioned because of that, go home and kill my neighbour? Not that I would but hypothetically speaking.
> (Eliza, photo-elicitation interview)

In the above excerpts Eliza and Lucy share parallel sentiments about the mental capacity test not being able to take into account the issue of safety. Various studies demystify and debunk the idea that psychiatric patients pose a higher risk of violence than people in the general population.[134] In fact, they are more likely to cause harm to themselves, and very few might pose risks to others. Lucy is the only participant who described symptoms that drove her into potential danger, recalling visual hallucinations and a persistent voice telling her she needed to kill her mother. In an attempt to appease the voice, Lucy wanted to harm herself in order to save her mum but admits that, on a few occasions, if it had not been for the intervention of the mental health services, she would have hurt her mum. However, she then backtracks and suggests that she would probably harm herself to avoid harming her mother.

Despite the intensity of her symptoms, Lucy contends she could have shown she had mental capacity and would have been able to present 'well' to others, especially if she had wanted to. Eliza, who did not exhibit dangerous behaviour towards others, raises an important question that might arise from a potentially perilous situation created in circumstances where mental health provisions are replaced with reliance on the MCA 2005. However, participants

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[134] See section 5.2. of this chapter for relevant discussion and literature.

felt that the legal obligation attached to mental capacity assessments or the MCA 2005 could mean that there was a greater potential for creating space in which professionals are not encouraged but required to take patients' views into account. Additionally, participants believed it to be unlikely that they had ever lost their mental capacity and that reliance on the test would mean that doctors could "wash their hands off of [patients]" (Katie, narrative interview) and that people who needed help would be "left on their own" (Eve, photo-elicitation interview).

It is clear, that advance consent invoked by incapacity is likely to result in the premise of advance consent to mental health treatment not being realised. This is because mental capacity appears to be underused in psychiatry when it ought to be used in practice, and that when it is used it might too often be relying on the concept of insight. Psychiatric survivors' expressed scepticism towards both concepts, which were viewed as constructs with little validity and certainty when it comes to their application in practice. Most importantly, invoking advance consent on incapacity would hamper its major asset of the prompt receipt of treatment which, consequently, would restrict the achievement of bodily integrity.

## 5.6. Insight as a barrier to advance consent

Although I discuss the overall desirability of advance consent and its necessary safeguards in Chapter 7, it is worth pointing out here that the vast majority of the psychiatric survivors in this study, 11 out of 12, thought that the premise of advance consent is empowering, and, overall, it was construed as a desirable legal mechanism enhancing agency, freedom and relevant capabilities. Thus, the majority of psychiatric survivors perceived advance consent as having practical, real-life benefits. However, advance consent was not seen as an example of empowerment that leads to the achievement of relevant capabilities by all psychiatric survivors.

One participant, Helen, strongly objected to the idea of advance consent and suggested that insight might be responsible for this position. Helen has been subject to a number of treatments and hospital admissions over the span of 50 years. She describes her experiences as a constant fight to be listened to. Her treatment refusals were not respected and were misconstrued for lack of insight, according to Helen. Unhelpfully, Helen has never found any treatment that she would like repeated. She thought, therefore, that advance consent would:

> … play into the hands of psychiatrists because you just gave them [permission to] treat you. It would give them more power. You would show insight. They love that. Insight. (Helen, narrative interview)

Helen's views regarding advance consent in this study link to the broader importance mandated by capabilities that each person must be treated individually and have means of support tailored to their needs, highlighting the importance of advance consent being always available on a voluntary basis. Helen's repeated negative experiences have shaped her strong position that only advance refusal should be allowed and only advance refusal could ever be empowering.

Moreover, Helen suggests that advance consent could become a tool in a psychiatrist's hands to enforce and justify compliance which in turn suggests that advance consent could become an expression of insight. This concern is not unfounded given the experiences of psychiatric survivors with the compliance component of insight in particular. Furthermore, the concern is possibly substantiated in recent literature on advance consent. In 2017, India passed the Mental Health Care Act which put both advance refusals and advance consent on a statutory footing.[135] In 2018, Gowda et al. conducted a study looking at factors influencing the making of psychiatric advance decisions. They found that 80% of participants followed psychiatric advice in their advance decision. Interestingly, Gowda et al. (2018) also suggested that lack of insight negatively impacts psychiatric advance decision-making. The uptake of advance

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[135] Mental Health Care Act (2017) (India), s 5.1.

directives was similar in those lacking insight as in those who were thought to have insight, but the majority of those who lacked insight opted for refusal of treatment against psychiatric advice. Additionally, refusals were seen by psychiatrists as less desirable than requests. This supports Case's (2016, 376) argument that refusals of treatment are pathologised in psychiatry. In another study conducted in the US, Swanson et al. (2006) found that concerns over a person's insight resulted in psychiatrists being more likely to override treatment refusals to allow time for patients to regain insight. Even though the legislation in various US states gives mental health professionals broad discretion over whether to carry out a patient's wishes, it was found that insight as a clinical concept played a significant part in the perceived applicability of advance refusals even though this is not a legally valid ground for not following an advance directive.

Although the notion of advance refusals for mental health treatment is beyond the scope of this thesis, it is nonetheless relevant to the experiences of psychiatric survivors. However, it is important that any framework for advance consent coexists along with a framework for advance refusals to ensure that people's bodily integrity is achieved in a way consistent with their values. If advance consent is seen as an expression of insight in psychiatry, then this risks advance refusals, or refusals in general, being further pathologised in clinical practice. Moreover, the insight could significantly impair the empowering premise of advance consent and become yet another mechanism that is experienced as a source of unfreedom. Of course, advance consent carries an implied refusal; by agreeing to some treatments, psychiatric survivors reject others. Yet, this may not explicitly be enough to protect patients from receiving treatment that was experienced as particularly harmful.

On the other hand, a reimagination of insight in light of David's and Ariyo's (2021) views could actually provide an additional justification for the importance of advance consent to mental health treatment not just in law but in clinical practice. If insight is reconceptualised as "self-knowledge" that allows people to live "authentic lives" (David and Ariyo 2021, 186) then the respect for this self-knowledge could lie in permitting people to make advance consent and to others respecting it. However, as David (2020) notes, it is unlikely that the notion of insight will be reimagined in clinical practice. It is therefore especially important that the law considers how insight could impact people's opportunities for advance consent-making because how insight currently permeates through the application of mental health and mental capacity law is currently invisible to law and free from legal scrutiny.

## 5.7. Conclusion

Overall, the practical benefits of advance consent provide psychiatric survivors with the opportunity to achieve an important capability, bodily integrity, if sources of unfreedom or barriers like insight or mental capacity are taken into consideration from the very beginning of thinking about legal provisions for advance consent. Bodily integrity in this context was understood as the ability to move freely from place to place which is closely associated with being free from unnecessary coercion and having opportunities for choice in matters of mental health. Advance consent was perceived as helpful in achieving bodily integrity because it was seen as capable of minimising coercion since it gives an opportunity for psychiatric survivors to be treated in accordance with their wishes: namely as providing a means for expressing a truly informed consent by being able to choose treatment in accordance with one's values and as being capable of providing prompt treatment translating into improved experiences of seeking mental health care.

When examining those practical benefits, I demonstrated how the concept of insight is depicted in the experiences of psychiatric survivors. I argued that insight acts as an extra-legislative criterion for coercion and for information disclosure. I then maintained that for the final practical benefit – the speedy provision of treatment – to be realised advance consent should not be invoked by incapacity. To not rely on capacity assessments for the application of advance consent is a matter of justice. This is because the incapacity requirement would prevent the realisation of prompt treatment which is crucial for psychiatric survivors' bodily integrity. Finally, mental capacity would risk the concept of insight seeping into the workings of advance consent. Consequently, risking advance consent becoming an expression of insight that would further pathologise non-compliance with treatment and undermine the practical benefits of advance consent.

In the next chapter, I continue the theme of advance consent's invocation. I argue that advance consent should apply at a point specified by psychiatric survivors. There, I will also address an important question on whether advance consent should preclude changes of mind at a material time and the relationship between preclusion and coercion. Examining my data, I suggest that advance consent should preclude those changes of mind to enable the realisation of bodily health, including mental health and the capability for emotion. In addition, I argue that a nominated trusted person framework could mitigate and safeguard patients' wishes should the' change of mind' dilemma materialise.

# CHAPTER 6: WHEN SHOULD ADVANCE CONSENT BE INVOKED AND SHOULD IT PRECLUDE CHANGES OF MIND AT A MATERIAL TIME? THE ROLE OF HEALTH AND EMOTIONS AS CAPABILITIES

## 6.1. Introduction

In Chapter Five, I analysed the perceived practical benefits of advance consent as depicted by psychiatric survivors and discussed how these benefits support the capability for bodily integrity. I also demonstrated how the clinical concept of insight seeps into the application of mental health and mental capacity law in practice. Insight was framed as a barrier to the premise and benefits of advance consent. In a similar vein, mental capacity was conceived as a barrier to advance consent because invoking advance consent on incapacity could increase the reliance on insight in decision-making practices in mental health care. In addition, it would prevent advance consent from applying at a material time so that the benefit of prompt treatment could materialise. In this chapter, continuing with the theme of invocation, I argue that advance consent should be invoked at a time specified by an individual as this respects the individual needs and unique experiences of psychiatric survivors.

Taking this position poses a number of legal and ethical challenges pertaining to the issue of coercion in particular. It forces one to consider the situation in which advance consent is supposed to apply, namely, when the material time arises but the individual refuses the treatment contained in their own advance consent. I refer to this scenario as the 'changes of mind dilemma'. This is an exceptionally difficult situation because it involves overriding current refusals of a capacitous patient in favour of their earlier treatment wishes. This raises a thorny legal and ethical question about the justifiability of precluding changes of mind, especially as they may be capacitous. Additionally, this presents a further challenge: when advance consent is framed in this way, it raises the possibility of treatment being experienced as forced, thus undoing the perceived benefits of advance consent. These questions are even more pressing if an individual in fact chooses for their advance consent to be invoked by their changes of mind because refusals at the material time might be what they wish to protect themselves from.

I begin this chapter by highlighting the presence of the changes of mind dilemma in literature which supplements the discussion in Chapter 1[136] highlighting the problematic nature of finding a legally coherent and ethically sound solution to this problem. Drawing on the capabilities approach, supplemented by building on the work of Nussbaum (1996; 2001; 2011) and Bielby (2021), I offer a new way of thinking about these challenging dilemmas through two central capabilities: health and emotion. By health, in particular, I refer to mental health in its widest sense, including its psychosocial aspects. By emotion, which is a broad term, I mean relational attachments of love and care and a compassionate approach to treatment. I propose that compassion is a crucial component of these interrelated and interconnected capabilities which might guide the process of providing support when questions around invocation/revocation arise.

By drawing on the photo-elicitation data, I argue that advance consent should preclude changes of mind at a material time. The data suggest that advance consent is intended to apply even if – and perhaps especially when – the individual attempts to revoke their advance consent at the material time. Drawing on the capabilities approach, I argue that by precluding changes of mind, advance consent cultivates the development of central capabilities to bodily health

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[136] See 1.5. Research Context.

and emotion. Drawing on Sen's (1999) work, I suggest that individually designed advance consent can be responsive to the levels of 'force' an individual is willing to accept. Therefore, the capabilities analysis of empirical data provides a new way of thinking about the changes of mind dilemma, moving us away from needing to reconcile past and present wishes.

Finally, I explore the possibility of a nominated trusted person framework as a way of mitigating changes of mind situations. By drawing on empirical data and the capabilities approach, I suggest that such frameworks may support the relevant capabilities when they are based on the notion of compassion. I then offer my concluding remarks and introduce the final empirical chapter of this thesis.

## 6.2. Invoking advance consent and overriding changes of mind dilemma: the literature and the capabilities

### 6.2.1. Literature: invoking advance consent and (im)permissibility of changes of mind

The question of invocation and permissibility or impermissibility of changes of mind has been present in ethico-legal literature since the early 1980s (e.g. Dresser 1982; Howell, Diamond and Wikler 1982; Radden 1996; Spellecy 2003; Bielby 2014). Dresser (1982) became a prominent cynic of psychiatric advance consent arguing only for invocation based on capacity status which is the way in which advance decisions tend to operate in law nowadays. But, even then, she suggested that it is likely that judges would find such arrangements to be an unconscionable limitation to one's liberty. For instance, advance decisions to refuse treatment

(ADRTs) under English law come into effect when the person loses capacity.[137] In the Indian Mental Healthcare Act 2017, advance consent or refusal of psychiatric treatment is also applicable at that point.[138] Proponents like Saks (2002, 206) argue for an impairment condition and suggest it is justifiable for one to self-bind for future instances in which their "subsequent self" is impaired to make the right decision. Saks' (2002, 206) impairment criteria is not a mere presence of mental illness or a diagnosis, but rather it is about the disabling effects of a mental health crisis which prevent the person from making decisions that they would value had they not been in this crisis. She notes that this is a lower threshold to one of mental capacity, and this distinction is crucial for Saks who notes that even in crisis people are likely to retain mental capacity in accordance with the legal test but nonetheless suffer "a fairly high degree of disability" (Saks 2002, 206). On this basis, Saks (2002) suggests that, when people present with impairment, any changes of mind as to their treatment requests/refusals should be disregarded. Bielby (2014, 125–126) suggests that Saks' (2002) impairment criterion is nothing short of a typical mental capacity test, as it would require the development of criteria against which this high degree of impairment can be measured, resonating closely with a functional capacity assessment under the MCA 2005. In agreement with Bielby (2014), I further add that Saks' (2002) ideas should be mindfully considered against the critique of functional tests of mental incapacity as not only being discriminatory but also at odds with the UN Convention on the Rights of Persons with Disability (CRPD) (e.g., Arstein Kerslake 2017; Harding 2017a).

As discussed in Chapter 1 scholars have also used different versions of autonomy to address the invocation and changes of mind dilemmas (e.g. Dresser 1982; Sheetz 2006; Davis 2002; 2009; Gremmen et al. 2008; Walker 2012; Bielby 2014). Nonetheless, for bioethicists

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[137] Mental Capacity Act 2005, s 24(1)(b).
[138] The Mental Healthcare Act 2017, s 5(1).

concerned with the questions of law and ethics, the idea that a single version of autonomy could justify the use of legal advance consent was unconvincing and often seen as widening the gap in the understanding of questions of implementation, application, and invocation (e.g. Dresser 1992; 1995; Maclean 2006; Wrigley 2007). In response, scholars became interested in the justification of advance decisions through certain conceptions of personhood (see Atkinson 2007; Hayes 2015) based on a variety of theories of personhood, which were also used for the justification of advance consent and for addressing the question about changes of mind. However, these theories often exist on a highly abstract level and, similarly to the versions of autonomy, are not always capable of addressing the changes of mind dilemma, which is both an everyday problem in the psychiatric context and a legal conundrum.

Proponents of advance consent have also begun to consider Dresser's (1982) earlier idea that giving third parties some recognition in an advance decision might be a practical solution for mitigating the situations when changes of mind arise or there are any other dilemmas about when advance consent should come into effect. Using relationality and vulnerability frameworks, Gremmen et al. (2008) argued for a formal role of a nominated representative whose responsibility would lie in confirming whether changes of mind are genuine and whether or not advance consent should prevail should any problems arise. Bielby (2014) goes further in proposing two ways for sharing legal capacity in an advance consent. The first proposal is for a joint representative whose involvement would be triggered by the individual's changes of mind and their role would be limited to confirming which wishes of an individual are genuine (Bielby 2014, 135). The second proposal is for an additional joint decision-maker, who would be given formal legal powers to provide a second opinion on the changes of mind, sharing legal capacity between the individual and their chosen initial joint decision-maker, noting the variety of legal challenges these proposals raise (Bielby 2014, 135-136). Clausen (2014) proposes a more practical model which focuses on a nominated person's role safeguarded by the need for them to justify their decisions in order to minimise the risk of abuse; a system of registration for advance consent and the extent of the role of the other person; limiting the number of times in which a nominated person may be able to override the wishes of the individual; and specifying the time at which their role should be triggered.

Rather, than revisiting those frameworks, I will explore a new way of conceptualising these difficult questions through the lens provided by the capabilities approach with a particular focus on the capabilities for health and emotions. I also suggest that a nominated trusted person may be a useful safeguard for the relevant capabilities in those challenging situations and for maximisation of advance consent’s benefits. However, what is new about my argument is that I propose to conceptualise these questions through the capabilities of emotions and bodily health, providing a novel framework for thinking about invocation and changes of mind in the context of advance consent.

### 6.2.2. The capabilities for health and emotion underpinned by compassion as a new way of thinking about questions of invocation and revocation

I begin with the premise that the capabilities of emotion and bodily health are intricately interrelated and interconnected when conceptualising the question of invocation and changes of mind. Nussbaum (2011, 33) defines emotions capability as:

> Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude and justified anger. Not having one’s emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development).

An expression of this capability can be spotted in earlier chapters of this thesis. For instance, in Chapter 4[139] I discussed how Sophie wanted to stop taking lithium because, despite finding it helpful, it was preventing her from feeling adequate emotions and from having adequate responses to her child's behaviour, thus suggesting that effective treatment may not always be the desirable option because it may not promote relevant capabilities. This further points to the idea that capabilities are interrelated and interconnected. However, in my formulation of emotions as a capability, relevant to psychiatric survivors, it has its expression in planning for the future to ensure that people's important relationships are preserved and cherished and that their abilities to have those attachments to others – to love, to care and to feel justified emotions – are not hampered by negative experiences of mental health care or excessive and unnecessary coercion. Consequently, the capabilities for emotions might help to understand advance consent as a social, not just medical, plan that can be realised with the help of those who might be crucial for the preservation and development of capability for emotion.

The involvement of others in the execution of advance consent is, of course, not a new idea, as discussed in the previous section. However, the previous justifications have inadvertently always focused on managing risks. For instance, Bielby's (2014) and Gremmen et al. (2008) formulations, by highlighting people's vulnerabilities, emphasise risks associated with non-provision of treatment and the level of vulnerability beyond everyday limits. Radden (1994) justifies the use of advance consent and preclusion of changes of mind by noting the effects that non-treatment would have on others. She suggests that the assessment of whether or not to follow earlier wishes expressed in an advance consent should turn on the "potential costs to others [caused] by its revocation", but when revocation or changes of mind do not have consequences for others then the advance consent should be respected (Radden 1994; 799).

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[139] See Table 4.3.

This is because Radden (1994) considers the consequences of broken promises to be ethically more detrimental than the consequences of changes of mind. Although, Radden's (1994) argument is an interesting relational account, it places greater value on preserving emotional capabilities over the health and agency of an individual. By focusing on the risks to emotional or relational lives and disregarding health consequences, Radden (1994) arrives at a justification limited to managing some risks which exist on some level of hierarchy. Similarly, Bielby's (2014) and Gremmen's vulnerability formulations also hinge on managing risks. In contrast, I propose that viewing changes of mind and the question of invocation through the capability for emotions offers a much more positive and balanced framing of these otherwise difficult situations because it is no longer about managing risks, but, instead, it is about developing capabilities for emotion and health and enabling people to thrive.

The capability for emotions applied to a changes of mind dilemma is strongly interconnected and interrelated with bodily health, and health is defined by Nussbaum (2011, 33) as:

> Being able to have good health, including reproductive health, to be adequately nourished; to have adequate shelter.

In my formulation here, bodily health includes mental health. Venkatapuram (2011, 143) uses the capabilities approach and develops a capability to be healthy framed as a meta-capability necessary for people to possess in order to achieve other capabilities. I do not agree with this approach in the mental health context because it is difficult to define what 'good' mental health is, and viewing this simply as the absence of illness or symptoms is limiting and could lead to the medicalisation of this capability while ignoring the social aspects of mental good or bad health.[140] This would also foster ignorance towards the fact that in reality not all symptoms of

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[140] Note that although Venkatapuram (2011) constructs an ethics-based definition of health rather than medical, he assigns this capability a higher value.

mental ill-health are distressing, and, as Ritunnano and Bortollotti (2021, 1) argue, symptoms like delusions can have and give meaning to individuals because "[delusions] can help make sense of one's unusual experiences and in some circumstances even support one's endeavours, albeit temporarily and imperfectly". Therefore, using Stavert and McGreggor's (2018, 83) conceptualisation of mental health, I suggest that it should be viewed in its "widest sense" which appreciates the biopsychosocial needs of people, and this might include support in decision-making processes. I purposely use the term 'capability for health' instead of 'mental health' to recognise the widest sense of the capability and to highlight the need for parity between physical, reproductive, mental and other sub-forms of health in this capability.

In addition, the capabilities for emotions and health should be underpinned by compassion, building on Bielby's work (2021), who develops 'compassion for thriving' in mental health ethics. More ordinary understandings of compassion are well summarised by Nussbaum (2001, 301) who defines compassion as a "painful emotion occasioned by awareness of another person's underserved misfortune". Therefore, compassion is inherently relational and, thus, requires relational and compassionate responses to the individual's suffering. In Nussbaum's (2001, 302–311) work, the suffering must be of a certain level of importance to an individual, the responses must be both empathetic and sympathetic and the evaluation of the "badness" of the suffering must be established. Compassion requires action because of the true concern for the well-being of another person in line with how that well-being would be defined by an individual (Nussbaum 1996, 57). In such a way, individual suffering can be given meaning which informs how challenges must be addressed and what action should be taken (Nussbaum 1996, 37). Therefore, compassion is a matter of justice because it provides a justification for taking actions which improve the well-being of another (Nussbaum 1996, 28). Bielby (2021, 300) notes that the focus on particularity is consistent with Nussbaum's (2011) work on the capabilities approach, but there are also other elements which are consistent with her work on capabilities, such as the importance of action, emphasis on well-being, and the focus on relationality and experiential meaning. However, this version of compassion is limited to responding to suffering that is already being experienced rather than on responding to future possibilities of suffering.

Bielby (2021, 298) argues for a novel understanding of compassion in public mental health which he refers to as "compassion towards thriving". This contribution provides a new framework for public mental health ethics and addresses a gap in previous such attempts which did not focus on the notion of compassion (e.g. Coggon 2017; Coggon and Laing 2019). Bielby (2021, 298) encourages shifting away from the focus on alleviation of actual suffering "to the prevention of potential future suffering through the facilitation of personal growth based on a 'psychosocial' understanding of mental health" (Bielby 2021, 298). In his approach, Bielby (2021, 301) argues that if one views compassion as mainly concerned with pre-existing suffering and future possibilities of suffering, then it forces one to consider measures that respond to this eventuality. The measures developed might require meaningful social support and such support should be provided compassionately and should be responsive to the psychosocial needs of an individual (Bielby 2021, 302).

Following on from Bielby's (2021) work, I suggest that the capabilities for emotions and bodily health are underpinned by compassion towards thriving, especially given Bielby's focus on understanding mental health in psychosocial terms. In particular, I envision compassion to be an underlying principle behind the capability for emotion. As previously explained in this Chapter, the capability for emotion is concerned with freeing people from fear and anxiety about uncertainties or not having their agency respected and it is also concerned with the emotional lives of people. For this capability to be available, one must have opportunities for preserving important relationships, undertaking those life pursuits that matter to them and to use those relationships as a support network if desired. Compassion here should be understood as a relational experience used where necessary in support of health and emotion capabilities and facilitated through advance consent which may prevent or minimise future suffering. It should be used to address the questions of invocation and changes of mind to ensure that capabilities for emotion and bodily health are promoted, nurtured and accessible to people. Exercising compassion towards thriving in this way means that individuals have the real opportunity to realise their capabilities for emotions by accounting for pre-existing suffering and developing appropriate responses and support networks.

## 6.3. Invoking advance consent at a 'material time': an empirical exploration

Psychiatric survivors in this research did not provide a uniform approach to the question of invocation. Instead, they had different ideas as to when it might apply to maximise the benefits for an individual. The most popular suggestion was that the material time is the point of relapse in order to facilitate their health capability. However, this raised the question of 'how far' relapsed a person would need to be for advance consent to apply and how they could ensure that the treatment would be provided. For some, relapse was defined as the point at which symptoms begin to reappear, while others wanted their advance consent to apply at the point when they have been sectioned; there were also those who felt that a set of triggers built into advance consent would help them identify the material time during which advance consent should apply.

| Table 6.1. Invoking advance consent - excerpts. |
|---|
| One of the things that struck me was that if a person who let's say had schizophrenia, went to the psychiatrist, and say "I'm feeling unwell etc." that would be the time when that |

advance decision would be applied. The fact that they have made the decision that they feel poorly enough to go and see a psychiatrist for help would suggest to me that they are well enough to recognise themselves that they need an intervention at that stage because they have made that decision, or they have decided to keep that appointment or whatever it might be. … If somebody chooses to go to the appointment and then explain they're not well, I would, as a psychiatrist take it as their consent to use their advance consent. Sort of like "we've talked about this; we've got it all planned out" …
(Lucy)

So, I think at the point of relapse, they need to carry out that assessment to see the impact on the day-to-day life and then to make a judgment call about how bad it is because if it's not that bad and somebody is just having a down day, which will happen from time to time, it happens to everyone, then I don't think at that point there's a need to rush them back in. There might be a thing we can say on the system. Okay, contact them in a couple of days' time to see how they are, even in a week's time to see whether it was just a one-off or something else. But I would more look at the day-to-day impact and go, okay, we've now reached the point where we need to intervene, and we need to do something. Again, not mental capacity, because you would probably still have it if you're depressed.
(Michael)

That is a difficult one. I think it should apply if you catch yourself then … it should. When you ask for help, that should … asking for help should be a very empowering thing. And a lot of people think that it is not of empowering thing. It is a negative thing. So, I think it has to be some immediate reward for you being able to self-manage yourself to the point that you can say, "well, I need some help now", okay let's look at your advance consent. So, I think that that is a primary.
(Sophie)

It should apply as soon as you are sectioned, I think.
(Eve, photo-elicitation interview)

It should apply before you get sectioned, so actually, you don't get sectioned.
(Eliza)

That's interesting because again, it's at what point that kick in and it might have to extend to your partner, carer or somebody who's walked the walk with you because we are clever at saying we're okay. We can start saying, no, no, you don't need to do that yet because I'm okay. … The great thing is you can call it yourself. … [Mental health is] so complex and so varied. And so, and the triggers, you can't put it into even 10 categories. You can't even shoebox a diagnosis into it. It's so varied. People can sit around and have similarities, but everyone's experience is different. (Robert)

From the psychiatric survivors' excerpts, it is clear that advance consent should apply at the point of relapse. Indeed the very idea of advance consent was seen as a measure used for the prompt delivery of treatment that would prevent deterioration of health and devastating everyday life consequences that might impact people's capability for emotions. However, the specific point in relapse at which advance consent should apply was affirmed differently by different individuals. Lucy identified this point to be when the patient themself admits that they are not doing well. She also suggested that what might work for her is a detailed graded plan, so that different treatment interventions apply at different points depending on how unwell she is. This is because Lucy's symptoms vary from mania to depression and psychosis. When she experiences mania (and depending on the severity), this might require a completely different medication than when she experiences psychosis. She explained that if she comes into contact with mental health services, in whatever way, then advance consent should be applied. In a similar vein, Sophie thought that advance consent should apply when one 'catches' oneself, suggesting this is at the point when an individual realises that they are unwell so that they can confidentially seek help knowing that the treatment provided will be the one specified in advance consent, thus minimising the possibility of unwanted intervention. Here, she frames advance consent as empowering and as a reward for seeking intervention.

Michael suggested that for someone like him, with a diagnosis of clinical depression, advance consent should not apply immediately after an individual presents as unwell, but rather when their symptoms are affecting their day-to-day life. Michael reflected that for him it would be at the point where he stops caring about his hygiene or his job. Furthermore, he elaborated that his suggestion is not dissimilar from the assessment of a doctor who diagnoses depression by asking a person a series of questions about how they are feeling and if they are able to perform different functions. The idea here is that, if Michael had advance consent, he would not need an appointment but could self-certify by making contact with the relevant services to inform them that the symptoms were now having an impact on his everyday life. He also stated that he would make an advance consent to therapy to speed up the process of receiving it by reducing the waiting time and initial assessments a person goes through when they are referred for the therapy by their GP. Meanwhile, Eve thought it should apply as soon as a person is sectioned, to ensure that they are treated in accordance with their wishes and their informed consent. Sophie's idea is opposed by the likes of Eliza, who thought that to minimise coercion advance consent should apply instead of hospitalisation. Finally, Lucy also thought that advance consent should apply at the point when she presents as unwell but refuses her treatment because of her symptoms, pointing to the changes of mind dilemma.

It is clear that, for advance consent to achieve the perceived practical benefits discussed in Chapter 5 and thus enable the achievement of the capability for bodily integrity, it needs to come into effect at a time specified by an individual to meet that individual's unique needs that are particular to their experiences of mental ill-health. This is consistent with the capabilities approach which treats each individual as an end and emphasises the importance of an individual's values.

Advance consent designed in this way may effectively address some of the main well-established challenges for advance decisions in mental health settings more broadly. Firstly, allowing individuals to establish the point at which advance consent comes into effect diminishes the use of the mental capacity threshold in mental health settings. In Chapter 5, I argued that there are two major benefits to this. Firstly that it minimises overreliance on the concept of insight which has detrimental effects on psychiatric survivors' understandings of justice and may be used as an extra-legislative criterion to justify coercive measures, while also ensuring that treatment is provided promptly. In this way, advance consent protects people who, despite having mental capacity, might struggle to assert their wishes due to difficulty experienced by their symptoms (Stavert 2021, 104). In addition, secondly, it addresses risk and harm issues which are an important consideration. These were alluded to by Lucy and Eve in Chapter 5[141] who contended that the risk is something much more real and material than mental capacity; these concerns are also widely addressed in the literature (e.g. Appelbaum 2010; Buchanan 2010; McKay and Stavert 2017).

Although in this thesis I do not engage with a human rights analysis in relation to advance consent, it is worth noting that advance consent which applies at the time specified by an individual has the potential to achieve a level of compliance with the UN CRPD. In its General Comment, the Committee on the Rights of Persons with Disability (2014, para 17) states the following:

> States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.

Stavert (2021, 104) argues that the Committee's approach "is a serious consideration for those states who are parties to the CRPD who are contemplating introducing advance planning mechanisms or have adopted such measures, but which are aligned to mental capacity assessments". Therefore, invocation of advance consent in compliance with an individual's wishes might be legally desirable from the human rights perspective.[142]

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[141] See section 5.5.2.

[142] Note that I do not claim that advance consent as presented in this thesis *is compliant* with the UN CRPD. This requires a nuanced assessment which adopts a human rights framework from the start. Undoubtedly, some ideas present in this thesis, for instance, the approach suggested to the changes of mind dilemma discussed later in this chapter might pose a challenge for the notion of the best interpretation of wills and preferences for CRPD compliance, but this is beyond the scope of this thesis. For analysis of psychiatric advance directives, and mental

Meanwhile, Sophie, in her excerpt,[143] frames advance consent as empowering because asking for help, she contends, is also empowering which could potentially have a positive impact on stigma. Pavlova and Berkers (2022)[144] established that, when it comes to tackling mental health stigma, measures which frame mental illness and help-seeking as something positive and empowering, rather than as something that is risk-orientated, had a particularly positive impact on tackling stigma. Thus, the freedom in the design of advance consent could convey the wider message that psychiatric survivors can be trusted to make their own self-binding decisions in accordance with their needs.

Following on from this empirical analysis, I propose that advance consent would best protect people's capabilities if it was invoked at a time specified by an individual in their advance consent; thus, also avoiding the need to rely on mental capacity assessments for invocation. This is likely to result in psychiatric survivor's developing greater trust in relevant healthcare professionals and prevents inconsistency win how the mental capacity is assessed in psychiatric settings. Furthermore, as previously suggested, this may increase the English law's compliance with the CRPD. However, it may also pose a challenge in relation to one's Article 5 rights under the ECHR. This could happen when a clause specifying invocation is poorly executed or when it is misinterpreted by healthcare professionals could raise questions surrounding unreasonable deprivation of liberty. Undoubtedly, implementing advance consent with a clause specifying invocation for each individual is likely to be challenging. Additionally, careful guidelines will need to be developed to ensure a necessary level of consistency to promote

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health laws more generally, in light of the CRPD see Weller (2013), Gooding (2017), Scholten et al. (2019) and Stavert (2021, in particular page 104).

[143] See Table 6.1.

[144] See also discussion on this in Chapter 4, 4.4.

people's rights and to protect them from unjustified coercion and unintended consequences of their invocation clause. It is clear that the premise of advance consent would be best realised by not aligning its invocation to mental capacity assessments and letting individuals decide when it should come into effect. However, this also raises a possibility that advance consent might come into effect against contemporary and capacitous refusals at the material time. This raises a question about the legal and ethical permissibility of overriding contemporary, and often capacitous, changes of mind in favour of earlier wishes expressed in an advance consent. These issue is explored in the next section.

## 6.4. (Im)permissibility of changes of mind: an empirical exploration

In photo-elicitation interviews, participants were asked directly about their attitudes towards the changes of mind dilemma and presented a strikingly uniform response, as demonstrated in Table 6.2. below, contending that changes of mind at the point when advance consent is intended to come into effect should not be allowed.

| Table 6.2. Attitudes towards permissibility of changes of mind at a material time - data from photo-elicitation interviews. |
|---|
| Of course, people with mental health problems get paranoid. They might think someone wants to poison them, for instance. I think, that if I had made a living will and then I got paranoid and delusional and ended up in a hospital and said "well, I don't want it anymore, I've changed my mind" and they [doctors] listened to me, I think I would be really cross. I think I would turn around and say "look, we agreed in advance when I was in my right mind, when I spent all this time considering this decision … that you would treat me and you didn't". … Yes, I'd be cross. I would be really cross that nobody respected what I agreed when I was in my right mind.<br>(Eve)<br><br>The very idea strikes me as something that prevents you from changing your mind … But regarding consent, I think if you've made a decision of going to the doctor and making |

advance decision, that’s your consent you can’t change your mind. … To have that [advance consent] would have really helped me: “look this is where we are, you’ve come here today and we are going to put it in place” I could have breathed and said “thank you”. It would be like somebody taking a breezeblock off me.
(Lucy)

When I’m low, I become very indecisive. I can’t make a decision. I almost become numb, like I don’t know anything; I can’t do this, I can’t do that, I’m not sure. And when I’m feeling good. Basically, can I borrow your pen? I’m going to draw a picture. Basically, say this is a normal line [draws a straight line]. Most people with depression and it goes like this [draws a line downward]. Mine goes like that [up and down line]. When I’m there [low], I become very indecisive. I can’t get there. That’s the thing. And when I’m there [high], I make so many decisions, I don’t know which one to concentrate on. Too many decisions and I can’t pick. And I keep changing my mind all the time. I don’t give a chance to that decision to work, right?
(Albert)

The whole idea I think of advance consent is that you’ve made the advance consent so we can’t change it. So that’s the whole idea of doing it. So no, that’s it. If you can refuse it, then what’s the point of having advance consent in the first place?

But what’s the point of having an individual contract of employment at the bottom line it says “the management reserves the right to change anything at any time.” … No matter what we’ve agreed, we can change it. Which I found absurd. So no, the advance consent is, that’s what it’s all about. … Absolutely. 100% [advance consent should be legally binding]. 100%.
(Robert)

I think if you’re really ill and you refuse treatment… So, for example, I use paranoid schizophrenia because it’s that paranoia about everybody being against you. It’s quite likely that paranoid schizophrenics, quite likely, that they would change their minds because they would think that the drugs are poison or whatever, not for their benefit. If you think of it in terms of policing, if somebody is drunk or under the influence, we cannot interview them. You can’t do anything with them. They’re in a cell there in a holding cell, waiting until they’re every sound minds. I don’t think that anyone can change their decision when they’re ill. … No one can change their decision when they’re unwell. Advance consent should apply.
(Sophie)

One of the safeguards which I would always say put in place is it’s legally binding.
(Michael)

The situation presented to participants as a changes of mind dilemma resonated closely with Lucy's experiences:

> Oh God, I can remember being in that scenario myself! Thinking "I'm doing really well here, nobody can tell what is going on" but being paranoid about treatment.
> (Lucy, photo-elicitation interview)

Impermissibility of changes of mind was inherently linked to advance consent being seen as an expression of autonomous wishes, supporting the shared valued functioning of agency freedom. As Robert suggests (Table 6.2 above), the very idea and point of advance consent is that one cannot change one's mind. It is worth considering participants' justifications for this in turn.

### 6.4.1. Justification 1: advance consent as a legally binding decision

There was a strong sense among the participants that advance consent should be legally binding to ensure that advance consent is not overridden, which indeed, as Michael contends (Table 6.2), would be a way to safeguard advance consent. The need for this can be linked to distrust in health care professionals executing advance consent and mental health law itself:

> The question mark that I have about this is that under the law if you are deemed insane, it doesn't really matter what you say when you are sane. … And so is [advance consent] legally binding.
> (Eliza, photo-elicitation interview)

Eliza was concerned that the law, as it is, gives more power to professionals over the individuals who are at the heart of mental health law. Indeed, she doubted that the law would permit advance consent to be legally binding but suggested this would be the desired outcome so that professionals were not able to easily disregard advance consent, even when changes of mind occur. Additionally, in this way, advance consent would also protect the individual nature of a person's treatment that will be unique to them, supporting their capability for health. In Table

6.2., Robert discussed the individuality of mental health experiences and thought that advance consent should absolutely be legally binding so that the unique health needs of people are respected.

Finally, my participants followed the logic that a legally binding advance consent would naturally preclude changes of mind at a material time, and the logic here resembles Howell, Diamond and Wikler's (1982) proposal for a voluntary commitment contract. Robert likened advance consent to a contract of employment with a clause suggesting that anything could be changed, suggesting that advance consent designed in this way would be ineffective, "absurd" and without a point to it. However, the logic that a legally binding advance consent protects against changes of mind taking precedence might not necessarily be true unless advance consent is specifically legislated for in this way, which is evidenced by how advance decisions have been developed or are being developed in English law.

ADRTs are legally binding advance decisions to refuse treatment which are subject to stringent criteria for validity and applicability. Under section 25(2)(c) of the MCA 2005, an ADRT will be invalidated if the person does something clearly inconsistent with their advance decision. The effect of this is that if someone attempted to state that their changes of mind should not be followed, could not be binding and are likely to be struck off by the court, they would not necessarily invalidate the refusal contained in the directive.[145]

The nature of this specific provision raises a question as to whether the 'doing' of something inconsistent includes the 'doing' post-capacity and whether 'doing' includes only actions or whether words are included in this too – questions which formed a part of a scholarly debate for over a decade (e.g. Coggon 2007; Maclean 2008; Christie 2019; Ruck Keene 2020).

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[145] In *A Local Authority v E* [2012] EWHC 2508 (COP), Peter Jackson J in his obiter dicta at [63] that any behaviour which appears to be in contradiction of the advance decision, should not be viewed as a change of decision.

The narrow interpretation of this provision, endorsed in *W v M*[146] by Barker J, suggests that the provision only applies to actions up to the point where the person loses their capacity and has not had a chance to withdraw their advance refusal in time. However, Poole J in the case of *PW*[147] held that:

> I interpret s.25(2)(c) as allowing for the advance decision to be rendered not valid should the person who made the advance decision do “anything else” (other than withdrawal or granting an LPA which displaces the advance decision) which is “clearly inconsistent” with the advance decision remaining their fixed decision, before or after they have lost capacity to make the relevant treatment in question. The question will only arise after they have lost capacity but the court may consider things done before or after that time. Munby J refers to a person being locked into their advance decision once they have lost both capacity to decide whether or not to accept medical treatment and any ability to express their wishes and feelings. Similarly, s.25(2)(c) allows for a person who has lost capacity nevertheless to do something or to have done something which renders the advance decision not valid.[148] … “done”: I read this to include words as well as actions.[149]

The Court of Protection has therefore clarified that doing something inconsistent consists of both words and actions during capacity but also post capacity, giving significant weight to the person’s wishes in such a circumstance.[150]

Additionally, in its proposal for statutory advance consent that would otherwise amount to the deprivation of liberty under the MCA 2005, the Law Commission (2017, para 15.13) suggested that “a person is subject to a confinement to which they do not have the capacity to consent, and to which their advance consent would on its face apply, but where their actions provide a clear indication that that advance consent should not be relied upon” and emphasised expressly that this provision would mirror section 25(2)(c). Although the advance consent to

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[146] *W v M and others* [2011] EWHC 2443 (Fam)

[147] *Re PW (Jehovah’s Witness: Validity of Advance Decision)* [2021] EWCOP 52

[148] *Re PW (Jehovah’s Witness: Validity of Advance Decision)* [2021] EWCOP 52, Poole J [50].

[149] *Re PW (Jehovah’s Witness: Validity of Advance Decision)* [2021] EWCOP 52, Poole J [52].

[150] A similar position was also adopted by Keehan J in *Re QQ* [2016] EWCOP 22, albeit his judgment is not as clear as Poole J’s.

care and arrangements that would otherwise amount to deprivation of liberty in this context did not find its way into the 2019 Amendment to the Mental Capacity Act, it has been included in the Draft Mental Capacity Code of Practice (DHSC 2022, para 12.55):

> The ability to provide advance consent should always be an important aspect of care planning. It ensures that the person can plan ahead and have a say in the provision made for their future care or treatment and avoid unnecessary and potentially distressing assessments.

Based on current policymaking and law-making for advance consent to mental health treatment and the recent clarifications regarding section 25(2)(c) of the MCA 2005, the legally binding nature of advance consent could preclude changes of mind only if this was explicitly reiterated in the statute, taking it further than simply making advance consent legally binding. This, in the views of psychiatric survivors, would support their health capability.

### 6.4.2. Justification 2: following a decision made by a ‘well’ individual precludes the wishes of an individual when ‘unwell’

Eve states[151] that she would be cross if her advance consent was revoked because she would have made it when she was in her “right mind”. In the accounts of psychiatric survivors, there was an implied understanding that advance consent should be made when one is well and in one’s ‘right mind’, thus justifying precluding changes of mind when they are in a mental health crisis. Eve in particular also reflected on the right timing of making an advance consent:

> I just think that if a person is kind of doing it too soon after the experience of being sectioned, let’s say. They are too much full of… emotion ... too much of “I’ve been held a prisoner and things have been forced on me.” I think in that instance they would be more likely to make a decision to say they don’t want anything rather [than wanting something].
> (Eve, photo-elicitation interview)

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[151] See Table 6.2.

Here, Eve suggests that people might not only need to be well but might also have some sort of hindsight following the treatment because they are likely to see the benefits of treatments later on. However, there is no consensus in the literature as to when is the optimal time for making a psychiatric advance decision. Thornicroft et al. (2010) suggest that it should be made outside of hospital settings and possibly in community settings. Khazaal et al. (2008) believe that it should be during the following admission as the acute stage of crisis passes, and Qin and Nordentoft (2005) suggest that it should be made at the beginning of a crisis when the person might still be able to express their wishes. There was also no clear sense from my participants when the best time for making an advance consent would be other than that it should be done when they are well enough to do so and that expressing wishes while being well should mean that these wishes should be followed in times of crisis. Atkinson (2007, 134) also states that:

> Common sense would suggest that the best time might be when the patient is receptive to a general consideration of the future, including future treatment. For some, this might follow on from a relapse or a hospitalisation. For others contemplation of another episode in the future at such a time is just too painful. Whilst some might see planning for future episodes as a positive step in gaining some control over what happens, others may see it as ‘giving in’ to a medically based philosophy or a model which is designed to keep them ill.

What Atkinson (2007) appears to suggest is that there might be a variety of optimal times and that the ‘one size fits all’ approach to finding such a time might be extremely challenging, which is supported by Robert’s focus on the uniqueness and individuality of mental ill-health experiences. Undoubtedly, this is a difficult question of implementation. However, Nicaise, Lorant and Dubois (2013) and Khazaal et al. (2014) suggest that psychiatric advance decisions are more likely to be made by individuals if they have been given some legal authority. From a legal point of view, therefore, it might be in the form of a requirement that individuals have the mental capacity to make an advance consent or that another process of authentication is developed to ensure that the wishes carry a desirable legal weight and that advance consent is followed at a time specified by an individual, regardless of the capacity status at that material time.

This raises a thorny question regarding the withdrawal of advance consent: if advance consent is made by a person with capacity, then should it follow that it can also be withdrawn by that person at a time of capacity? However, this would inadvertently mean that when changes of mind are capacitous, albeit illness-ridden, they would be respected despite a clear indication from my participants that changes of mind at a material time should not revoke an advance consent. In thinking about the changes of mind, Sophie reflected that changes of mind should only be accepted from a 'well' individual:

> I think the psychiatrist could be part of that process to reiterate the fact that this person is doing really well and verify they are not doing it out of sickness at the time. You've got to be well consistently for a period of time etc.
> (Sophie, photo-elicitation interview).

This suggestion is consistent with participants' view that advance consent should only be made by an individual who is well enough to make it. Indeed, Sophie's opinion that the person needs to be "well consistently for a period of time" mirrors Eve's suggestion for making advance consent after a reasonable amount of time has passed since a crisis that was met with treatment. The suggestions from participants do not necessarily suggest that by 'well' they mean someone with capacity, but, as argued earlier in this chapter, it is problematic to define what good mental health is, and therefore it would be rather difficult to measure in some way how well one is to make such a decision. Illustrating this point, Michael suggests that being well enough for him to make such decisions requires the illness not to be affecting his day-to-day functioning. Drawing on this and the broader experiences of psychiatric survivors, one suggestion would be to allow individuals to define what being well or in their right mind means to them, similarly to allowing them to decide when advance consent should be invoked. Nonetheless, this might lead to over-complication of the implementation and possibly the effectiveness of advance consent. A practical solution would be to preclude changes of mind at a material time which is defined by an individual but allow these at any other time without placing additional strains on decision-making processes regarding advance consent.

An additional challenge to the implementation arises with previously discussed legally binding advance consent, which, as explored, may not protect people adequately from their changes of time at a material time-taking effect if advance consent were developed in parallel to advance refusals. Nonetheless, I advocate for a hard enforceability position to advance consent, ensuring that it is a legally binding mechanism. This will ensure that advance consent is not easily disregarded and that people's wishes are followed despite apparent changes of mind if advance consent's legal applicability is not dependent on the "inconsistent behaviour" clause. This is likely to pose a challenge for legal implementation because lawmakers will have to consider carefully whether there are situations or reasons where changes of mind will be followed, which extends far beyond accepting one's revocation at a material time as absolute. To tackle this, I suggest that developing a framework for nominated trusted other could aid the implementation of advance consent, as discussed in section 6.5 of this chapter.

### 6.4.3. Justification 3: the emotional unburdening

Lucy has also shown me an excerpt[152] from one of the journals she kept when unwell in which she wrote how, during the current time of crisis, the voice she heard forbade her from taking her medication or telling her psychiatrist what was really happening. There was a sense that

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[152] I was unable to reproduce the original quote from Lucy's journal in this thesis due to the confidentiality concerns.

medication was going to harm Lucy herself but, most importantly, it would result in the voice killing Lucy's mother. To avoid hurting her mother, Lucy contemplated throwing herself down the stairs but, in the meantime, she banged her head hard on the wall over and over again. Following several hours of this ordeal, and prompted by the home treatment team, Lucy took her tablet but continued to feel scared, and frustrated, and wrote how this made her unable to make any decisions and, even if she managed to make a decision, she suffered immensely. She explains how exhausting that day was for her and how much energy and strength are required to take the medication. Similarly, in Table 6.2, Eve notes that it is possible for people in a mental health crisis to think that treatment will be poisonous, which may lead to changes of mind. Thus, in considering those situations, both Eve and Lucy expressed that changes of mind should not be allowed at the material time.

For Lucy, having advance consent to work in this way would mean that she would not be blighted by the fear created by her symptoms which negatively impact her capability for emotions because her decisions regarding medication would have already been taken and so the treatment would be provided. In a similar way to Lucy, Albert reflects on how burdening decision-making can be when he is feeling low due to the effects of his depression. Allowing changes of mind would undo the work of making advance consent in the first place and leave people unable to make decisions for themselves whether it is because of the voice they are hearing or because they are experiencing indecisiveness which is hindering their emotional capabilities while blighted by the suffering they are undergoing and burdened by the necessity of making decisions.

#### 6.4.4. Development of capabilities for emotion and health through participants' justifications

My participants have unequivocally attached more weight to wishes made in advance consent than wishes expressed at a material time when advance consent is supposed to come into effect. I will argue in this section, that a capabilities conceptualisation offers a more practical and holistic way of thinking about the changes of mind dilemma by providing an alternative to the impasse created by having to reconcile present and past wishes purely through notions of autonomy. The desirability of advance consent as precluding changes of mind was also affirmed in clinical research on psychiatric advance decisions. Swanson et al. (2003) found that not only patients but also doctors and family members supported the idea that changes of mind at the material time should not revoke an advance decision.

It is worth noting that advance consent raises a different dilemma than that of advance refusals. Atkinson (2007, 150) suggests that, when a person has decided to refuse treatment but later changes their mind, health care professionals are likely to follow the change of heart, but when the patient attempts to opt-out of treatment they have previously requested, such a change of mind will be harder to accept by professionals. The willingness to override advance refusals in favour of changes of mind is likely to appeal to the inherent duties of healthcare professionals to alleviate suffering and treat people, which might be further explained by Nussbaum's (2001) understanding of compassion as alleviation of suffering in another. On the other hand, following changes of mind in advance consent could be perceived by healthcare professionals as causing more suffering by leaving the patient without help or having to section them to provide treatment against their wishes. Following advance consent despite contemporaneous changes of mind raises a thorny question about whether advance consent could amount to an experience of coercion in this context because providing that treatment against changes of mind might require the use of some force. However, even though participants were clear that the treatment provided through advance consent is consensual and therefore does not amount to coercion, the fact that it might require the use of force requires a closer conceptualisation.

Sen (1995; 1999) suggests that coercion is unnecessarily viewed dichotomously as something that either is or is not present, depending on where a person stands on consequentialists and libertarian theories, and so represents either paternalism or autonomy or pure coercion or pure freedom respectively, leaving no space for appreciation that coercion, on some levels, can coexist in harmony with freedom. What follows is that maximisation of rights or, in this context, the benefits of advance consent, might generate a set of consequences which can be experienced as coercion, but which were fully anticipated and accepted when the advance consent was made (Sen 1999; 212–213). Therefore, people are free to choose to accept a certain level of coercion, which is justified If it leads to the maximisation of advance consent's benefits[153] and also supports relevant capabilities. A measure of this nature is acceptable if the person making the advance consent is informed of the potential of some coercion and has opted into it voluntarily (Sen 1999, 214).

Sen (1999, 221) further indicates that coercion may be less problematic than the influence of oppressing social variables, the consequences of which are more damaging to an individual than an accepted coercion because of the importance of relevant rights, benefits and capabilities. In the context of psychiatric survivors, such a 'social' but more 'legal' variable could be said to be involuntary detention and compulsory treatment. The law permits the exercise of non-consensual treatment and detention of people, regardless of their capacity status, and an argument that advance consent is controversial or legally problematic because of

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[153] Benefits of advance consent were discussed and examined in Chapter 5.

changes of mind scenarios (i.e. ‘hard case’ situations) is not sustainable in light of the capabilities analysis. Even if some level of coercion or force would be involved in the execution of advance consent, this would not outweigh the perceived benefits as highlighted by my participants or the ways in which advance consent supports important capabilities. Disallowing advance consent on the basis of the possibility of coercion but retaining provisions for involuntary treatment would amount to what Sen (1995, 223) describes as the “temptation of duress” to achieve certain goals, which would perpetuate the cycle of over-protectionism and the disablement of people with mental ill-health.

Sen (1995, 225) indicates that the effectiveness of the presence of coercion which coexists alongside freedoms requires a close examination of the link between well-being and agency freedom. If the presence of coercion does not prevent well-being and agency freedom from amplifying, then coercion can be regarded as effective. In the context of advance consent and in line with the theoretical drivers in this chapter, I propose that this evaluation should hinge on the link between agency freedom and the capabilities for health and emotion. The preclusion of changes of mind cultivates the capability for emotions because it respects their value and the need for preservations of relationships and emphasises that the decision to preclude changes of mind in advance consent is inherently linked to relational aspects of people’s agency. Moreover, in this way it supports the capability to health through the exercise of agency freedom to maximise the health-related benefits of receiving treatment. Ultimately, advance consent which precludes changes of mind is an effective solution because it “calls for more freedom, not less” (Sen 1995, 226).

The relational aspects of the capabilities discussed present an opportunity for considering ways in which changes of mind could be mitigated and in which people’s wishes can be supported.

In the next section, I, therefore, turn to the potential of the nominated trusted person(s) framework for invoking or revoking advance consent at a material time.

## 6.5. Mitigating changes of mind dilemma: exploring the role of nominated trusted person(s)

### 6.5.1. Nominated trusted persons: the role of loved ones

In the previous part, I discussed that participants were uniformly against revoking advance consent at a material time. For most, this appeared to be an easy decision, but Lucy has taken some time during the interview to ultimately decide that advance consent should preclude changes of mind because it would be unburdening to her in times of crisis where she considers decision-making to be incredibly taxing. Initially, although Lucy thought that people's wishes in times of crisis should be taken into consideration, she, however, decided that advance consent contained the actual wishes made with sufficient consideration not be revoked by illness-induced refusals, as demonstrated in Table 6.2. above. Lucy and other participants recognised that in some situations, particularly where a professional is unsure whether to follow advance consent or changes of mind, some safeguards should be provided to check whether advance consent should still be invoked. In thinking about mitigating the changes of mind dilemma, Lucy suggested that there should be a system in place, so that people review whether their wishes remain unchanged, and, therefore, changes of mind would be allowed only during the review stage when the individual is well enough to do so. Sophie shared a similar sentiment, as demonstrated in the first paragraph in Table 6.3.

Table 6.3. Sophie - nominated trusted person, photo-elicitation interview.

I think the psychiatrist at that point would actually be quite reckless to take the word of a very ill person and act on that, rather than an agreed thing, was drawn up with a family at a time of health and prosperity. When they're well [they can change their mind]. I think having any decision that ultimately decides your fate needs to be done when I don't know … having your family around you, I think is really important because they're the ones that know you. By family, I'm not just going to put it on blood. Family like you can have family that are best friends.

In terms of solicitors and lawyers, I find it might complicate the process. Yeah, it might complicate process because obviously, you know, they like to make money and write letters, so that might be overcomplicating it.

Yes, so I think it needs to be made with as little complication as possible but because it involves giving you a drug potentially somebody saying yes, you need to shoot her in arse with that drug. Yeah, I think there has to be some sort of some responsibility taken to say that this person is trusting this other person to be part of this decision. I don't think it should take weeks. I don't think it should have to go through solicitors. It should just be respected as part of your doctor's notes. Kind of like donor cards. Yeah, I think that's changed now that everyone in this country is automatically, but I used to carry something like that.

Sophie was the only participant who suggested that advance consent should actually be drawn up with the help of the loved ones. Sophie said that her experiences of mental health are going to fundamentally impact the closest people to her and so their involvement was justified. Robert similarly highlighted the impact of advance consent on other people by suggesting that precommitment is an everyday part of life and so is making promises to others. Robert told a story about a trip he planned with his friends for his birthday, but then, when his birthday came round, he no longer wanted to go as he had started to experience symptoms of relapse. He decided to follow through with the trip because:

> Sometimes you have to do the right thing. You have to follow a procedure. Pardon me; The problem is if you're gonna have sex with someone, you don't want to make them pregnant, you make sure you wear contraception. It's that kind of responsibility for me. It's that kind of, that kind of responsibility. You have to make that decision and that's it. (Robert, photo-elicitation interview)

These examples resonate with Radden's (1994) account about the impermissibility of changes of mind because of promises made to others, as discussed in section 6.2. Radden (1994) uses an example of a person with bipolar disorder who is trying to revoke their advance consent at the material time, but this is likely to cause a financial strain on their family because, in crisis, the individual tends to spend money recklessly. This example resonates with Sophie's story, whose experience had been similar in the past. Thus, the impermissibility of revocation is based on reasons relating to the impact it would have on the loved ones of the individual. Radden (1994) therefore suggests that revocation should be permitted when it does not have consequences for others, regardless of the consequences it has on an individual who is self-bound through advance consent. This absolute relational account of Radden's (1994) represents an ethical imbalance regarding one's well-being as being of lesser importance than promises an individual makes to others, thus one's well-being is only valuable when it is in line with those promises. On the other hand, the capabilities conceptualisation appreciates both the relational aspect of Sophie's suggestion and self-regarding well-being because of the interconnection between the capabilities for emotion and health, which gives regard to both Sophie's health and the importance of the consequences of her decisions on her family. Sophie did not see advance consent as just beneficial for her family life but primarily important for her health and emotional capabilities. Advance consent, in Sophie's account, was, therefore, a relational and capabilities-developing experience.

Similarly, following through with a decision was important to Robert because of the promise he had made to others, and he emphasised in both interviews how important this was to him, yet acknowledged that he is only able to care for his family and care about their feelings when he is well because when he relapses he becomes selfish. Consequently, this highlights that the capability for emotion includes the preservation of relationships which might consist of fulfilling promises and commitments. However, this capability is inherently related to the health capability. Roberts's likening of pre-commitment to advance consent has also been highlighted in relevant scholarship and used as an ethical justification for advance consent as being no different to everyday life precommitments that people follow through despite not feeling like doing so at the material time (e.g. Jaworska 1999; Bielby 2014). Therefore, for some people, justification for preclusion of changes of mind might also be related to the impact that allowing changes of mind would have on others, thus justifying involving other persons in the thinking and making of advance consent from the start.

### 6.5.2. Familial tensions and professionals as nominated trusted persons

Other participants did not conceive of advance consent as being something that is made with loved ones but instead recognised that others could act as a support network in challenging times, especially when changes of mind arise, a situation which was particularly well articulated by Eve in Table 6.4. below.

| Table 6.4. Eve - nominated trusted person, photo-elicitation interview. |
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| You know how when people go for abortion, they are supposed to have some sort of counselling to understand the options, to see are they being pressured by somebody else, do they really want to do it or is it only because their mother or their boyfriend thinks it's a good idea, that kind of thing. I wonder if there should be some counselling on advance consent, not from a psychiatrist, but perhaps from a mental health nurse who is trained as a counsellor in this field. So, its need to be proactive, it needs to go to all these patients and say "this is a possibility" and to sit down with you and say what actually happened to you? That would help people. Just someone, who would sit and say "what actually happened?". They would have to be the right sort of person, of course, non-judging and directive, you can't have someone who would secretly try to direct them to say "you need to have this medication". Maybe not even someone from a mental health background, but a proper counsellor, non-judgemental, a good negotiator. Maybe someone from not a medical background then! A proper counsellor, who is proactive, lets you talk about your experiences of the hospital and they try to tease out of them what would be helpful, what was helpful, what was abusive and really damaging and what is it that the person absolutely hated but has actually had to be done. Like for me now, I know I had to be held under section. I didn't have any family to go |

to, I was running around the streets. It was either that or put me in a women's shelter or get attacked or something on the streets. So someone who can tease it out, a counsellor or someone, but they would have to be proactive because people quickly get a label of being a trouble maker. If a person says "I want this, I want one of these" it's like in a psychiatry "oh look at that patient, they're the trouble maker". Because that happens, "they're the ones wanting the rights".

And I suppose the family could come into this. There also has to be some sort of review system, because if the family came into it, let's say and you know you haven't spoken to them [doctors] in five years and so you have changed your mind, how is anyone going to know. There has to be some sort of appeal or a review system but I think it should always automatically apply.

But [family could come into this] only then [in situations of conflict]. Sort of like a power of attorney, that would be a very good thing. So, you thought about what you want, you maybe talked to your family or maybe you made it secretly. You go to the counsellor, you work out what you want, you go to the psychiatrist maybe with an advocate discuss what seems reasonable with the psychiatrist if it seems reasonable on both sides I think it would be good to nominate a backup. And that back up could be the counsellor that was there in the first place and that could be the system. But either a counsellor or a trusted nominated person whoever that might be who knows, because they would have probably been talking recently, they would have had hearts to hearts and things and they might have better idea about their current mind. So if you've nominated that person in advance someone you trust, at the point when you get paranoid, oh god, that's the problem, people get paranoid! What if start going "I don't want that person, they're not my best friend, they're spying on it!"

What I'm trying to say is about, at what point, as a loving person, do you feel that the person has a right to make their own choices? Sometimes it comes to a point, where you, as the person who loves them have to make those choices for them, just go, sorry I'm stepping in, this is right for you. So, I think the backup thing would be to have the nominated person. Sort of like the power of attorney but less, not binding, only someone as a backup. And I think you have to stick to it, to the advance consent.

Here, in the last paragraph of Eve's excerpt, she suggests that a nominated person could act as a 'backup' if or when the change of mind dilemma arises. In arriving at this suggestion, Eve told a story about looking after her mother with dementia who categorically refused to live with anyone and contended that she wants to die alone at home. Eve tried to offer support to fulfil her mother's wish until it became clear that Eve's mother was experiencing much more than anticipated suffering, and so Eve felt in that situation that her mother's wishes should no longer be respected. Eve thus considered that stepping in at times of mental health crisis might be a compassionate thing to do. This resonates with Nussbaum's (2001) understanding of compassion as connected to the alleviation of existing suffering by ensuring that advance consent is followed, and at the same time it resonates with Bielby's (2021) 'compassion for thriving' because it follows the plan made for this future suffering in mind.

This idea of having a nominated person as a 'backup', which was closely connected to the ideas of compassion, was also shared by Robert:[154]

> I've been lucky because she's probably suffered as much as I have. She knows me inside and back to front or vice versa. But there are people out there who don't and they're relying on others or maybe there is any contact with their GP or someone who isn't as distant or somebody is using the situation to their advantage and these kinds of things. Yes. And that's interesting and I know that isn't available for everybody. … Absolutely [would give my wife formalised role in advance consent]. Yeah. Absolutely, definitely. And that's interesting and I know that isn't available for everybody.

Robert suggests that he would like his wife to be a nominated trusted person and would even give her a formalised role in advance consent-making because of this notion of shared suffering between them, which suggests again that the compassion element of relevant capabilities is a relational experience. This shared suffering would enable Robert's wife to act in line with his own understanding of what is right for him in a given situation of conflict.

Robert suggested he would extend his advance consent to his wife to ensure it also "kicks-in" at the right time. He suggested that he would likely not want to follow advance consent at a material time because admitting relapse can be challenging for him. As he suggests, someone like his wife who knows him and his history could assist with an invocation at the specified time when this arises, which would help to implement advance consent in practice.

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[154] See Table 6.1.

Although Lucy did not suggest that a nominated trusted person be involved in such processes, she told an interesting story of what happens when she begins to experience mania. Following several years free from psychotic symptoms, Lucy sometimes relapses into mania followed by a period of a depressive episodes. She said that she is aware when she begins to experience mania because it means she has a lot of energy, cannot sleep and becomes very active. Jokingly, Lucy said she ignores the symptoms for quite a while and capitalises on this energy because she has two small children and, during those periods, she feels she is able to catch up on doing things she normally would not have the energy to do. However, the challenge is that if she allows the mania to go on for too long, she experiences difficult depressive episodes. Usually, it is Lucy's husband who will point out to her that her symptoms of mania have been lingering for long enough, and that she needs to slow down and increase her medication to prevent the depressive episodes. This resonates with Robert's experience of being self-aware of relapse but needing that other person to suggest it is time to get help. On the contrary, Sophie noted that her husband can be a bit nervous when Sophie experiences extreme emotions – anger or joy – and usually suspects that Sophie will immediately relapse, whereas these emotions are not symptoms of relapse but just everyday emotions. Sophie expressed frustration with her husband's nervousness about her relapse. Thus, she felt the making of advance consent should be done with the family, but the implementation of advance consent should not perhaps depend on the family but, rather, advance consent should be invoked in circumstances clearly specified by herself, as discussed earlier in this chapter.

However, other participants were against the idea of involving family members in their advance consent, even when they have had a positive experience of their family support in a mental health crisis, as demonstrated in Table 6.5. below.

| Table 6.5. Nominated trusted person - excerpts from photo-elicitation interviews. |
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| But if there’s anyone making decisions about myself, I’d like it to be my family, not a doctor. Okay. So, partner. My husband. Yeah. My husband and my mom. But my mom is pretty religious-ish, so I think she should have a lot of problems in doing things that I’d like her to do. Last resort.<br>(Fred)<br><br>And we don’t know who people class as friends or family members … I think in a sense it is potentially creating a dangerous situation.<br>(Lucy)<br><br>The family wouldn’t be good for my advance consent.<br>(Eliza)<br><br>Certainly, for me, I don’t tend to speak to family about these types of things, that’s just my personal preference. And I think with family, there’s always that tendency to interfere. … I think you’ve got you’ve got that too much of a potential influence you can have on them. And it’s always difficult. I think for family members you have to be very strong, strong will to be able to go, “no, actually I’m doing this because I think it’s in your best interest” and I don’t necessarily know whether on a broader scale the majority of people would do it. … There’s a lot of conflict with family members. Just completely take out of their hands and give it to somebody completely independent. … I think somebody who could just the third party, whether it’s a social worker, whether it’s a mental health practitioner, whether it’s somebody who’s trained in CBT or a psychologist or just someone to be able to look and go, okay, “this is what X said”, “this is what Y said” and this is what … I recommend. Yeah, that sounds good.<br>(Michael)<br><br>When you have advice from your psychiatrist like you said to your friends or your family, one of the first thing they tell you don’t talk to them because talking to your friends, talking to your family they said to me a first of all, they will not understand what you’re going through because they haven’t been through themselves. Or and the other thing, you’re going to see them from their reaction you’re upsetting them. They’re getting upset. You will be more upset and you will get drawn down. You go downhill further because then it is.<br><br>It is a catch 22. Yeah. That’s why they advise you to leave that side. Talk to professionals. But when you talk to professionals. I mean, if you see something, psychiatrists, they’ve got a timeline. They can only see you seven times a maximum of 10 times. That’s it. After that, they’re going to drop you. Then you have to go to the doctor, you’ve got to make another appointment. They get it, then they have to write a letter to mental health. And then they have to get another therapist another 10 days, 10 times 10 weeks or whatever. But that’s another therapist. |

Just give them the cherry. Don’t give the whole cake. Just keep them happy. If they’re not happy, give them a little bit more cream and leave it there. That’s it. But if you had a professional, it would feel less like you’re burdening someone like that. Yeah, I would give them the whole cake, because it’s not like a friendship that you depend on. Every time something happens, it’s kind of someone who’s that’s their role.
(Albert)

Here, Fred contends that letting his family affirm decisions made in advance consent would be a last resort. He was worried that his mother’s religious beliefs would influence her decision more so than whatever he had requested in an advance decision. However, he would still prefer the nominated trusted other to be a family member over a doctor. Others object more strongly to the idea. Michael suggests that his family would not be appropriate because he does not talk to them about his mental health, and so they would not have enough understanding to act in times when his current wishes would be at odds with advance consent. Similarly, Albert talked about how his family does not know enough because he offers them a minimal amount of information for fear that they would not be able to understand what he is going through. However, Michael also notes that there are possibilities for familial tensions to arise and that family might not want to contradict contemporaneous wishes in favour of wishes expressed in advance consent. Meanwhile, Lucy, who spoke very highly of her loving and caring family, strongly objected to the idea of their involvement, stating that this could create a “dangerous situation” putting her wishes expressed in an advance consent in danger. She was also concerned that the family would be inclined to think through the lens of the worst experiences and might not have a full appreciation of where the person is now in their mental health recovery which had resulted in an advance consent. Eliza has not received good support from her family and, thus, she did not consider that it would be good to involve them in her advance consent.

In summary, there were a number of suggestions that a nominated trusted other could be a professional or an independent person, other than a lawyer, because, as Sophie suggests, this would imply additional costs and would overcomplicate the process with formalities. Eve[155] suggests that there should be an independently trained counsellor who could come in in any situation where there are doubts about invoking advance consent. This idea presented by Eve would be of particular benefit to those who do not have family who would support them and especially because it does not involve mental health professionals. Albert and Michael also call for a professional to be a nominated trusted person in this situation with a view that this could include a mental health professional and that such a professional would be better at judging the situation at hand.

However, what participants fail to consider are the everyday complexities of making a professional the nominated person. Even though some acknowledged that this proposal might require significant financial resources from the state or the NHS, they did not consider the availability of professionals who would undertake this kind of role. It is possible that there might be a shortage of professionals willing to engage in acting as nominated trusted persons. Even if found, the said professional would not be available for an indefinite amount of time – they might get sick, retire, move home or change jobs – and substitution might not be available or desirable, especially for a person experiencing a mental health crisis and encountering a different professional to their nominated one. Additionally, if a nominated trusted professional were not available and a different one were substituted, there is a danger of reinserting substituted decision-making back into the equation, especially when professionals are not adequately informed of the lengths and breadths of their powers.

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[155] See Table 6.3.

### 6.5.3. Decision-making powers of a nominated trusted person

An important caveat to nominating trusted others who would come in to mitigate instances of changes of mind is the level of authority granted to these persons. Robert was the only one who stated that he would give his wife formal, legal decision-making power in that situation through his advance consent. This resembles Bielby's (2014), Gremmen et al.'s (2008) and Clausen's (2014) proposals for a joint-decision maker whom Clausen proposes should have legally enforceable decision-making powers. Here, the joint decision-maker is a "legally recognised second-opinion" and their role is triggered by an individual's changes of mind (Bielby 2014, 136). In this context and in Robert's understanding, the nominated person's second opinion would be decisive. Bielby (2014, 136) suggests that this role would be closer to a Lasting Power of Attorney (LPA) for health and welfare matters. The MCA 2005 introduced an entirely new scheme for LPAs which replaced the scheme under the Enduring Powers of Attorney Act.[156] The MCA 2005 introduced two types of LPAs, one for financial and property affairs and another one for health and welfare.[157] The financial LPA can be used as a support framework with appropriate consent regardless of the donor's capacity status, but the health and welfare LPAs cannot because these are designed to come into force when the donor lacks capacity.[158] Thus, the proposal is actually closer to the financial LPA, further suggesting that LPAs for health and welfare could not be used as replacements for advance consent when a changes of mind situation arises because of its dependence on the status of incapacity.

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[156] The legal effect of existing Enduring Powers of Attorney is preserved, so the two will co-exist for the time to come, see s. 66(3) and Schedule 4 of the MCA 2005.

[157] Mental Capacity Act 2005, ss 9-11.

[158] Mental Capacity Act 2005, s 7(a).

A more popular view was that a nominated person should not be given legally recognised decision-making powers and should instead have a role of a consultee if a changes of mind situation arises. These ideas are similar to Bielby's (2014, 135) proposal for a joint representative who would be able to give a view as to the strength of the individual's wishes and changes of mind. Bielby (2014) suggests that this is a similar role to the welfare LPAs but without legal powers. These proposals could be useful for ascertaining an individual's values and wishes, but they do not ascertain who is the final decision-maker. It is not clear whether the wishes contained in advance consent are simply to be followed or whether a doctor ought to take advance consent into account and consult the individual's nominated trusted person when these challenging circumstances arise; effectively making the doctor the final decision-maker.

This proposal bears similarity to section 5 of the MCA 2005 which grants general legal authority (usually to a treating clinician or the hospital generally) to make a decision on behalf of an individual using a best interests checklist under section 4 which includes a provision that the final decision-maker consults with the individual's loved ones or other relevant persons. To avoid a similar situation happening in the context of advance consent, an individual would need to clearly state the extent of the powers of their nominated trusted person and whom the final decision belongs to.

#### 6.5.4. Nominated trusted person: where do we go from here?

Regardless of the differences in my participants' attitudes, the role of the nominated trusted other was almost exclusively seen as limited to the situation where advance consent is at risk of being revoked due to the changes of mind occurring at the material time. The idea of nominating others in such a situation is closely related to the compassion component of the capabilities for health and emotion. This is because people who make advance consent accept the possibility of future suffering which might have more serious implications if attempts at unjustified revocation were to take place, and so they consider involving trusted others to be "an effective response to the prospect of [what] future suffering involves", to borrow from Bielby's (2021, 301) language. Furthermore, this means that the compassion component is forward-looking in ensuring that the capabilities for emotion and health are available. The choice of the nominated trusted other – whether that person is a loved one or a professional of a sort – will be a person whom an individual trusts to share certain understandings with. Relatability to one's experience also appears important because my participants reflected on choosing someone who understands their experiences in a non-judgemental way or has even shared some suffering with or alongside them. This relatability might therefore form an integral part of providing opportunities for emotions and health through compassionate relational initiatives, like the nominated trusted person.

The capabilities for emotion and health in this framework are also important capabilities for achieving agency freedom. The relational component of these capabilities is therefore an important safeguard of autonomous choices. In Nussbaum's account of capabilities (e.g. 2006; 2011) the role of others in supporting capabilities plays a vital part and forms a distinction between autonomy and paternalism. Thus, the value of relational aspects of supporting relevant capabilities cannot be overstated. Therefore, allowing the possibility of involving nominated others reinforces social justice.

From a practical point of view, Atkinson (2007, 129) suggests that involving others would be a useful method for triangulating revocation which takes place at a material time. Dresser (1982) has been especially cautious in suggesting the involvement of others, worrying about the possibilities of exploitation and abuse. However, Swanson (2003) found that doctors and family members were predominantly against revocations at a material time, although there is evidence suggesting that a nominated trusted other would not want to change the wishes unless it was deemed necessary. In line with Clausen's (2014) proposal, I suggest that there should be additional procedural safeguards which require a nominated trusted person to carefully record reasons for going against advance consent, should this situation arise. I, therefore, suggest that advance consent, due to its presumed flexibility of design, could allow people to voluntarily choose to give a specific person a role in the advance consent, but the extent of that person's powers needs to be clearly stated. It is likely that making this a requirement rather than an option would be seen as an overcomplication to the process of making an advance consent. Therefore, it is likely that such an option would be taken up by only a few people, while others who make advance consent would be likely to accept the impermissibility of revocation desired by my participants' when changes of mind take place.

## 6.6. Conclusion.

In this chapter, by developing a framework for interrelated and interconnected capabilities for health and emotions, I have offered a new way of conceptualising the changes of mind dilemma that moves beyond the autonomy reasons for justifying advance consent which precludes changes of mind. I suggested that advance consent should come into effect at a time specified by an individual to maximise the benefits of advance consent and to support the capability for health. The primary justification for precluding changes of mind lies in psychiatric survivors' views on the issue and how they conceive of advance consent: a legally binding mechanism, made by the patient when well to plan for the future which provides emotional unburdening associated with decision-making in crisis. I argued that changes of mind do not pose a risk for coercion because the treatment is provided upon the patient's valid consent and, even when it may involve some level of force, individuals accept this as a possibility when making their advance consent. This idea at first may appear legally controversial because of the long-standing principle in English law that patients have a right to consent or refuse to consent to treatment if they have mental capacity. However, the law already allows for overriding capacitous decisions of those with mental 'disorders' by giving various professionals the right to involuntarily commit patients (who may have the relevant capacity) and to treat them without their consent regardless of their capacity status. Considering the negative experiences of forced treatment discussed in Chapter Five and the empowering premise of advance consent, it is difficult to sustain the argument that advance consent is legally controversial or inconceivable due to the possibility of a changes of mind dilemma arising. Instead, precluding changes of mind clearly supports the capabilities for health and emotions.

Finally, I explored the nominated trusted person framework which could be used as a safeguard when changes of mind dilemmas occur. I suggested that a nominated trusted person could be given a role in such a situation, but this should be an option, not a requirement. This could improve the legal confidence in advance consent further. However, the nominated trusted person framework is conceptualised through compassion – a component of health and emotions as capabilities – which also supports shared valued functioning, which is agency freedom.

Throughout this chapter, I also argued that the way in which I suggest advance consent can work in practice, will minimise the use of coercion. However, the challenge is to implement advance consent which precludes changes of mind in a way in which it does not simultaneously promote forced treatment in a situation where the treatment is administered despite changes of mind. I suggest that some level of force may be unavoidable and is undeniable but I also arued that there is perhaps a level of coercion which people may wish to accept and Sen's (1999) conceptualisation of coercion allowed to reach this conclusion. Nonetheless, for some, an acceptable level of coercion may not exist and to achieve social justice, it might be necessary to also offer an option of advance consent which is revoked by changes of mind. This decision should be left to each individual who is recording their wishes in advance consent. Moreover, I highlighted that not all changes of mind will be induced by mental ill-health and so implementing advance consent into practice will require clear guidance or a test as to which changes of mind should be listened to, as these may exist. To aid such implementation, I suggested the framework for nominated trusted others, noting its benefits and problems, but other safeguards may need to be also developed.

In the next chapter, which is the last empirical chapter of this thesis, I develop a central capability valued by psychiatric survivors, which is a capability for safety. I use this capability to evaluate and examine the desirability of the more recent proposals for advance decision making in English mental health policymaking, namely advance consent to confinement and advance choice documents. Finally, I evaluate advance consent to mental health treatment as conceived of in this thesis to examine whether it supports the central capability for safety.

# CHAPTER 7: DEVELOPING A CENTRAL CAPABILITY FOR SAFETY TO EVALUATE PROPOSALS FOR ADVANCE DECISION-MAKING

## 7.1. Introduction

In the previous chapter, I refined advance consent to mental health treatment grounded in my empirical data and conceptualised through two central capabilities – for health and for emotions – which I argued should be underpinned by the notion of compassion. I proposed that advance consent should be a legally binding mechanism, invoked at a material time as specified by an individual; that it should preclude changes of mind at such a time and that individuals should be free to incorporate a nominated trusted person(s) in their advance consent and decide on the extent of powers that this person(s) would hold. I argued that advance consent conceived in this way will support the achievement of health and emotions capabilities, highlighting the interrelated and interdependent nature of capabilities.

In this chapter, I develop a new central capability valued by psychiatric survivors – a capability for safety. I begin by offering an explanation as to what the capability for safety is. I then use this capability to evaluate the desirability of advance consent to mental health treatment and mental health advance decision-making in recent policy considerations. The evaluation is considered in the context of the level of freedom provided by each measure in allowing people to do and be what they value and have a reason to value.

By analysing the data on the desirability of confinement, I suggest that advance consent to confinement (ACC), also originally considered by the Wessely Review (2018), has limited scope for supporting the safety capability because it lacks appropriate safeguards of people's choices and rights which means that it would likely be experienced as a source of unfreedom. I then begin evaluating advance choice documents (ACDs), originally proposed by the Wessely Review (2018). I argue that these are a step in the right direction because they recognise a range of capabilities by supporting everyday life considerations associated with receiving treatment. However, I argue that their premise is severely limited because of their reliance on capacity assessments and detention. Thus, it is unlikely that they could support the capability for safety to a desirable threshold. I then move on to evaluating whether advance consent to mental health treatment fosters the capability for safety. I argue that its premise lies in providing an alternative to those treatment experiences which are experienced as unfreedoms. Here, I suggest that the capability for safety is linked with increasing individual responsibility which supports freedom, and thus leads to the achievement of social justice.

## 7.2. The central capability for safety

In Sen's (1999, 285) articulation, the basic premise of a capability is that it will allow people to lead the kind of lives they have a reason to value and lives that are free from injustices. It is the injustices, or unfreedoms, which create inequalities for certain groups of marginalised individuals. The consequences of those unfreedoms are that people from marginalised groups are persuaded into thinking that some of those unfreedoms or injustices are 'necessary evils' because they enable to restore human flourishing or wellbeing in that context. This results in thinking that there are no alternatives to unfreedoms and that finding such alternatives can be "a laborious and challenging process" (Sen 1999, 287). At the minimum level, the change needed to achieve justice begins with the acknowledgement of injustice (Sen 1999, 287).

The acknowledgement of injustice in the context of mental health law requires a recognition that the concept of safety as it stands, familiar to mental health law as the protection of others, is one of the sources of unfreedom because it contributes to the denial of decision-making opportunities for people with mental ill-health. In Chapter 5, I emphasised that mental health laws are oftentimes designed with the safety of the public in mind, and the idea of dangerousness is not just about forensic mental health patients: in fact, it influences how society views all mental health patients and serves as a justification for compulsory treatment and compulsory admission of people with 'capacity' – something that is seldom permitted by law for the treatment of physical ailments and when it is, it is subject to stringent procedural requirements. Critics like Szmukler and Holloway (2000) argue that lawmakers demonstrate greater or at best equal concern for the safety of others than about people's mental health, and thus scholars like Gooding (2017) highlights the need for rethinking measures like involuntary detention and compulsory treatment of people with mental ill-health. However, compulsory treatment is only one of many examples of unfreedoms in psychiatric survivors' lives. Other sources of unfreedoms as highlighted throughout this thesis include stigma, abusing the clinical concept of insight and the legal concept of mental capacity and not valuing the broader needs of people at the heart of these discussions.

The capability for safety which I propose reformulates what safety means for psychiatric survivors in the context of mental health laws and, in particular, advance decision-making. Here, safety is both an opportunity and a freedom; thus it is a capability rather than a functioning. What follows is that, as a capability, safety does not have to be achieved on an individual level (but it can be). Instead, it needs to be made available and accessible for people as a matter of social justice. Finally, I define this capability as including the following: being free from unnecessary coercion and having alternatives to coercion; having opportunities for choice and active participation in decisions about treatment; being provided with a place of safety when needed; to have people's interests reflected in policy and legal developments; to be free from undue influence; and to be guilt-free in relation to one's mental ill-health. I particularly focus on the freedom from coercion aspect of this capability throughout this chapter.

The capability for safety is not present in Nussbaum's (2011) list of central capabilities. However, a version of it appears to be articulated within the definition for bodily integrity which includes "to be secure against violent assault" (Nussbaum 2011, 33). Robeyns (2003) developed a single capability for safety and bodily integrity when conceptualising gender inequality and sexual violence. In her account, Robeyns (2003, 78) states that: "bodily integrity and safety are important states of being. This capability is adversely affected when people experience all sorts of personal violence." In Robeyn's (2003) application, this singular yet interrelated and interconnected capability has a gender dimension because she argues that women experience violence more often than men do.

In my conceptualisation, safety has a mental health dimension because it is psychiatric survivors who experience structural, physical and emotional violence because of stigma, and misconceptions about mental illness which underpin the justification of coercive measures on a societal level. Thus, mental health laws should be reformulated primarily with psychiatric survivors' safety, as a capability, in mind. Throughout this chapter, I refer to this capability in my evaluation of ACC, ACDs and advance consent to mental health treatment.

## 7.3. How desirable is advance consent to confinement through the lens of capability for safety?

### 7.3.1. What is advance consent to confinement in policymaking?

The Wessely Review (2018, 26–27) was concerned about the falling number of informal (voluntary) admissions and the rising number of involuntary detentions. In the spirit of aspiration for making voluntary admissions ‘a new norm’, the review introduced the idea of ACC, which was envisioned as an opportunity for mental health patients to give consent to future admissions for treatment at a time when they lack the capacity to consent to voluntary detention. The consent would be provided through an ACD or through the powers given to others through a power of attorney. In this way, it was hoped that fewer people would require involuntary detention. The review noted that the falling numbers of informal patients are a result of a steady reduction in hospital beds and the effect of the *Cheshire West*[159] decision (Wessely Review 2018, 26–27; 81). The ruling provides a set of criteria for what amounts to deprivation of liberty which includes any admission for assessment or treatment for mental illness when the person lacks capacity to provide consent to those. The effect of the ruling is that patients who are incapacitated due to their mental ill-health cannot be lawfully admitted except as detained patients under the MHA 1983 with the authorisation of the Deprivation of Liberty Safeguards.[160] Therefore, incapacitated patients cannot be voluntary patients “who are not detained by the state” (Wessely Review 2018, 81).

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[159] *P v Cheshire West and Chester Council and another* [2014] UKSC 19.

[160] For relevant discussion see Harding (2021) and Series (2022). Harding (2021) explains legal developments in this area as Deprivation of Liberty Safeguards are soon to be replaced with Liberty Protection Safeguards.

However, this raised a number of legal and implementation challenges identified in the review. As discussed in Chapter 5, the law requires that those who are voluntarily admitted to mental health hospitals are treated with their valid and informed consent. The review recognised that this poses a serious challenge to the ACC because the reviewers did not recommend advance consent to a specific mental health treatment (Wessely Review 2018, 83). Recognising that different hospitals provide different levels of care, the person making an ACC might end up being confined in a place they have not envisioned, and which may be very different to the places they have experienced before (Wessely Review 2018, 82).

There was a serious concern that ACC would result in perpetuating the *Bournewood* Gap.[161] This refers to a situation in which an incapacitated, yet compliant adult is treated for mental health problems but without access to the safeguards offered by the MHA 1983.[162] Effectively, the concern was that incapacitated adults who are compliant (or perhaps show insight) admitted under an ACC would be treated not only without their valid consent but also without access to safeguards such as Mental Health Tribunals or the section 58 safeguards which prohibit compulsory treatment of involuntarily detained patients for longer than three months.[163] Additionally, the review (Wessely Review 2018, 82) raised a concern that people who are admitted under their ACC may be coerced "into not demonstrating an objection to being there, meaning they would remain informal when they should have transferred to formal detention under the MHA. Or they may be so unwell or medicated that they are not able to express an objection." The concerns of the reviewers are valid, especially considering people's experiences of lack of insight which appears to be an extra-legislative ground for coercion in

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[161] *R v Bournewood Community and Mental Health NHS Trust Ex Parte L* [1999] 1 AC 458

[162] As this thesis does not offer an analysis of this problem due to its unique context, for an overview and analysis of the *Bournewood Gap*, the first attempt to bridge it (the Deprivation of Liberty Safeguards inserted by the Mental Health Act 2007 as amendments to the MCA 2005, soon to be replaced by the Liberty Protection Safeguards) through the capabilities lens see Harding (2021).

[163] See Chapter 5, section 5.3.1.

mental health settings.[164] In the report outlining the responses to the Government's consultation on the issue, respondents expressed a concern that ACC does not guarantee informal detention "because if a patient objected or tried to leave, they might be detained" (Department of Health and Social Care 2021b, 50). Additionally, by not recommending advance consent to a specific treatment (Wessely Review 2018, 83), people would not be able to provide informed consent to the specific treatment received under the ACC.

In thinking about addressing these legal challenges, the review considered ways in which these risks could be managed: for instance, placing a time limitation on the ACC so that it is only valid for the first two weeks of detention. Once this time has passed, an individual would either be released or sectioned (Wessely Review 2018, 82). The benefit of this approach is that it provides psychiatric survivors with a place of safety for up to two weeks without the use of non-consensual treatment. However, it is not clear – and would require specific guidance – what happens if someone in a serious mental health crisis were to be detained for two weeks but could not be treated, resulting in a deterioration in health, alongside the trauma of isolation, and potentially physical restraint. On the other hand, a patient released beyond the two-week point might experience prolonged suffering which could eventually warrant involuntary detention. Other safeguards included using independent advocates who would be consulted when questions around the validity of ACC are raised and a "get out clause" allowing people to state that they do not want their ACC to apply when it is no longer reasonable to do so, such as when there are grounds to believe that ACC was not informed or if individual's actions are inconsistent with their ACC (Wessely Review 2018, 82; Department of Health and Social Care 2021a). The reviewers, unable to reach a consensus on ACC and related safeguards, recommended that the Government consults on this issue (Wessely Review 2018, 82). The

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[164] See Chapter 5, section 5.3.2.1. also see O'Keeffe (2022); Gurbai, Fitton and Martin (2021).

same concerns were reiterated in the Government's White Paper (Department of Health and Social Care 2021a, 64–65), and then again highlighted in the consultation responses with particular concerns over administering treatment whilst in detention which might become coercive and non-consensual (Department of Health and Social Care 2021b, 50–54). These concerns were well espoused by the Care Quality Commission cited in the White Paper (Department of Health and Social Care 2021a, 64):

> Once admitted, an informal patient is required to make a series of ongoing decisions including over treatment, discharge and time off the ward during the admission. A current informal patient with capacity makes these decisions, and the hospital team cannot restrict them or enforce treatment upon them. It is unclear how these decisions would be made for an incapacitated individual admitted informally under the advance consent proposals. It would not be realistic for all scenarios to be considered sufficiently in advance of admission.

Despite the repeated concerns over the legality and implementation of ACC, the Government has not provided a firm position on this, instead stating that the issue will continue to be explored (Department of Health and Social Care 2021b, 52).[165] In the next section, I will therefore consider, whether ACC appears desirable in the views of my participants, conceptualised through the capability to safety.

### 7.3.2. Advance confinement: experiences of detention in hospitals and the 'place of safety'

When thinking about what people might want to request in their advance consent to mental health treatment, my participants would most often mention medication or therapies, and only

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[165] It is worth noting that the Draft Mental Capacity Code of Practice (Departament of Health and Social Care 2022a) has included advance consent to care and arrangements which would otherwise amount to deprivation of liberty.

two participants, Lucy and Eve, suggested there are benefits to hospitalisation for people who are in need of a safe place when they are experiencing a mental health crisis.

Table 7.1. Lucy’s experience of hospitalisation and place of safety – narrative interview

On 6th June, so, less than a month from my initial breakdown I became an inpatient on the female acute unit. Thankfully, it wasn’t too far from my house, and it was useful for my parents. I was worried that they would put me over somewhere far. I was there for 3 weeks at first, it felt like a lifetime.

But I must say it was just such a relief, I felt safe for the first time in months. I felt like … I didn’t have the worries of knowing that there was a drawer with all the knives in and sharp objects and just knowing that I was in a safe place. The structure really suited me at the time. I remember going in and actually phoning my mom and saying to her that I was the sanest one in here and my mom being like “ermmm, are you sure about that?” and me saying “yes, definitely, you should see the others”. And I wasn’t by a long shot, but I was surrounded by other women who struggled with psychosis and that was a big thing for me. Being surrounded by people with psychosis was strangely comforting for me and we’d sort of sit outside and share with one another about how we were feeling, what was going on in our heads. That was something that was never facilitated by a member of staff, it was always just something that we did for one another.

…

So, I came out of hospital, the first time. By that time, my medication had started working and although I was still hearing a voice, it was infrequent. I felt like I was starting to improve a little bit. I think one of the key things the early intervention service had done for me is that they told me that recovery was possible, where I never thought that before.

…

There was a lady who would come in once a week to do an Indian head massage and she was lovely, but it was so popular like everyone wanted it. She and an art worker would come in for an hour a week and basically, that was it. That was our week. We had like board games and things like that, but pieces were missing, and things were mangled up and things like that. So, people who got to leave – thankfully I got to leave – would come back with a DVD or something for us to do in the evening. We all used to do that for one another, whenever someone got to leave. The one night we ordered a Chinese takeaway and that was like the best night. I really liked the food but nobody else liked the food but maybe that was my medication changing my taste buds – I don’t know.

> I weirdly really enjoyed being in the hospital, it is surreal, but I look back on it quite fondly. I had a second inpatient stay for a bit longer, for 5 weeks, just before Christmas. And I remember, feeling kind of the same. Not like "oh, I'm at home" kind of feeling but "okay, I can relax a bit now, I am safe, I don't have to worry about mum and dad so much." I don't have to worry that mum is exhausted and what I'm putting her through, because that was always at the back of my mind, "like how is mum and dad coping?"

Here, Lucy gives an account in which she speaks of the hospital as somewhere that was her safe place in times of crisis. Indeed, she states that this was the first time she had felt safe in a long time. This was not only because she was away from sharp objects, access to which would make her uncomfortable while at the same time making harming herself or others easy, but it was also about no longer having to worry about burdening her parents or, in fact, actually harming them. In her interview, Lucy talked about how much her parents, and in particular, her mother had sacrificed to look after Lucy full time when she was unwell. Being in the hospital meant that Lucy felt safe and guilt-free; guilt being something she experienced in relation to her parents.

In a candid way, she recounts the value of the friendships she had made with women who, like her, were experiencing psychosis. Lucy reflected that being surrounded by people she could relate to was comforting and, undoubtedly, this was an important aspect of the capability for emotions, while the comfort she felt speaks to safety as a capability. Being in a place with others in a similar situation was also the reason why Lucy experienced the hospital to be a safe place, even though she elaborates on the limits of her safe place characterised by their being little entertainment available to residents. Moreover, Lucy emphasises that this comfort was something facilitated by the other patients and not by members of staff.

However, there is a clear dichotomy between how Lucy talks of her hospital stay and how she talks of receiving treatment whilst under a voluntary section. In Chapter 5, I discussed Lucy's experiences of treatment which she described as abusive, uninformed and therefore non-consensual.[166] More so, these experiences made Lucy feel unable to refuse treatment fearing what might happen if she did. Therefore, it was the treatment, not the hospitalisation itself, that was experienced as highly problematic and as a source of unfreedom. Hence, an important element of a safe place is that it must be free from coercive interventions.

In a similar vein to Lucy, Eve emphasised that the benefit of hospitalisation is the provision of a safe place for those who need it:

| Table 7.2 Excerpts on ‘safe place’ – Eve, narrative and photo-elicitation interviews |
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| The good thing about it was, I obviously did need a safe place. You know, I was lodging, I didn’t have any family around me, nobody knew me and so it was obviously good that I was in the safe place. So, that’s the first thing, people do need a safe place. Eventually, because I was sectioned, they must have held me down and inject me with some sort of drugs, probably. However, I knew that to get off the section was to agree to treatment, so they say it is voluntary, but it isn’t voluntary, because they’re going to make you. Because, either you are going to have this abusive treatment and they will forcibly hold you down and you’re basically having physical and emotional abuse or you can agree to voluntarily pop the things in your mouth, you’re not but what they think is that you’re showing ‘insight’, it isn’t, I’m just avoiding physical and emotional abuse, thank you very much.<br>(Narrative Interview)<br><br>I did need a safe place, not to cry about being sectioned and being put in the hospital, because I was running around the streets, not sleeping and not eating, so I am not going to cry about that.<br><br>There’s one thing, keeping people safe. And often people will get better just because they have a safe place and some food. You cannot underestimate how being given a bed, because some people are on the streets, they’ve got very disturbed life, so being there with a bed and some nutrition can do wonders.<br>(Photo-elicitation interview) |

Just before Eve was involuntarily detained, she was homeless and unable to take care of herself due to the presence of her symptoms. She describes experiencing mania: running around the town for hours to use up some of her energy and not sleeping for weeks. Eve does not speak

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[166] See Chapter 5, section 5.3.2.2.

fondly of the hospital, as Lucy does, nor does she reflect on the relational aspects of being in a hospital. For Eve, safety was provided because it met her basic needs like food and shelter, and she maintains that the benefits of having those basic needs met cannot be underestimated. At the same time, the treatment she received, again, was experienced as non-consensual and abusive. By explicit reference to insight, Eve suggests that the choice for people in mental health hospitals is between compliance with treatment or having it forced upon them, which she contends to be true even for voluntary patients.

### 7.3.3. Place of safety and the law.

Bearing in mind the desirability for the delivery of a safe space, it is worth considering whether the provisions of the MHA 1983 for a "place of safety" could sufficiently cultivate the capability for safety with a 'safe place' being one of its components. A place of safety is usually a police station or a hospital, but it may also include places like an emergency assessment unit and ambulatory care. Under section 136 of the MHA 1983, if a police officer in a public place comes across a person who "appears to him to be suffering from mental disorder and to be in immediate need for of care and control", the officer may remove such a person into the place of safety when they deem it beneficial to the person and the safety of the public; and, under section 135(1), an approved mental health professional (AMHP) could make an application to a magistrate for a warrant permitting a police officer to enter premises, even by force. The AMHP must be sure that "there is a reasonable cause to suspect that a person believed to be suffering from a mental disorder a) has been, or is being, ill-treated, neglected or kept otherwise than under proper control …, or b) being unable to care for himself, is living alone". If a situation like this arises, the police must be accompanied by an AMHP and a doctor when removing the person to a place of safety without formally sectioning them. In both instances, people are removed to a place of safety for up to 72 hours. While in a place of safety, these provisions do not provide authority for the treatment of people without their valid consent. Thus, the place of safety is limited to just that.

It appears that, before she was sectioned, Eve was initially removed to a place of safety – the police station. This story paints an important picture and so it is worth reproducing here in its (near) entirety:

| 7.3. Eve: police station experience – narrative interview |
|---|
| … I was doing all this walking, marvellous walking, actually through the woods. And I've seen so many owls and mice and just because I'd sit for hours. When you're normal, you get bored after sort of five minutes, but when you're mentally ill you think there's some higher purpose to this. I sat there and I saw the most marvellous wildlife, you know? I saw some wonderful things. But my emphasis being I was at no point was I ever suicidal. At no point was I depressed. When you're having that sort of mental illness, you have a sense of purpose because all these delusional things are telling you what your purpose in life is and you're trying to fulfil it with these various rituals or wherever you know.<br>…<br>The delusions went on for so long that I couldn't sleep. And I wonder if I was getting a bit manic because basically, I went about three weeks without sleeping, right? So that's not good for anybody.<br>…<br>Then I was getting to the point where I went really nutty and started with where I was living outside of Oxford and I and was kind of running for hours. I was running up and down. So, you can imagine I was not eating, completely exhausted, running myself into the ground. Not sleeping. And then one day I went, and I stood outside of the Oxford College, and I just stood like a statue and stopped speaking.<br>Now, the guy in at the door of the college eventually saw me standing there for about half an hour so he rang the police. So, the police came and said "how are you?" and I just didn't speak to them on. So, they arrested me and put me in the police car. […]<br>They put me in a cell, and they took everything off me including my bag. I was on my period at the time I asked if I could keep my towel, you know the period thing. But they didn't want |

> me to have anything, they've taken my shoes and so they allowed me to keep one sanitary towel, right. There was no woman in this police station, so … they put me in that cell, and I was there for hours I can't even remember, and I must have been on the suicide watch because they looked in every quarter of an hour. It was a bare concrete, literally bare concrete with a metal toilet in the corner with no top or anything. I was on a very severe period and thinking how the hell am I going to change my towel without those men looking at me and go into that toilet without these men looking at me. And then, what am I going to do with that towel? Like it's kind of offensive to leave that bloody towel out, but you can't put it in a toilet, and you know there are only male police officers there who will have to see that.
>
> But anyway, eventually they got a psychiatrist, the social worker and I can't remember who else is there that usually comes. They questioned me and I sort of knew what was going to happen because I'd been on the other side of it. So, I knew I was going to get sectioned, not that they explained that. I don't know what I would have been thinking if I didn't know the system, but anyway. I knew I was getting sectioned, and I thought, I might as well go in for broke. So, they asked me about my delusions so I told them and they were clearly like "she's nuts, we are locking her up". So, they took me to the local psychiatric hospital and at this point things do get more blurred, because if you think about it I'd not slept for weeks and the emotion and medication, so I don't remember everything.

Eve's narrative is an intrinsic example of the nuance and complexity of mental illness. Eve explains how happy she was experiencing her delusions which gave her meaning and purpose, an experience highlighted by researchers (e.g. Rituanno and Bortolletti 2021; Bielby 2021). But it did not mean that she was safe: she was not sleeping, she was overexercising and she was not eating, and she did not have shelter. In her narrative, Eve does not realise that perhaps she was not actually arrested. Instead, she was most likely removed to a place of safety under section 136 of the MHA 1983. Her experience of detention under this section instituted the rest of her experiences as detention. Even though, in hindsight, she thought she needed to be sectioned and it had been helpful (to an extent), the experience was one of force, abuse and lack of consideration for her needs that went beyond the alleviation of her mental ill-health symptoms. At the height of her symptoms, she found herself in a cell thinking about how to preserve her bodily integrity while on her period and without any privacy. This was the beginning of Eve's struggle to reconcile feeling like a prisoner and therefore guilty of doing something wrong whilst understanding that she was also being provided with help.

Eve's story raises a question about the appropriateness of using police stations as a place of safety. Smith et al.'s (2020) analysis suggests that there has been a 617% increase in the use of "place of safety detentions" in England with increasing numbers of police stations being used despite the MHA Code of Practice (Department of Health 2015, 16.38) which states that police stations should only be used as last resort. In England, the suggested reasons for this are legal developments like the *Cheshire West*[167] decision and the amendments introduced by the MHA 2007 (Penny and Exworthy 2015; Care Quality Commission 2018; Wessely Review 2018; Smith et al. 2020), and bed management and various demographic and social changes (Care Quality Commission 2018). However, a significant influx of such detentions has been reported across many jurisdictions (Lebenbaum et al. 2018; Turnpenny et al. 2018; Stavert 2021). Research into section 136 describes people's experiences of such detentions as frightening, with feelings of being treated like a criminal, emotional distress, lack of attention to their needs (Riley et al. 2011) and stigmatising and embarrassing, while also perpetuating the idea that mental illness ought to be criminalised (Hampson 2018). All those descriptions resonate with Eve's experiences.

On the face of it, the benefit of the place of safety is that it allows people in mental health crises to be put in a place in which they would not be able to cause physical harm to themselves or others whilst not being at risk of receiving treatment during this type of detention. However, this does not guarantee that they will not be involuntarily detained for assessment or treatment under sections 2 or 3 respectively and subjected to compulsory treatment under section 63. Additionally, the very place of safety might impose emotional harm

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[167] *P v Cheshire West and Chester Council and another* [2014] UKSC 19.

on people, curtailing not only their capability for safety but also health, emotions and bodily integrity. Instead, the place of safety must be attuned to people's needs, again shifting from a primary focus on risk towards provision of a space that is free from coercion, guilt, stigma and fear, all of which lead to experiences of injustice.

### 7.3.4. ACC capabilities, safety, safe place and advance consent

In assessing the desirability of ACC through the lens of safety, I have focused on the analysis of inpatient experiences of those participants who found confinement, as an aspect in its own right, helpful because the positive experiences of detention could possibly result in those people utilising ACC should this become available. The potential desirability lies in confinement itself if it represents a place that is free from access to objects which would make physical harm possible, provides the basic needs of food and shelter while facilitating the development of friendships based on relatability and freeing people from being guilt-ridden about their mental ill-health. These aspects are important for cultivating the capability for safety in mental health settings. In addition, there is a sense of a move away from thinking about the risk that people in mental health crises pose to others, to letting individuals have some level of control of that risk.

The capability for safety encourages the consideration of safe places, which are real, physical places,[168] for when an individual might be experiencing a mental health crisis. Hospitals, in this regard, were thought about more fondly than police stations. The narrative data suggests that the physical spaces are important for supporting safety. The physical spaces in which people are detained must be carefully thought about so that they meet people's broadly

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[168] It is worth noting, that there is emerging socio-legal scholarship which looks at the spatial elements of confinement (particularly in the mental capacity context), see Series (2022) and Clough (2022).

conceived needs which support the experience of safety, bodily integrity, emotions and health. As people will not be able to confine themselves to a self-chosen ward which they know meets their needs of a physical space for safety, then it is unlikely to be desirable.

Ostensibly, the actual experiences of voluntary and involuntary inpatients are not too dissimilar from one another with differences lying in the ability to leave, a privilege that voluntary patients have, and in experiencing less force initially when agreeing to hospitalisation rather than being involuntarily detained. However, the experiences of voluntary and involuntary patients converge when it comes to receiving treatment, as seen in Chapter 5. Because ACC would not protect people from non-consensual treatment, which is the real culprit of negative experiences of unfreedom and lack of safety, then its desirability would be substantially watered down.

## 7.4. Advance choice documents: desirability

Although the Wessely Review (2018) did not recommend legally binding advance directives in the psychiatric context, it did recommend an introduction of ACDs, a proposal accepted by the Government and which is expected to feature in the new Mental Health Act as part of the strategy to strengthen people's rights to choose and refuse treatment (Department of Health and Social Care 2021a).[169] The ACD is set to be a comprehensive document allowing people to express the following wishes: treatment preferences (both medical and non-medical approaches); preferences on how the treatment ought to be administered; who should be informed of the individual's detention; communication preferences; behaviours/triggers which

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[169] Despite this commitment from the government no provision for ACDs was included in the Draft Mental Health Bill (Department of Health and Social Care 2022b).

indicate a relapse; circumstances indicating that the person has lost capacity to make decisions; religious and cultural preferences; and information about other health needs and crisis planning arrangements, including details of dependents, pets, employment, housing and any other important information/arrangements a person wishes to include, as well as the names of people who would be able to appoint a nominated person who can advocate for the person's wishes (Department of Health and Social Care 2021a, 37).

An ACD would come into effect when the patient is detained and lacks the capacity to make their own decisions. Although ACDs would not be legally binding, because they are going to be put on a statutory footing mental health professionals will be legally required to consider the wishes set out in an ACD. This arrangement is presumed to protect the wishes of people better than advance statements which are contained in the Code of Practice rather than in a statute. The document will be authenticated by a professional so that doubts are not raised at a later date about the person's capacity at the time of the making of an ACD (Department of Health and Social Care 2021a, 35-39).

The proposal has received considerable support in the Government's consultation, with 69% of consultees being in favour of it (Department of Health and Social Care 2021b, 94). This is a commendable development providing people with an opportunity to express their preferences in a comprehensive way. However, despite its wide scope, its reach appears quite limited, which is clearly demonstrated by two significant differences between an ACD and advance consent to mental health treatment. Firstly, unlike advance consent, an ACD is not legally binding for treatment preferences, thus making it more prone to invalidation. As discussed in Chapter 6, the legal status of advance consent formed an important safeguard for people's treatment wishes. Secondly, advance consent is designed to apply at a time specified by an individual which is likely to come into effect before the criteria for detention are present, thus decreasing the likelihood of detention. The idea for many people was that advance consent would prevent their mental health from deteriorating so far that they require detention.

ACDs would only come into effect if the person is incapacitated, which raises a number of issues discussed in Chapters 5 and 6, the main one being that capacity was perceived as a barrier in psychiatric settings. It could lead to situations where the mental capacity test is abused in order to maximise the chances of ACDs applying in detention. Additionally, there is a danger that treatment wishes expressed in ACDs which are not properly secured by law will be followed by responsible clinicians only when they concur with their professional opinion. These are important implementation aspects which require clear guidance and some level of oversight to assess their effectiveness in strengthening individual choices and preferences. An ACD is therefore not a final decision, but a component informing substituted decision-making for incapacitated and detained patients to determine their best interests, whether this is the best interest in medical terms or within the meaning of the MCA 2005;[170] thus, further muddying the waters by encouraging the use of the MCA 2005 within the mental health context and alongside the MHA 1983 and MHA 2007.

Nonetheless, the introduction of ACDs will be a valuable step for informing mental health care providers of the person’s wishes. In Chapter 4, I discussed how people delayed seeking care because of the worry that if they receive mental health treatment or become hospitalised their life pursuits and life roles could be severely impacted with many people worrying about their children, should they, themselves, be detained. Thus, the opportunity to have instructions about the care of people’s dependents, pets and in relation to employment is likely to be a welcome development, which could potentially entice people to seek help at earlier stages. However,

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[170] See Mental Capacity Act 2005, s 4.

this will be dependent on the general awareness about ACDs; whereas anyone will be able to make one, it will be a requirement to offer one to people following their detention. Nonetheless, the concern for people's everyday life might also result in better uptake of ACDs.

The extent to which ACDs will become supportive of people's capabilities will depend both on their implementation and their use. In terms of the capability for safety, it is unclear whether ACDs offer sufficient alternatives and protection from coercion. As they are designed to only come into effect once the person is detained, they do not give people a choice of their safe place, but, by fulfilling cultural, religious and other needs, they might enhance aspects of places of detention which could then be experienced more as a place of safety with ACDs in place. However, unless treatment preferences are followed, an ACD does not offer a sufficient guarantee against the real culprit of unfreedom – non-consensual treatment.

## 7.5. How desirable is advance consent to mental health treatment?

### 7.5.1. Empirical analysis to general desirability

In previous chapters of this thesis, I examined different aspects of advance consent through its benefits conceptualised through capabilities and the potential for addressing sources of unfreedom. The development of capabilities inherently linked to achieving agency freedom and the concern for sources of unfreedom results in the achievement of social justice. I suggested that the premise of advance consent understood through capabilities is thought to improve everyday experiences of receiving mental health treatment. Nonetheless, legally binding advance consent to mental health treatment was rejected outright by the Wessely Review (2018, 84), and the review did not offer any analysis or reasons as to why this was the case. However, it is likely to be linked to policy concerns similar to those of ACC, which was conceived as opting out of certain safeguards. Additionally, it might be linked to a long-standing concern that patients as non-medical professionals are not able to request specific treatments. Clearly, this poses a challenge to the implementation of advance consent. For psychiatric survivors to be able to request treatment in advance, the policymakers will be required to reconsider this longstanding principle or create special rules that apply only in mental health settings and are specific to advance consent. For this to materialise, a clear justification will need to be developed. However, as empirical data in this thesis suggests, it may be harder to predict how a psychiatric survivor will react to specific treatments. Thus, their self-knowledge developed through lived experience is imperative in informing future treatment positions. This means that advance consent becomes an important expression of that self-knowledge that works with, rather than against, clinical advice.

The majority of participants, 11 out of 12, thought that advance consent to mental health treatment should be made available and that, as a voluntary measure, it had significant potential for improving their treatment experiences and would support various capabilities. Its benefits were highlighted in previous chapters of this thesis, and its desirability is apparent. However, it is important to emphasise that support for advance consent to treatment was not universal among participants. Two lines of arguments were presented, and the first one comes from Helen:

> I have to say in no way, shape or form do I relate to this [advance consent] part of your research as a good idea.
> (Helen, narrative interview)

To Helen, the idea that she could voluntarily self-bind to future treatment was troublesome. There were several reasons for this stance. Firstly, Helen had been treated as a psychiatric patient for over 50 years and, in all that time, she felt that she had not found the treatment that was successful. Helen’s treatment consisted of medications, electroconvulsive therapy (ECT), controlled therapy with psychedelic drugs (lysergic acid diethylamide – LSD) and inpatient group therapies. In her interview, Helen said that the LSD therapy was helpful and allowed her to get better, but that she would never willingly put herself through this treatment experience again despite its apparent benefits. She said that the sensory intensity and the intensity of thoughts and emotions experienced were more than she could bear ever again. Additionally, any improvement from treatment was short-lived for Helen and was often associated with severe side effects. Therefore, her stance against advance consent is objectively easy to understand. Helen's narrative highlights an important nuance of mental health treatment in that the desired treatment is not always the most effective treatment. Again, this encourages to reflect once again on Sophie withdrawing from lithium, a decision that she found incredibly helpful not because of the lithium's lack of effectiveness but because it did not support her mental health understood in a wider psychosocial sense. Similarly, Lucy would also not choose to bind herself to treatment that was effective but potentially detrimental to her reproductive needs.

Secondly, Helen believed that advance consent would give psychiatrists even more power to treat. This concern was addressed in the discussion of insight becoming a barrier to advance consent.[171] Finally, Helen thought that the idea of any consent in psychiatry is fundamentally flawed because in her experience any 'consent' was not her own, and it was coerced. She felt that advance consent would further deteriorate opportunities for making decisions that are best for her because it was more important for Helen to be able to refuse treatment at any point, regardless of how well or unwell she was. Helen's account highlights that she distrusts mental health professionals due to the trauma associated with forced non-consensual treatment, undesirable side effects and ineffectiveness of the said treatments. Paradoxically, the same experiences were mentioned by Lucy, Eve and Eliza, who were in

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[171] See Chapter 5, section 5.6.

strong support of advance consent to mental health treatment. The difference between their accounts and Helen’s lies in Helen’s belief that she should always be able to make decisions whereas Lucy, Eve and Eliza thought that their illness-ridden decisions were likely to be in conflict with what they truly want and who they truly are.

The second line of argument, which might be more related to the issue of uptake than desirability, came from Albert who supported the idea that advance consent should be available to patients in theory but said that he himself tends to follow doctors’ advice anyway and, as no particular treatment was especially effective, he would continue to rely on guidance from medical practitioners. Similarly to Helen, Albert had found the treatment received so far to be ineffective and, in this scenario, he could not justify making an advance consent for himself. A similar sentiment was shared by Edward. Nonetheless, research on mental health advance directives in Australia has found that some patients prefer to always follow their doctor’s advice because they themselves make unwise decisions when ill (Maylea et al. 2018). So, it seems that, for reasons such as distrust of medical professionals or distrust of one’s own judgement, some patients would wish to avoid consenting to treatment in advance. This suggests that (in parallel with the advance decision to refuse treatment already set out in law) the advance consent mechanism would not be appropriate for everyone.

Recognising the various benefits of advance consent, other participants not only saw the value and premise of advance consent for others but also expressed the wish to make it themselves, most commonly for specific medications in the case of Lucy, Sophie, Fred, Robert and Millie, while others, like Eliza, Michael and Katie, would like to make advance consent to specific therapies. Based on the analysis of these lived experiences, it is clear that advance consent will benefit a specific “sub-group” of psychiatric survivors; those who recognise the premise of advance consent to enhance their agency and well-being. Unfortunately, psychiatric survivors have been experiencing denial of agency in mental healthcare settings. In turn, this means that implementing advance consent will require both raising awareness of its benefits and improving trust between professionals and those who need mental health treatment to maximise the number of people who may benefit from making and using advance consent. Thus, in the next section, I will analyse advance consent to mental health treatment through the lens of the capability for safety, thinking about additional safeguards as well as limitations on advance consent.

### 7.5.2. Advance consent and provision of a safe place

One of the key components of the capability for safety is the provision of a safe place, as already discussed throughout this chapter. The use of advance consent was seen as much broader than applying only in a hospital setting and, as highlighted in Chapter Five, it was indeed seen as a way of minimising or avoiding hospitalisation. Incontestably, this raises a challenge for the implementation of advance consent, but my participants contended that with the right 'safety factors' in place, the treatment could be provided in a safe place like a person's home or in the community:

> I suppose there are people who have CPN [Community Psychiatric Nurse]. I suppose if people said they wanted to keep at home, a CPN, who goes in anyway, would continue [to support that].
> (Eve, photo-elicitation interview)
>
> I had the CPN come and see me twice a day, and had my partner and my daughter that were sort of my safety factors. So, they said "right we won't put you in the hospital but you're going to have to come off this [medication] and take [another]."
> (Sophie, narrative interview)

In the above, Eve suggests that people who regard their home to be their safe place could be treated with their advance consent with the help of a community treatment service through having continuity of care provided by a community nurse. This was indeed the way in which Sophie avoided sectioning, by agreeing to be treated at home with the help from the community nurse and her family who would notify the nurse if Sophie was struggling or if something unexpected were to happen. Sophie was incredibly grateful for receiving all this treatment at home, a place where she felt safe. Thus, advance consent was envisaged as a way of being kept in a safe place, more so than being provided with one. Undoubtedly, providing treatment under the auspices of advance consent outside of hospital settings poses challenges to its implementation. To receive such treatment in a community or other settings, different processes would need to be put in place like deciding who is going to be the provider of treatment; in what circumstances, if any, an individual ought to be transferred to a hospital for treatment and what is the appropriate process of doing so.

What safe place means for individuals in mental health crisis will differ between people. For Lucy, in the midst of psychosis, home was not associated with a place of safety, but a hospital was. Someone with experiences similar to Lucy could make an advance consent which would be invoked when the person becomes hospitalised, whether voluntarily or involuntarily. This would mean that, while in the place of safety, the person is avoiding abuse associated with non-consensual treatment because they would be being treated with their valid consent. Advance consent, here, acts as an aide to the place of safety, which for some, might be a hospital. It is not possible to argue with certainty that advance consent would prevent unwanted detentions under sections 135 and 136 of the MHA 1983 or under sections 2 or 3, but it is possible that using advance consent at an appropriate time would prevent people's mental health from deteriorating, minimising the chances of the possibility of detention. Stavert (2021, 102) also suggests that advance statements and advance directives have the potential for what she refers to as “crossing the divide from clinical to law enforcement settings”, suggesting a promise for realising various human rights. However, it is clear that consent could be one of the pieces in a puzzle for providing valuable support in challenging circumstances and thus improving the sense of physical safety.

### 7.5.3. Alternatives to coercion

In the first part of this chapter, and indeed throughout this thesis, I discussed how coercive treatment is an example of a source of unfreedom in psychiatric survivors’ lives that is often passively accepted as a ‘necessary evil’. This is a result of societal conditioning of marginalised groups who are made to believe that there are no viable alternatives to coercion. However, finding such alternatives is both a matter of safety and thus a matter of justice. In the previous section, I discussed the potential of advance consent to mental health treatment in relation to the provision of a safe place and thus suggested that it may lead to the delivery of treatment in places where people feel safe.

Undoubtedly, the benefit that advance consent has over ACC is that it provides an alternative to coercive treatment, a culprit in circumstances of experiences of unfreedom. In this way, it is supporting the capability for safety:

> The whole reason of this is so that you feel the safest things are in place at the right time. The mechanics are in place. Yes. The decision is removed from you and you’ve; it’s going back to you before you agree to what you agreed to at the time, you made that agreement. … That’s what I think. … Well, I’ll be this week, let’s try bipolar. We’ll try bipolar this week. That fits, we’ll see where we go for that. Yeah. Yeah. It should be like McDonald’s shouldn’t it? So you know what, you know what a quarter pounder with cheese and fries tastes like wherever you have it down the road here or up in Scotland. It’s the same thing and it’s a bit like that. And I suppose when you’re going through, you have this case file with you, a legal case file with you all the whole thing and you should be able to go to any medical professional about to handle and you get

> the same response treatment, understanding everything as a person A from person B wherever you were because you've got that thing with you.
> (Robert, photo-elicitation interview)

> I think it kind of [about] justice, but I would say that it's more related to being free, being free to choose the treatment you want. … there must be other ways to have it. So, I think that being included in your in your decision-making process is the most important thing because then you can think for yourself and say, I want this because I think it's the best for me and not I want this because or and not the doctor is saying to you, this is the best. This is the best because it's the best for most people. And you might not be most people.
> (Fred, photo-elicitation interview)

Robert directly refers to the idea that advance consent provides a strong sense of safety because a person knows what to expect in times of crisis. Similarly to Fred, he draws on the individuality of mental illness or diagnosis. Nussbaum (2007) suggests that people's choices, especially for those who have disabilities, cannot be left to the chance of someone else making the right decision for that person when caring for them. This capabilities insight suggests that a just society would not permit such crucial matters as mental health treatment to depend on chance as to whether people's important self-knowledge and wishes will be considered. Being able to ascertain this self-knowledge in advance consent is a matter of social justice.

There is also an appreciation among my participants that, with the opportunity to choose treatment, there is responsibility for that choice to the extent that the resulting actions are actions they personally have opted for (Sen 2009). Fred's excerpt suggests that people would like to exercise their own individual responsibility through decision-making. He frames it as both freedom and justice. Moreover, to take responsibility for their own treatment and be seen as worthy of such a responsibility is also important for the safety capability. This idea should not be conflated with the notions that suggest health is solely a responsibility of the 'patient' or that each individual is responsible for what happens to them. Instead it is about recognising the interdependence of freedom and responsibility.

Sen (1999, 283) argues that, when the responsibility for a person is divided and is placed on another person, or the state or whatever organisation it might be, it is likely "to lead to the loss of many important things in the form of motivation, involvement and self-knowledge that the person herself may be in a unique position to have. Any affirmation of social responsibility that replaces individual responsibility cannot but be, to varying extent, counterproductive." He further suggests that the substitution of individual responsibility cannot ever be more valuable than individual responsibility, whilst acknowledging that personal responsibility, in the same vein as agency freedom, is "extremely contingent on personal, social and environmental circumstances" and thus has its limits and "cannot be exclusively relied on" (Sen 1999, 284). The inability to exercise individual responsibility within society denies people the necessary freedom to act for themselves and others "as responsible human beings" and so "responsibility requires freedom. The argument for social support in expanding people's freedom can, therefore, be seen as an argument for individual freedom not against it …" (Sen 1999, 284).

The psychiatric survivors who experience coercive treatment (both legally formal and extra-legal) live in a "nanny state". (Sen 1999, 284). This means that they live in a society, or a state or an organisation or a group of people, which takes responsibility for an individual and denies them freedom, limiting their choice, at least in the context of important, substantive decisions which may have an impact on the wider society. This speaks to the concern for public protection in the mental health context. Alternatives to the "nanny state" are not only large-scale projects but also a variety of arrangements which might even include contractual relations between individuals and the provision of such instruments which increase freedom and choice, support individual responsibility and are a major part of the social responsibility borne by each and every person (Sen 2009, 284). Those alternatives lead to the achievement of justice "because they lead to the kind of lives we have a reason to value" (Sen 1999, 285).

Advance consent to mental health treatment is this alternative; an alternative to being controlled, to lack of choice and to the lack of responsibility given to people for their treatment choices. This individual responsibility as freedom is clearly explicated in Fred's view on decision-making. The ability to make decisions also speaks to the capability for safety because it allows people to ensure that they are being treated for their unique needs and that they are not being treated in a way that "most people are" because they might not be most people, to borrow from Fred's language, and so safety requires that the alternative – not the norm (i.e., coercion or a doctor-knows-best decision) – will be followed.

Advance consent, however, does not present unlimited choice but instead is contingent on a limitation to requesting treatment that was previously experienced by an individual. When this question was posed to participants, the majority agreed that advance consent should be limited to requests for treatment that the person has previously received:

> From the safety point of view, my opinion is very much now that a professional should be involved. Whether that is a person's particular psychiatrist – I don't know! … It's hard, isn't it? Because you really want to be able to empower that service user to make a choice that's right for them. But let's say for example that it was me, and I didn't remember the exact dosage. So say, I said I was on Duloxetine and Olanzapine but actually that combination didn't work. So maybe a little bit of [fact checking].
> (Lucy, photo-elicitation interview)

> But I definitely think that for someone who wants to make an advance directive … let's say if someone requested a medication, then you want to make sure it's safe and at the right dosage, absolutely … they would benefit from going to the doctor and making advance consent.
> (Eliza, photo-elicitation interview)

The limit of mental health professionals' powers in this context was seen as simply affirming that the treatment requested, especially in the context of medication, is the correct one and that the previous dosages are stated, although it was thought that the issue of dosage might be acknowledged in advance consent as depending on medical opinion. Similarly, participants thought that advance consent would naturally be invalidated if it was no longer medically safe because of, for instance, a recent change in someone's medical history. Therefore, participants showed an appreciation for the value of health care expertise at the point of implementation. However, beyond those reasons, professionals were not to be able to question advance consent. Thus, implementing advance consent will require close cooperation from mental health professionals, who will develop a clear understanding as to where their role begins and ends. Their role should be seen as a supporter in a supported decision-making framework. Here, a psychiatrist or other mental health professional supports the informed choice made by a person by providing all relevant information relating to their previous treatment and answering any medical queries an individual may have.

This safeguard of advance consent is consistent with participants' frequent emphasis on the uniqueness of their experience of treatments whose workings cannot be as easily predicted as those of treatments for physical ailments. The view is also consistent with the stakeholders who took part in the Wessely Review (2019) as demonstrated in the supporting documents. It appears that the review discussed the possibility of advance consent to specific treatment but was limited to neuro-surgery and ECT. Although the participants could not agree on whether this should be possible, they suggested that it could be made available subject to stringent safeguards including that consent was based on the prior experience of such treatment (Wessely Review 2019, 106).

Advance consent contingent on previous experience means that, in some cases, it will not prevent the initial experience of coercion. A similar concern was raised in relation to preclusion of changes of mind in Chapter 6. For some people, advance consent would follow an initial (at least) experience of coercion, while, for others, advance consent could follow treatment received with consent outside of coercive settings. This safeguard appeared more important in participants' conceptualisation of safety than the complete avoidance of coercion through consenting to a treatment they did not wish to experience. Naturally, this is linked to the importance attached to 'informed consent' which facilitates social justice through supporting capabilities. Nonetheless, advance consent conceived in this way is limited because it is only available to those with prior experiences meaning those with secondary experiences (e.g., adult children of parents who received mental health treatment) and others who may wish to prevent experiencing future coercion in psychiatric setting would not be able to benefit from advance consent. However, as demonstrated in Chapter 5, this position is imperative in order to respect and promote informed choice and informed consent in mental health settings.

## 7.6. Achieving justice for psychiatric survivors through capabilities: concluding remarks

In this chapter, I began by developing a capability for safety for psychiatric survivors, suggesting that its components include: the provision of alternatives to coercion; provision of safe places for people in a mental health crisis; being free from undue influence; and not experiencing guilt in relation to one's mental ill-health. Using this capability, I established that advance consent to mental health treatment by addressing the issue of non-consensual and coercive treatment has promise as a valuable alternative to coercion in the mental health context, and its desirability is linked to fulfilling this component of the capability for safety. Here, the capability for safety was linked with enabling people to exercise individual responsibility, which expands people's freedom to live the kind of lives they want to live and value, thus enhancing their achievement of social justice. I emphasised that to fulfil its potential, advance consent must coexist alongside important safeguards, such as being limited to consenting to treatment that had previously been experienced. The importance of this safeguard lies in its securement of informed consent, and informed consent was possible through having those prior experiences. This is an important aspect of justice because it prevents the sources of unfreedom from seeping in and taking away peoples' ability to exercise choice, responsibility and freedom.

The importance of informed consent, capability for safety and safeguards points to the insufficiency of ACC which limits the number of protections available to people against their deprivation of liberty/involuntary detention. The unpredictability of the place of confinement places a significant constraint on the provision of informed consent, limiting the capability for safety and, in particular, its component for the provision of a safe place. However, an ACD is a valuable development because of its wide scope which considers peoples' social needs and, therefore, might result in a good level of uptake. However, its role in supporting the capability for safety is limited unless treatment preferences are always followed. In addition, it does not present the same practical benefits that advance consent does: namely, provision of speedy treatment which minimises the chances of coercion. By relying on incapacity for invocation, it further diminishes instances in which it may be used.

However, the different instruments considered in this chapter are not necessarily in competition with one another. Instead, they could all be used to meet different needs of different people and exist as alternatives enabling psychiatric survivors to exercise choice, individual responsibility and freedom. Nonetheless, if implemented into practice, both ACC and ACDs may warrant a closer examination through the capabilities lens. The achievement of social justice is complemented through the capability for safety, which does not exist in a silo but is once again interrelated and interdependent on other capabilities discussed in this thesis. Social justice is therefore much more than choice and its limits and the institutions that impact it. In fact, it is about the enablement of people to live the lives they want, and it is about creating alternatives to everyday experiences of unfreedom, like coercion.

Overall, this chapter has demonstrated that the capability for safety is a vital additional capability which should be formally recognised as one of the central capabilities to be considered within the capabilities approach. Moreover, safety is a practical capability which invites the law and policymakers to reconsider current position of the mental health law and re-define safety as a subjective experience of an individual, moving mental health law away from its disproportionate concern for the public safety versus the safety of a psychiatric patient. Adopting this approach should allow people to decide their own constellation of rights, the level of coercion they are willing to accept so that it does not infringe on their safety as a capability and promote more person-centred approach to psychiatric treatment. Implementing this capability can be achieved through the development of laws and policies that act as alternatives to coercion, such as advance consent (as well as advance refusals) or other supported decision-making mechanisms, and recognising that the "place of safety" does not include police stations.

The following chapter provides a conclusion to this thesis. I discuss how I have answered my substantive research questions, make recommendations for law reform and policy, discuss my contributions and the value of the capabilities approach, and suggest future research possibilities.

# CHAPTER 8: CONCLUSION

## 8.1. Introduction

In Chapter 1, the introduction to this thesis, I emphasised a growing appetite for understanding the desirability and premise of advance decision-making in a mental health context. In this thesis, I have explored the notion of advance consent to mental health treatment by utilising narrative and photo-elicitation interviewing methods. In this way, the thesis was informed by original, real-life, mental health-related stories told candidly by people with mental health treatment experiences. The capabilities approach gave those experiences meaning and informed the development of knowledge on advance consent presented in this thesis. Although exploring advance consent and its desirability was the main goal of this research, I also considered the value of the capabilities approach in thinking about developing people's rights to decision-making to be an equally important aspect of this thesis. The capabilities approach enabled me to develop a more intricate understanding of psychiatric survivors' needs that extend far beyond autonomy, which has been one of the main concerns of previous scholarship.

In this chapter, I bring all my findings together to summarise how I answered my research questions. I then move on to discussing the contribution of this thesis, its limitations and future research possibilities before providing recommendations and suggestions for future law reform. The future research possibilities and future law reform sections should be read as complementary to one another. I then offer a conclusion to this chapter.

## 8.2. Achieving social justice for psychiatric survivors: answering research questions

In this section, I set out how I have answered the four questions which have guided this thesis and an overarching question about the desirability of advance consent in English law. The research questions pursued in this thesis were: 1) To what extent would advance consent to mental health treatment be able to minimise coercion in the experiences of treatment? 2) What role, if any, should the mental capacity assessment play in facilitating a legal framework for advance consent? 3) Which capabilities are valued by psychiatric survivors and to what extent can advance consent translate into securing those? 4) What are the sources of injustice experienced by psychiatric survivors, and what challenges/barriers do they pose for advance consent? Throughout this section, I explain how my capabilities analysis supports my claim that advance consent could lead to achieving or experiencing social justice, for psychiatric survivors.

### 8.2.1. Advance consent: desirability and social justice

The overarching question of this thesis was concerned with the desirability of advance consent to mental health treatment based on lived experiences of such treatment. Unlike previous work, which tried to address this question by assessing desirability in a purely normative sense (e.g. Davis 2002; Spellecy 2003) or by assessing the plausibility of advance consent within existing legal frameworks (e.g. Dresser 1982) or those who attempted both (e.g. Bielby 2014), this thesis was concerned with the relationship between lived experiences of mental health treatment and the potential of advance consent provided by the law. Nonetheless, in Chapter 1, by tracing legal and policy developments on advance decision-making in English law, I argued that there is a growing appetite for exploring the role and legal status of and the need for such instruments in facilitating treatment and care.

By drawing on the original empirical data, I maintained that advance consent is a desirable mechanism when construed as a voluntary and well-safeguarded instrument. By highlighting that advance consent is only desirable when it is voluntary, I acknowledge that rather than it being an option for everyone, it is therefore not appropriate for some people. The desirability which would result in uptake of advance consent is likely to be affected by a) whether a person has experienced a successful treatment they would wish to consent to in advance (the 'successful' treatment being in line with the support for their capabilities, which is more than the treatment being medically effective); b) whether the benefit of treatment outweighs associated side effects; c) whether the person chooses to rely on advance consent or upon a medical opinion; d) whether some people can request psychological treatments such as therapies; and e) whether advance consent is perceived as empowering by an individual themselves.

In Chapter 4, through the construction of the metanarrative, I evinced the struggles of mental ill-health and, in particular, the challenges associated with pursuing, receiving and 'living' the treatment. In doing so, I unearthed various sources of unfreedom and argued that psychiatric treatment impacts not only mental well-being but also everyday reality. Therefore, improving the experiences of treatment is a matter of social justice and highlights the importance of the 'process' in receiving treatment in that the benefits of effective treatment can be offset by a delivery process which does not respect people's needs. Following on from this, in Chapter 5, I discussed the practical benefits of advance consent which support the capability for bodily integrity such as reduction in coercion, the opportunity for informed consent and speedier provision of treatment.

Chapter 6 demonstrated that desirable advance consent bears more similarities to Ulysses Arrangements than advance decisions under the Mental Capacity Act (MCA) 2005. This is because advance consent in this thesis is intended to apply even if – and for some, perhaps, especially when – the individual attempts to revoke their advance consent at the material time. To safeguard such a position in law, my participants pictured advance consent as legally binding. These arguments were conceptualised through the capabilities for health and emotions underpinned by compassion.

These empirical socio-legal chapters, complemented by the legal explorations in Chapter 1, did not provide a straightforward answer to this question. Instead, they highlighted how the lack of opportunity to provide consent to treatment damages crucial capabilities leading to experiences of injustice and unachieved agency freedom. The culminating answer to this question is provided in Chapter 7, the last of the empirical chapters. There, using narrative and photo-elicitation data, I contended that for psychiatric survivors advance consent to one specific treatment is more crucial than advance consent discussed in current English policymaking. This is because non-consensual treatment is the real source of unfreedom and the capability for safety requires more effective measures than advance consent to confinement or non-legally binding advance choice documents (ACD) to protect people from unwanted coercion.

### 8.2.2. Advance consent and coercion

An important and complex question which I have answered in this thesis is about the relationship between coercion and advance consent. My data confirmed that psychiatric survivors experience an unprecedented amount of coercion in the course of any psychiatric treatment, be it legal or extra-legal coercion, as highlighted throughout the empirical chapters. As demonstrated in chapters 4 and 5, treatment can have profound (good or bad) consequences. Unfortunately, psychiatric treatment at first was always seen as compromising the everyday lives, goals, and ambitions of psychiatric survivors and these constituted their reasons for delaying treatment, which resulted in holding off the actual breakdown and then suffering immensely.

In investigating the presence of coercion in lived experiences, I explored how the concept of insight acts as an extra-legislative criterion for coercion in psychiatric practice, highlighting how much remains invisible to the law and how ineffective the current law is in adequately protecting people's rights relating to their treatment and to consent in general. One of the main benefits of advance consent was its perceived ability to reduce the need for coercion by ensuring that individuals would only be treated with their valid consent. In addition, if the individual is free to specify the point in time at which their advance consent should come into effect, then it further minimises the chance of the need for coercive measures.

This led me to consideration of the changes of mind dilemma, resulting in an argument for advance consent precluding an individual's changes of mind at the material time. Some participants viewed this scenario as a very real possibility and expressed concern that, if their advance consent was dismissed in favour of – oftentimes illness-ridden – contemporaneous changes of mind, this would result in advance consent becoming ineffective for protecting their wishes, especially in situations of a mental health crisis. This led to a practical concern; if advance consent is followed despite attempts to revoke it at the material time, would the provision of treatment be experienced as coercion, especially when it may involve some level of force? The participants were clear that, as they would be being treated on their informed consent and wishes, then this would not constitute coercion according to their views. The overarching emphasis on the notion of informed consent led to my participants suggesting that advance consent should be limited to treatment previously experienced, thereby potentially suggesting a level of lenience towards fully informed consent. This position on changes of mind was of such great importance that participants strongly wished for advance consent to be legally binding.

Of course, the position on limiting treatment in advance consent to a previously experienced treatment is likely to be more medically desirable because participants recognise that, as they are not medically trained themselves, it would not be plausible to request just any available treatment. Conceived in this way, advance consent has its limits in terms of reducing coercion in that it would not be able to prevent the first experience of coercion for some people. On the one hand, advance consent would be made by people following mental health treatment outside of the hospital setting, and, in that case, there is a chance it will minimise or even prevent experiences of coercion for that individual. On the other hand, for others, advance consent might come after they have already experienced coercive interventions, which evidently points to the limitation of advance consent. Therefore, advance consent is better understood as minimising the need for future coercion and as a potential alternative to future coercion, but it cannot be said to be capable of displacing coercion completely. Indeed, psychiatric survivors also suggested that, if they knew they had advance consent to treatment in place, they would be more likely to seek treatment earlier, knowing that they could expect to receive a chosen treatment that they already considered effective, thus minimising the chances of being sectioned.

Although participants struggled to articulate the instances in which changes of mind ought to be followed, they recognised that there is a small chance that circumstances in which this would be legitimate may exist. One suggestion was that, if the treatment was no longer medically safe, for instance because of a change in medical history, then, naturally, advance consent should not be followed. Some recommended what I call ‘a nominated trusted person’ framework for mitigating any dilemmas arising from an advance consent and for safeguarding individuals from unjustified coercion. In Chapter 7, I highlighted that the focus of policymaking on advance consent to confinement is unlikely to minimise coercion, which is primarily experienced through coercive treatment rather received whilst in confinement.

Furthermore, the capabilities approach was helpful in conceptualising the relationship between advance consent and coercion. Using Sen’s (1999) theories, I argued that a true expression of freedom allows people to experience only the level of coercion they are willing to accept. This is also linked to individual responsibility discussed in Chapter 7; allowing people to exercise individual responsibility is both a matter of freedom and justice. Last but not least, I have shown that addressing coercion in the experiences of mental health treatment through advance consent supports the capabilities for bodily integrity, health and emotions and exemplifies compassion.

### 8.2.3. Advance consent and mental capacity

Another question answered in this thesis is about the place and the role of mental capacity in the provision of advance consent. I began to answer this question in Chapter 5. Drawing on people's experiences of insight and attitudes toward mental capacity, I argued that mental capacity is an unhelpful and inadequate legal concept in the context of improving mental health treatment experiences and in thinking about advance consent. I suggested that there is a strong likelihood that expanding mental capacity assessments into the mental health framework would lead to an overreliance on the concept of insight, which is likely to negatively impact the bodily integrity of psychiatric patients. I have shown that psychiatric survivors consider mental capacity to be an insignificant concept and, based on their experiences of insight, feel that the concept might be used against them; any non-compliance could result in the abuse of mental capacity and deeming people incapacitated. Moreover, my findings suggest that if advance consent were to be invoked on incapacity it would offset its premise of providing a speedier treatment response.

In Chapter 6, I contended that advance consent should preclude even capacitous changes of mind, making this the most legally controversial finding of this thesis because of the general principle that a person who has the relevant mental capacity can make their own treatment decisions, including unwise decisions. However, the controversy of this finding is offset by the fact that mental health laws already permit clinicians to override the capacitous wishes of their patients, while the use of advance consent means that clinicians would not be overriding capacitous wishes, but rather respecting the wishes of their patients who had anticipated the possibility of changes of mind. I also suggested that, for a legally binding consent in line with general elements of a valid consent, it might be necessary to contend that people ought to make advance consent when they have the capacity or that another way of authenticating advance consent might be required.

### 8.2.4. Advance consent and valued capabilities

Throughout this project, I was concerned with finding out which capabilities are valued by psychiatric survivors and how these relate to advance consent. Although I conceptualised my empirical chapters in light of different capabilities, it is clear that these capabilities are all interrelated and interconnected and so understanding the relationships between them is necessary for the achievement of social justice. Capabilities do not exist in silos separate from one another.

In this thesis, through my narrative analytical framework, I discovered that provision of advance consent would support the capabilities for bodily integrity, health and emotions. In addition, I found that the capability for safety – which is not present in Nussbaum's (2011) central list of capabilities (and this list began my narrative analysis) – is key for psychiatric survivors. In developing this capability, I highlighted the need for revisiting the 'place of safety', and safe places in general, for people who are experiencing a mental health crisis. In unravelling what capability for safety is, I highlighted that its components include being free from unnecessary coercion and having alternatives to coercion, being free from undue influence and guilt about one's mental illness, having opportunities for choice and active participation in decisions about treatment and being provided with a place of safety when needed, among others. The intricate focus on 'being free' and having freedom highlights the interconnectedness between freedom and justice. The capability for safety along with other capabilities quite plainly requires one to consider sources of unfreedom.

### 8.2.5. Sources of unfreedom and barriers for advance consent

To deepen the understanding of social justice in the context of psychiatric survivors' lives, it was also crucial to understand sources of injustice or unfreedom, in the capabilities lexicon. I found that one of the biggest sources of unfreedom is a coercive, non-consensual treatment prescribed by law that dominates negative experiences, discussed primarily in Chapter 5. This is linked closely with experiences of not having one's views respected and not being listened to, which also leads to injustice. However, sources of unfreedom can also be more subtle. In Chapter 4, I highlighted that the lack of relational continuity of care is experienced as a source of unfreedom leading to obstacles to receiving appropriate treatment. Advance consent, unlike joint crisis plans, for example, would enable people to receive required care without the necessity for having or needing a relational continuity of care. The treatment and the side effects associated with treatment can also lead to injustice which further highlights the importance of advance consent. It was not that people wanted to receive a particular treatment long-term, but rather it was important for them that, when this treatment was needed, it was accessible and that it was the treatment which had worked for them previously. By looking at sources of injustice in Chapter 4, I found that agency, understood as a higher-level capability, is an important aspect of living the lives that people want to live, and agency intricately underpins advance consent, but ultimately capabilities give it more meaning. In addition, in Chapter 7, I highlighted that police stations as a place of safety are likely to be experienced as a source of unfreedom.

The clinical concept of insight was also experienced as a source of unfreedom. This is because, as lived experiences reveal, lack of insight is perceived as non-compliance with clinical advice. Thus, advance consent could be viewed as an expression of insight by clinicians, which could further pathologise any departure from medical advice or refusals of treatment. It would be, therefore, necessary to explicitly consider the relationship between insight and advance consent from the start and at the point of implementation. As already discussed, mental capacity could also pose a challenge to the premise of advance consent, if its role is parallel to how advance decisions operate under the MCA 2005.

In Chapter 4, I argued that stigma leads to experiences of injustice in all aspects of life: from interactions in familiar religious communities to wanting insurance cover. By drawing on people's narratives, I suggested that stigma is not only a source of unfreedom/injustice but an example of structural violence. Stigma experienced at a higher societal echelon leaves psychiatric survivors unable to realise desired capabilities into functionings. Indeed, it could be a contributing factor in denying psychiatric survivors the ability to make their own decisions. Psychiatric survivors need to experience full inclusion in society to really achieve social justice and the freedom to live the kind of lives psychiatric survivors have a reason to value, which was beautifully articulated by Sophie:

> Ending stigma kind of creates social justice for people with mental [ill] health or contributes to social justice. In a way that's what society owes you. But it's about having freedom. At the end of it, it's about having freedom. The most basic right of everybody is to live as they want.
> (Sophie, photo-elicitation interview)

Here, Sophie's quote perfectly represents the capabilities approach to social justice. Sophie recognises that stigma is an example of unfreedom and that ending it would contribute to social justice. Justice, through the lens of capabilities, is about acknowledging unfreedoms and tackling them with alternatives and support for capabilities. In this way, people have a chance to expand their freedom, so that they can live the lives they want. Advance consent is a relatively modest, but important, component of achieving that freedom because it allows people to have control over their treatment and it allows them to exercise responsibility for their lives.

## 8.3. Contribution, limitations and future research possibilities

In this section, I will discuss areas where further research is required or where there is a potential for future research. I begin by describing the original contribution made by my methodological approach. I then discuss some limitations of the framework and suggest how this presents opportunities for future research. I then move on to discussing the contribution, limitations and research possibilities of the capabilities approach and the law.

### 8.3.1. Methodology

Law as a field finds many proponents and advocates for doctrinal analysis which has its place and importance in the study of law. It allows one to clarify what the law is through the careful examination of legal instruments, judgments and statutory provisions. Moreover, it enables one to examine the fitness of legal ideas and proposals within current or future legal frameworks.

The law, in general, has previously been criticised for its over-reliance on legal instruments and its limited focus on the impact that it has on people’s everyday lives (e.g. Smart 1989; Harding 2011). The legal framework for English mental health law is incredibly complex and riven with legal technicalities and a relatively small body of case law in comparison with other areas of law – mental capacity being the closest one. Whilst there has been empirical research on the importance of psychiatric advance decisions (e.g. Swanson 2003; 2006; 2008; Henderson 2004; Ruchlewska et al. 2016), there is a glaring gap in socio-legal scholarship which could explore the everyday experiences of mental health laws and how they operate in practice. Mental health laws or proposals for new laws in this area are usually ethically charged and give rise to difficult policy and legal questions – and questions of implementing them. In fact, research in this area is lacking input from socio-legal approaches at the very least. This is because the law relating to people with mental ill-health does not exist in separation from people's social contexts, nor is it disconnected from relevant disciplines like psychiatry or psychology. Therefore, ideally, future research in this area should adopt an interdisciplinary outlook.

Foregrounding this research in the experiences and voices of psychiatric survivors was important to the current research from the very early stages. Recognising my own methodological training limitations when first embarking on this project and understanding the constraints of a doctoral thesis, I still wanted to ensure that my methods of 'data collection' would allow me to immerse myself as much as possible in experiences of mental health treatment and to capture uninhabited stories which are not constrained by too much agenda-setting. The in-depth capturing of psychiatric voices appeared to be missing in the literature, policymaking and relevant debates. As Hui and Stickley (2007) argued, policy and legal developments have treated people with lived experiences as silent partners whose views would always be secondary to other stakeholders. Drawing on the socio-legal work of Harding (2011; 2017b) and social work of Ward (2009; 2012), I utilised narrative interviews familiar to law and socio-legal studies. Then, borrowing from works in psychiatry and psychology (Erdner and Magnusson 2011; Sandhu et al. 2013), I also chose to pursue photo-elicitation interviewing as a method. The use of photo-elicitation methods in socio-legal scholarship is a novel pursuit and contributes to socio-legal scholarship more broadly. I suggest that as a method, photo-elicitation could be utilised in future socio-legal research, especially when it concerns itself with sensitive topics like disability, health, reproduction, violence, trauma, or abuse. This method allows the researcher to immerse themselves in the experiences they are studying and is likely to challenge any preconceived ideas they have brought with them about the studied phenomena. In the context of mental health law research, photo-elicitation builds a bridge for understanding the relationship between law, psychiatry, and sociology.

Nonetheless, my methodological approach has given rise to several limitations that should be addressed in future research. The first pertains to bridging the gap between the law and psychiatry. As shown throughout this thesis, there is a significant discrepancy between what the law is in statute and what it is thought to be in psychiatric practice based on the experiences and attitudes of psychiatric survivors. In this research, I interrogated lived experiences of mental health treatment from the patients' perspectives. I suggest that future research on advance consent should also establish the views, opinions, and attitudes of psychiatrists who would be key stakeholders in facilitating this research. This will result in an additional set of findings ensuring that advance consent can be effectively translated to and implemented into practice. In addition, research on advance consent might benefit from an empirical exploration of those people who are informal carers of loved ones, especially when considering further research into nominated trusted person(s) frameworks for advance consent.

This research is limited to the experiences of 12 participants, resulting in 21 interviews. This is not a large number but, as I have argued in Chapter 3, I was interested in the depth and variety of experiences. However, as a result of the small scale of the study, I do not suggest that the findings can or should be generalised to the psychiatric survivors' population more broadly. Nonetheless, this research captures a variety of experiences, highlighting that each person should be treated as an end in themselves while also unearthing the capabilities that may be important in this context, regardless of the range and diversity of people’s interactions. In addition, as highlighted in Chapter 3, it is important that future research examines the issue of identity, which I did not consider from the outset but which contributed to my difficulty in recruiting participants from diverse backgrounds.

The future research possibilities stemming from this project include refining the photo-elicitation method to further explore its methodological potential. This method in particular was key to capturing uninhabited stories; it organically resulted in better researcher–participant power dynamics; and allowed me to become immersed in those experiences. Future research should also focus on developing a feasible and meaningful way of conducting co-production research and more participative methods.

To conclude, further strong interdisciplinary empirical research underpinned by inclusive or participatory methods would strengthen knowledge in this area. In addition, I suggest that researchers should take the methodological potential of the capabilities approach and develop it further. In this study, the capabilities approach allowed me to develop a unique analytical framework to evaluate the micro, meso and macro structures that shape people’s experiences of the sources of unfreedom which hamper social justice and the capabilities which people value, particularly in a specific context.

### 8.3.2. The capabilities approach

This is the first study which uses the capabilities approach as a theoretical framework for socio-legal, empirical exploration of advance consent, contributing to a new way of thinking about advance consent’s thorny questions and about social justice itself which is understood through capabilities. The idea of social justice in the capabilities framework does not exist on an abstract level and can lead to practical recommendations. For each capability examined in this thesis, I used the approach developed by Sen (1999; 2009) and Nussbaum (2006; 2011) to deepen the understanding of each capability. In addition, I utilised Nussbaum's (2001) and Bielby's (2021) work to think about compassion, which underpins health and emotions. Although this is perhaps a modest contribution to the capabilities approach at large, it offers a new theoretical hook and application on which further future studies can build.

A capabilities approach adopted for this thesis has led me to recommend a legally binding advance consent to mental health treatment that secures central capabilities. This recommendation requires an allocation of significant resources to be implemented in law and in practice – an issue discussed in this thesis. The capabilities approach is a useful framework for contemplating the allocation of resources based on the idea of justice (Sen 1999; 2009) and could be used for the purpose of thinking about resources in this context because ideas without resources lead to poor implementation outcomes.

Lindsey and Harding (2011) suggest that the capabilities approach may not directly change the law, but it can inform the everyday practice in which the law operates. I concur with this view, but I add that the capabilities potential goes far beyond everyday practice. The capabilities method is useful as a policy approach and could be further utilised in aiding the implementation process, particularly as it has been established to be an appropriate framework for thinking about the mental health population in the UK (Simon et al. 2013). This use of the approach would place the focus on practical solutions and "impede policymakers from using mistaken assumptions" (Robeyn 2017, 15) about psychiatric survivors in their policies, including what is valuable in their lives and what kind of legal and societal support is needed in order for people to flourish.

Finally, I developed a new capability, the capability for safety. I argued that safety can be incorporated as a new capability in several ways. Firstly, I suggested that it should become part of the central list of capabilities. This means that safety can be adopted by other capabilitarians in their future theoretical and empirical pursuits. Secondly, I argued that safety as a capability encourages law makers to reform mental health laws in line with patients' subjective understanding of safety and forces one to consider alternatives to coercion. Thus, future research should develop on this concept of safety as a capability to realise its full potential.

### 8.3.3. The law

The contribution of this thesis also lies in the socio-legal exploration of advance consent for mental health treatment which is a timely pursuit in light of policy and lawmaking in this area, both in England and elsewhere. Even though I focused on the English law context, my findings are translatable on a larger scale as they address broad questions about the relevance of mental capacity, coercion and the changes of mind dilemma. Additionally, my contribution lies in exploring advance consent for people with mental ill-health regardless of their diagnosis, rather than focusing on specific mental health diagnoses. This is an important contribution suggesting that advance consent may be helpful for the wider mental health population.

In Chapter 1, I mentioned human rights developments as a contributing factor to advance consent, completing the 'full circle' and reviving debate in this area. Therefore, an obvious limitation of this research is that it did not engage with human rights developments and, in particular, the CRPD. As noted in Chapter 6, advance consent invoked on people’s specified wishes rather than on incapacity is more desirable in terms of the CRPD. However, the hard legal enforceability and preclusion of mind which might lead to people’s wills and preferences not being respected at the material time evidently warrants careful human-rights analysis. The human rights approach is also likely to lead to a much broader focus: for example on advance planning more generally rather than on advance consent to mental health treatment specifically. The future research potential lies in building on the existing work in this area (e.g. Weller 2013; Gooding 2017; Stavert 2021; 2022) and the developing body of general comments and other CRPD instruments to unearth the potential of advance care planning in this area. Beyond CRPD, there are doctrinal human rights questions pertinent to Article 5 and Article 8 rights. Considering whether various versions of advance consent sit within the scope of those rights will be a valuable future pursuit. In addition, there is an important potential of marrying the capabilities approach, as a rights-based framework, with the capabilities approach to inform legal and interdisciplinary research in this area, building on the small body of work in this context (Harnacke 2013; Stavert 2022).

Another limitation of my research is that it did not address the issue of psychiatric advance refusals, which may or may not be of greater importance to psychiatric survivors (see e.g. Scholten et al. 2019). In this thesis, however, I have not focused on advance refusals because it is advance consent that remains under-researched. Nonetheless, empirical inquiry into advance refusals would strengthen proposals for adequate advance decision-making for mental health patients, especially because advance consent should not exists without a framework for advance refusals. If it did, it could further pathologise legitimate refusals of treatment in favour of treatment requests. In Chapter 5, I contributed to the growing concern about the relationship between the concept of insight and the law (e.g. Case 2016; Gurbai et al.

2020; O’Keefe 2022). I did this by offering an empirical exploration of insight in the legal context and in analysing the potential relationship between advance consent and insight which has the potential for further empirical exploration of this concept in the context of advance decision-making.

Lucy’s story of being told she has been on medication causing medical sterilisation suggests that there is scope for researching the relationship between the reproductive rights of women with a diagnosis of mental ill-health and informed consent or decision-making more broadly. Although some research has been done looking at advance directives for pregnancy in the context of mental illness (Halliday 2016), I suggest that more research is needed to examine how the reproductive rights of women are protected when they receive legally mandated psychiatric treatment. More broadly, the issue of coercion in psychiatry and alternatives to such require more research.

Weller (2013, 160) suggests that the question of legal enforceability and whether advance decisions should be legally binding may remain open. Interrupted by the course of the global pandemic, I was unable to conduct my overseas fieldwork to study advance decision-making in British Columbia (Canada). I suggest that there is scope to learn from other jurisdictions which already utilise psychiatric advance decisions with different levels of enforceability. Therefore comparative or cross-jurisdictional research presents a strong potential area of study. There are important questions related to legal enforceability which I did not address such as doctors’ liability for not following a legally binding advance consent, courts’ or other legal oversight of such instruments and the exact validity and applicability criteria which would need to be established. These questions could be informed through careful socio-legal inquiry into the workings of advance directives in other jurisdictions. Lastly, my modest contribution for putting forward the nominated person framework suggestion should be explored further with more research focused specifically on this aspect.

Finally, commenting on the case of a patient with a bipolar disorder who wished to be given dialysis despite refusing it at the material time due to the symptoms of his mental ill-health,[172] I have suggested that advance consent would be a useful measure in this context (Furgalska 2020). Undoubtedly, there is an important and largely unexplored question about advance consent to medical treatment for physical ailments made by people with mental health diagnoses who fear they might refuse needed and even life-saving treatment as a result of their mental ill-health.

## 8.4. Future possibilities for reform

This discussion on future research possibilities is intricately linked to my recommendations because firm recommendations should be based on comprehensive research. Nonetheless, it is clear that there is a value in and potential for advance consent which should be further explored in future law reform.

In this thesis, I argued that psychiatric survivors do not have legal and meaningful opportunities for giving advance consent to treatment even when they have relevant mental capacity. This position of a psychiatric ‘patient’ can be contrasted with a physical patient who has the right to consent to or refuse any treatment; a privilege not afforded to mental health patients. This adds to the experiences of stigma at both a personal and societal level. In effect,

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[172] This is unreported case which was observed and reported by Kitzinger (2020) on her blog.

the law discriminates against the interests of psychiatric survivors, creating stigmatising rules and fostering patients' distrust in the mental health profession. Therefore, my first recommendation is that the law should consider the place and value of advance consent to mental health treatment and the issue of consent more broadly.

Here, I recommend that consideration be given to the inclusion of advance consent to the treatment framework by amending the MHA 1983. This instrument should be voluntary, and psychiatric survivors should be made aware of it as a possibility as soon as possible after they come to contact with mental health services and treatment. However, advance consent should also be available to those patients with prior experiences of mental health treatment, and therefore advance consent ought to be limited to requesting treatments already known to the patient. The instrument should be authenticated to prevent doubts about its validity, but the workings of the authentication process need to be carefully researched and established. In turn, advance consent should be invalidated if the treatment requested is no longer safe at the time of its application because of a new aspect of the patient's medical history (for instance, a physical illness that could be negatively impacted by the requested mental health treatment). It should be noted that advance consent in this thesis is recommended for adults only. Furthermore, advance consent should not be invoked on incapacity but in circumstances clearly specified by an individual. These recommendations are subject to further research on issues outlined in the previous section.

One of the themes and threads that permeates this thesis is the need for safeguarding the rights of patients. Thus, future reform should consider how people's rights and wishes can be safeguarded from abuse and exploitation. It should also consider the impact of the concept of insight and provide clear guidance on its (in)appropriateness in applying the law. Future reform should also aim to clarify the relationship between the MCA 2005 and the MHA 1983 to provide clarity and certainty of the law. These areas for future research are tightly linked to those highlighted in the previous section, and so should be informed by that research.

In Chapter 7, I suggested that, although limited, the proposed framework for ACDs is a valuable step in securing advance care planning for psychiatric survivors. However, the pre-legislative scrutiny of the Draft Bill on the Mental Health Act, published on 27th June 2022 (Department of Health and Social Care 2022b), does not put ACDs on a statutory footing. The principles which guide the proposal in the Wessely Review (2018) appear to be reflected in ss 56A and 57A, but there is no provision specific to ACDs in this context. I recommend that the lawmakers review this position in future stages of legislative reform because, without statutory provision for ACDs, their use and, consequently, respect for people's wishes are not likely to increase in practice.

The final recommendation I make, complemented by my earlier discussion of the capabilities approach and future research possibilities, is that the capabilities framework should be utilised in policymaking at the point of implementation and in practice. By taking a bottom-up approach to the study of mental health law, the capabilities framework brings to light previously invisible but highly relevant issues that lead to experiences of injustice and may emphasise the ways in which justice can be achieved in practice.

## 8.5. Final reflections and conclusion

This research has challenged my beliefs about mental illness and what is considered good and helpful for people. It taught me that for a very long time I understood that what is in the best interests of psychiatric survivors does not always match their lived perspectives. It made me realise that, even though I was familiar with lived experiences of mental illness, I was not ‘really’ aware of the thoughts, considerations, and meanings that psychiatric survivors protect from the outside world. I never knew the story of mental illness in this depth. For that, I am indebted to psychiatric survivors who shared their experiences with me so candidly.

As researchers, we do not afford enough attention to the emotional labour associated with doing empirical research of this nature. Although doing research that seems important or even personal can be motivating, doing such research can be emotionally taxing. On the one hand, I was ‘prepared’ for the stories that people told and did not find interviewing difficult. However, transcribing data, which of course required me to re-listen to those stories, proved to be the most difficult part of this work. I suggest that researchers in a similar situation ensure that they find a supportive person whom they can debrief with and, when necessary, not be afraid of seeking professional support.

I am aware that the findings of this thesis may not have uncovered all objective truths, but such findings might not be possible given the diversity of human lives and experiences. However, I suggested that using a material-narrative empirical framework underpinned by the capabilities approach enabled me to present findings appropriate to the group of people at the heart of this thesis: psychiatric survivors. I emphasised how the capabilities approach can conceptualise socio-legal inquiry and uncover those aspects which are invisible to the law. Although the focus of this thesis was on advance consent to mental health treatment, I hope that I have provided useful insights into mental health law more broadly and into socio-legal scholarship. What has become clearer as I was carrying out this research is that we need to reformulate the basis of mental health law; it should be made for the benefit of psychiatric patients and not because of the concern for others. Once reform begins with this premise, of providing safety and justice for psychiatric survivors first and foremost, it has the potential to improve people's experiences of mental healthcare. I also hope that future research and legal reforms will seek the expertise of psychiatric survivors; facilitating their needs is not just a matter of law but also a matter of policy and is relevant to society at large. Stories offer a deeper and richer understanding of the law, and I am grateful to everyone who has shared their personal accounts with me. I also hope that my contribution will be useful to other researchers and that together we can take steps towards achieving social justice, respect and capabilities for psychiatric survivors to ensure that they are able to live the kind of lives they value.

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# APPENDIX 1 DEMOGRAPHIC INFORMATION

1. **What is your gender?** (Circle as appropriate)
a) Male
b) Female
c) Non-binary/Other

**2. How old are you?**
a) 18-24
b) 25-34
c) 35-44
d) 45-54
e) 55-64
f) 65-74
g) 74+

**3. What is your ethnic group?**
a) English/Welsh/Scottish/Northern Irish/British
b) Irish
c) Any other white background ________________ (please specify)
d) Indian
e) Pakistani
f) Chinese
g) Bangladeshi
h) Any other Asian background ________________ (please specify)
i) Black African
j) Black Carribean
k) Any other Black/African/Carribean background _____________ (please specify)
l) Mixed (White and Black)
m) Mixed (White and Asian)
n) Mixed (Black and Asian)
o) Any other mixed/multiply ethic background ______________ (please specify)
p) Arab
q) Any other ethnic group ________________ (please specify)

**4. Do you consider yourself to have a disability?**
  a) Yes _________________ (please specify)
  b) No

**5. Do you have a diagnosis of mental illness/psychosocial disability?**
  a) Yes
  b) No
  If yes, please specify……………..

**6. Do you have any of the following legal mechanism in place:**
  a) Advance Decision to Refuse Treatment
  b) Advance Statement
  c) Lasting Power of Attorney
  d) Other (please specify) ………………

# APPENDIX 2: RECRUITMENT MATERIALS

Mental Health Treatment and the Law

Seeking participants for research

- **Have you had any experiences of mental health treatment?**
- **Would you like to tell your story?**
- **Have you considered ways in which law can protect your treatment choices?**

If you answered YES to any of the above, are aged 18 or over and self-identify as a **psychiatric survivor** then I would love to speak to you about your experiences as part of my PhD research on Mental Health Law.

## TO PARTICIPATE AND FOR MORE INFORMATION

**Contact:** Magda Furgalska

Email to networks and charities in England and Wales:

Dear X,

I hope this email finds you well.

I am Magdalena Furgalska, a PhD student at the University of Birmingham. My PhD is in the area of mental health law and the title of my project is: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law. I am interested in the issue of advance consent to mental health treatment. Advance consent refers to a self-binding advance decision to request a mental health treatment for the future, when a psychiatric survivor may not be able to make decisions for themselves.
My research seeks to find out how desirable advance consent is based on psychiatric survivors' lived experiences of mental health.

As you might know, the Independent Review of the Mental Health Act has recently considered the issue of advance consent for mental health. This project aims to explore some of the ideas from the review. In order to gather data, I am looking to interview people with experiences of psychosocial disabilities/mental health problems to learn about their experiences of mental health treatment and their journey more generally.

I was hoping to make contact with you to see if there would be an opportunity for [organisation name] to advertise my research project. Please see attached poster should you wish to advertise the research. I would be also happy to meet with you/your team/members and discuss/present my research. Please let me know if you would like to have a telephone conversation about any of this. Alternatively, please do not hesitate to contact me via email.
The Economic and Social Research Council Midlands Graduate School Doctoral Training Partnership fund this research project. My research supervisors are Professor Rosie Harding and Dr Emma Oakley. The research has ethical approval from the University of Birmingham.

Kind regards

Magdalena Furgalska

Tweets: England & Wales

Tweet 1: Psychiatric survivors needed for research on mental health treatment and the role of law. To find out more see my research website here bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 2: Do you have an experience of mental health treatment? If so, I would love you to be part of my research which aims to explore ways in which experiences of mental health treatment can be improved! For more info see here bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 3: People with experiences of receiving treatment for schizophrenia needed for research exploring experiences of mental health treatment and the law. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 4: People with experiences of receiving treatment for bipolar disorder needed for research exploring experiences of mental health treatment and the law. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 5: People with experiences of receiving treatment for borderline personality disorder needed for research exploring experiences of mental health treatment and the law. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 6: People with experiences of receiving treatment for eating disorders needed for research exploring experiences of mental health treatment and the law. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 7: People with experiences of receiving treatment for depression or anxiety needed for research exploring experiences of mental health treatment and the law. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Tweet 8: Are you a psychiatric survivor? I would love you to take part in my research exploring how experiences of mental health treatment can inform a law reform in England & Wales. See: bit.ly/AD-2020 #AdvanceDecisionsBhamLaw

Website text

Reserved website URL: https://blog.bham.ac.uk/advancedecisionsbhamlaw/

Reserved bitly link for this (I will use individual biy.ly links for different kinds of recruitment processes (twitter, website, poster etc.) so I can trace which ones are more effective.: e.g. bit.ly/AD-2020-W.

The Website will have a menu of pages with text information: Home, About the Researcher, Information About Narrative Interview, Information About Photo-Elicitation Interview; Information About Interviews in British Columbia, Contact and Updates.

TEXT FOR 'HOME' PAGE

The research explained on this website is carried out as part of a Law PhD at Birmingham Law School, University of Birmingham. This research is funded by the Economic and Social Research Council Midlands Graduate School Doctoral Training Partnership and has been approved by the University of Birmingham Social Sciences Ethics Committee.

In this research I aim to explore lived experiences of mental health and mental health treatment from the perspective of psychiatric survivors. It explores, in particular, the issue of Advance Consent for Mental Health Treatment. Advance Consent to Mental Health Treatment is a mechanism which allows people with psychosocial disabilities/mental health problems to make a request for treatment in advance of losing their ability to do so (for instance in advance of losing mental capacity). Advance consent could mean that request a specific treatment that you know works well for you (such as specific medication). It could also mean that you self-bind to be treated by medical professionals for when you are unwell and may not have an ability to consent to this.

This legal mechanism is not currently available in England & Wales, but is available in other places in the world, including British Columbia (Canada), Austria, Germany and the Netherlands. However, the issue of advance consent is currently on the law reform agenda in England & Wales. The Independent Review of the Mental Health Act 1983 (published in December 2018) considered the issue of advance consent (especially to confinement) in a considerable depth.

This research project is designed to privilege the lived experiences of psychiatric survivors. Any outcomes and recommendations will be based on people's experiences of their mental health, treatments, opinions and attitudes. Currently, the literature and research exploring advance decisions lacks empirical evidence about the desirability of, and the need for, advance consent in Mental Health Law. This project aims to address this gap.

If you are a psychiatric survivor, please explore this website (menu section above) and consider whether you think you could help to inform this research. If you know someone who is a psychiatric survivor please let them know about this research as they might wish to have their story heard.

I look forward to hearing from you.

***Please note that a psychiatric survivor in this research refers to persons aged 18 or over, who have experiences of receiving treatments for the following but not limited to: anxiety, bipolar disorder, borderline personality disorder, depression, eating disorders, episodes of psychosis, schizophrenia.

TEXT FOR ‘ABOUT THE RESEARCHER’

My name is Magdalena Furgalska and I am a PhD Candidate at the Law School, University of Birmingham.

My primary research interest lies in how the law can be used to improve the experiences of mental health treatment by providing psychiatric survivors with more options, greater legal protection and increased autonomy in decision-making processes.

I believe that law should be made in accordance with the needs of the society and as such I privilege the meanings people assign to their experiences in my research.

Prior to starting my PhD, I have gained a Law Degree (LLB) from the University of Hull, Law Masters (LLM) from the University of Birmingham and the MA in Social Research from the University of Birmingham. I have also worked in various capacities at a leading set of Barristers’ Chambers in Birmingham throughout my studies.

Outside of my PhD studies, I have also worked on a number of research projects which were informed by experiences of everyday life. These were in the following aspects of law: supported decision-making, supported will-making, medical law and ethics, reproductive rights, criminal law and counter-terrorism.

For my academic doctoral profile please visit: https://www.birmingham.ac.uk/schools/law/research/postgraduateresearch/profiles/furgalska-magdalena.aspx

Feel free to ask any questions about my background or anything mentioned above.

## TEXT FOR INFORMATION ABOUT NARRATIVE INTERVIEW

Have you got any experience of receiving mental health treatment?

Would you like to share your story?

Do you want to be part of research recommending ways in which experiences of mental health treatment could inform future law reform?

I am currently looking for research participants who have experiences of receiving treatment in England or Wales.

If you self-identify as psychiatric survivor, are aged 18 or over and have any experiences of receiving treatments for the following but not limited to: anxiety, bipolar disorder, borderline personality disorder, depression, eating disorders, episodes of psychosis, schizophrenia, please consider taking part of this research.

### What is narrative interview?

Narrative interview means that I will ask you to tell me your story of mental health and treatment. You can share as much or as little as you are comfortable to. Your views are invaluable in shaping the outcome of this project.

### What happens if I take part?

- You and I meet at your chosen location (your home, café, University of Birmingham)
- I use a digital audio recorder to record your story
- I will transcribe this interview, anonymise it so you cannot be identified and use it to inform my findings
- I will ask you to consider taking part in the follow up Photo Elicitation Interview
- Once I finish this project I will send you a summary of my findings. You will be given access to the full thesis if you wish to.

### What happens to the above information?

- Everything is in your control. You can stop the recording at any time and change your mind about taking part during the interview or up to 12 weeks after.
- I will be the only person to listen to the original recordings. Anonymised transcripts may be read by the research team only (myself and my supervisors).

- The recording will be destroyed once I complete my PhD research. Anonymised transcripts must be kept securely for 10 years. All data will be kept locked up or password protected.
- If you consent, I may offer your anonymised transcript to the UK Data Service for archiving.

Are there any benefits to taking part?

- You have a chance to tell your story
- You can help me understand experiences of mental health treatment
- You can help me make recommendations that could benefit people like yourself in the future

Can I have more information about all of this? Of course, please contact me if you wish to take part or need more information.

TEXT FOR ‘INFORMATION ABOUT THE PHOTO-ELICITATION INTERVIEW’ PAGE

If you have taken part in the Narrative Interview, you will be asked to consider taking part in this follow up photo-elicitation interview.

What is Photo-elicitation Interview?

Photo-elicitation is a method of interview that uses images to elicit information and improve researcher’s understanding of people’s experiences, feelings and attitudes.

**What will happen?**

Once you have told me your story in the narrative interview, I will ask you to meet me again in approximately two weeks or whenever is convenient for you. I will ask you to prepare some photographs you may already have/or take some photographs that you think will help me understand your experiences of mental health better. You should only choose to share photographs with me that you are comfortable with sharing. I will give you some guidance and ideas of what photographs you may wish to consider.

What happens to the photographs?

- You can choose to show these photographs to me only. These means that we will talk about them during an interview that will be audio-recorded and that’s it.
- You can choose to permit me to take copies of your photographs for me to use in my thesis or publications or conference talks. We will have a conversation about the different ways in which photographs may be used and you will have a complete freedom in deciding what you allow me to do and what you do not allow me to do.

# APPENDIX 3: THE FUTURE OF ADVANCE DECISIONS.

# EVENT FLYER.

UNIVERSITY OF BIRMINGHAM | BIRMINGHAM LAW SCHOOL

## The Future of Advance Decisions in Mental Health and Mental Capacity Law

Thursday 2 May 2019

Birmingham Law School, University of Birmingham

**PROGRAMME**

**12:30 – 1:30pm Lunch and Registration**
Senior Common Room, Birmingham Law School

**1:30 – 3:00pm Session 1: Contemporary Practice in Comparative Perspective**
Moot Court, Harding Building

**Professor Celia Kitzinger**, Cardiff University "Supporting People Who Want to Refuse Treatment in Advance of Losing Capacity: Report from the Coalface"

**Professor Samantha Halliday**, University of Huddersfield "Advance Decisions – Comparative Reflections upon the Promise and the Reality"

**Discussant:** Professor Rosie Harding, University of Birmingham

**Chair:** Magdalena Furgalska, University of Birmingham

**3pm – 3:30pm Refreshment Break**
Senior Common Room, Birmingham Law School

**3:30 – 5pm Session 2: Future Perspectives from Theory to Law Reform**
Moot Court, Harding Building

**Magdalena Furgalska**, University of Birmingham "Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law"

**Alex Ruck Keene**, 39 Essex Street and Kings College London, "Translating Theory into Practice – Advance Decision-making and Law Reform"

**Discussant:** Professor Jean McHale, University of Birmingham

**Chair:** Professor Rosie Harding, University of Birmingham

# APPENDIX 4: ADVANCE DECISIONS EVENT FEEDBACK FORM.

## Feedback Form

## The Future of Advance Decisions in Mental Health and Mental Capacity Law

*Please tick the most relevant box*

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| The event was well advertised | | | | | |
| I was kept informed about the event | | | | | |
| I received helpful joining instructions and my queries about the event were answered | | | | | |
| This event raised important questions about Advance Decisions | | | | | |
| The event was informative | | | | | |
| The event was relevant to me or my line of work | | | | | |
| I am satisfied with the location of the event | | | | | |
| Overall, I am satisfied with the venue and facilities | | | | | |
| The venue was easy to find | | | | | |
| I could see the presentations clearly | | | | | |
| I could hear the presentations properly | | | | | |
| The venue was accessible | | | | | |
| I was satisfied with the quality and variety of food provided | | | | | |
| I was satisfied with the speakers | | | | | |
| Time was used efficiently | | | | | |
| Organisers were approachable and friendly | | | | | |
| The event run smoothly | | | | | |

*Please let us know any comments you may have*

**Would you like to be kept informed about similar events in the future?**

Yes/No

**Would you be interested in taking part in future research about advance decisions?**

Yes/No

If you have answered yes to either of these questions, please provide your name, email address and organisation below:

Name:
Email:
Organisation:

By providing your details, you consent to the University of Birmingham processing this in accordance with the GDPR and the Data Protection Act 2018. We will not share your details with third parties. You can withdraw your consent at any time.

[ ] I understand the above data protection notice and consent to my personal data being used in this way.

# APPENDIX 5: NARRATIVE INTERVIEW SCHEDULE

**Dissertation title:** Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law.
**Topics:** Advance consent; mental health treatment; forced treatment; relationships; everyday life and mental health; doctor and patient relationship; safeguarding; support; legal mechanisms for decision making

## INTRODUCTION AND EXPLANATION ABOUT THE RESEARCH.

Explain the interview process and that the interview will be video recorded. Explain that the researcher is interested in hearing their story in their own words. Discussing and receiving consent. In this phase I will tell the participant the specific topics I am interested in: advance consent, advance decision, treatment/forced treatment, patient-doctor relationship, safeguarding, everyday life relationships.

## THE NARRATIVE.

The narrative will begin through the use of open broad questions. Non-verbal encouragements will be used by the researcher. Interviewee will not be interrupted unless there is a clear indication that the story has been finished or that a prompt is needed. The researcher will make mental/field notes of questions to pursue later/or during follow-up/second interview.

## QUESTIONING PHASE

Using participants' own language to fill in the gaps in their story or ask for more details for the most prominent/unclear parts of the story. This will be used purely to clarify context, events and not to ask for opinions/attitudes/why questions. Examples of questions used: 'what happened then?', 'when did this happen?', 'was anyone with you when this happened?'.

## CONCLUDING NARRATIVE INTERVIEWS

Explaining next steps – photo elicitation interviews if participants wish to take part, transcription, feedback, further input from the participants. Participant will be given opportunity to ask any questions here.

# APPENDIX 6: PHOTO-ELICITATION INTERVIEW SCHEDULE

**Dissertation title:** Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law.

**Topics:** Advance consent; mental health treatment; forced treatment; mental capacity; relationships; everyday life and mental health; doctor and patient relationship; safeguarding; support; legal mechanisms for decision making

**Introduction**

- **Thank the participant for agreeing to interview.** Overview of the topic. Answer any questions.
- **Overview of the interview** (format; length; audio-recording)
- **Important issues** (confidentiality; no right or wrong answers)
- **Signing of consent forms** and giving participants time to read through and sign as appropriate
- **Signing consent form for each photograph**

Themes:

1. **Reasons for choosing these photographs.** (Prompts: are they showing how your mental health has changed your life/influenced your life? Are these pertaining to your experiences of treatment).

2. **Asking participant to talk me through each photograph.** (Questions here will be dependent on the context of photos, previous narrative interview and to fill gaps in people stories: therefore themes below are indicative only)

3. **Experiences of mental health treatment.** (Prompts: [you told me about your experience of mental health treatment last time we met, upon reflection how do you feel about it?; experiences of other treatment, treatments that are helpful?)

4. **Experiences of treatment without consent.** (Prompts: confinement, forced feeding, Electro-convulsive therapy, medications, feelings/experiences, helpful/unhelpful**)**

5. **Mental health/treatment and relationships**. (Prompts: family or others as supporters/hindrance to recovery; how long episodes last; how quickly treatment eases symptoms; do you continue taking medication when relapsing)

6. **Mental health and relationship with the health system.** (Prompts: trusting doctor, social worker, nurse, specific person; improvements)

7. **Legal Mechanisms.** (Prompts: Lasting Powers of Attorney, Advance Decisions to Refuse Treatment, opinion on advance consent, issues of mental capacity, wishes regarding advance consent/decision).

8. **Any comments or questions which participant wishes to make.**

Conclusion:

- **Sum up the interview** (reiterate confidentiality; say how valuable participant's views were and what I got from the discussion).
- **Opportunity for participant to ask questions.**
- **Reviewing the consent form for each photograph to ensure participant's consent is informed.**
- **Thank the participant.**

# APPENDIX 7: LAY SUMMARY OF FINDINGS

## SUMMARY OF FINDINGS AND RECOMMENDATIONS

### *Project Title: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent to Mental Health Treatment*

I have been doing this research as part of my PhD at the University of Birmingham. If you have any questions about this summary or would like to know more, please get in touch with me, Magda Furgalska, via email: [redacted] After my PhD has been awarded, you will be able to access the full thesis on the University of Birmingham Repository Website. Alternatively, if you wish, I can email you a PDF version.

## INTRODUCTION: ADVANCE CONSENT TO MENTAL HEALTH TREATMENT

This project investigated the desirability of advance consent to mental health treatment based on the lived experiences of people who had previously received any mental health treatment. Advance consent to mental health treatment is a decision made by an individual to consent to a specific treatment for future instances when a person expects not to be able to make that decision themselves. This might be because of their symptoms or because the law would prevent the person from making this decision. Advance consent means that how future treatment is provided to a person is decided by them rather than others.

Currently, there is no provision in English law allowing people to make advance consent of this kind. The law provides for making legally binding Advance Decisions to Refuse Treatment in accordance with the Mental Capacity Act 2005. However, Advance Decisions to Refuse Treatment were designed with ‘physical’ health in mind and refusals of mental health treatment would not be valid once a person is involuntarily detained under the Mental Health Act 1983. This is because the law allows clinicians to override people’s wishes and treat individuals without their consent. Instead, people can make Advance Statements to specify their treatment preferences. However, the doctor is not legally required to follow wishes expressed in this way.

People with experiences of mental health treatment often report not having opportunities for making their own treatment-related decisions. Many people are subjected to coercive interventions, non-consensual treatment or treatment that has not been sufficiently informed. Ensuring timely and appropriate responses to people who experience mental ill-health or crises is essential.

## Why is it essential that legal research on this issue is conducted?

Mental health treatment is regulated heavily by the law. For example, the decision about whether to section an individual or allow them to be an informal inpatient of the mental health hospital is a decision that is made by relevant provisions of the Mental Health Act 1983. This law also allows doctors to treat people for their mental ill-health without their valid consent. Even when people are treated outside of a psychiatric context, the law regulates how much information they are given about their medication prescribed by a GP or other health professional. This suggests that people's mental health treatment experiences are also legal experiences, and how the law is experienced in the everyday lives of people who experience mental ill-health should be investigated.

Recognising the variety of people's needs and providing opportunities for decision-making is a matter of basic justice and so is finding new legal ways of empowering people who might require mental health treatment. I, therefore, set the following research aims:

- To understand people's experiences of mental health treatment.
- To determine whether advance consent to mental health treatment would be a desirable legal instrument.
- To help make recommendations for the law on how to ensure that people's decisions and needs are respected.

## Who did I speak to?

I conducted 21 interviews with 12 different participants between 2019-2020 to inform this project. This consisted of 12 narrative interviews in which I encouraged people to tell me their stories related to mental health. I then conducted 9 follow-up photo-elicitation interviews. For those follow-up interviews, people were asked (but this was not required) to prepare photographs which would help me understand their experiences better. I also asked more specific questions about participants' stories, advance consent, and mental health treatment generally.

I was interested in a wide range of experiences; therefore, whether interviewees had a specific diagnosis was not necessary. It was only important that they have sought/or were given mental health treatment previously and were willing to share their experiences, attitudes and opinions.

The number of interviews conducted is relatively small; therefore, I cannot claim that these findings can be generalised to all people with mental health treatment experiences. However, these in-depth interviews allowed me to gain a deeper understanding of people's experiences, what people value and what constituted negative factors in the provision of treatment.

All participants remain anonymous.

## FINDINGS

### What did people say about their treatment experiences?

As might be expected, the interviewees I spoke to had various experiences, some good and some bad. Participants often reflected that finding the right treatment is a very long process because mental health is individual, and even people with the same diagnosis might require different interventions and approaches, including non-medical approaches. Therefore, interviewees emphasised "self-knowledge", which means knowing one's experiences and having intimate knowledge about what is helpful and unhelpful for them when experiencing symptoms of mental ill-health.

There were, however, common themes as to what made these experiences positive or negative.

*Negative experiences of treatment were associated with:*

- Not being listened to and not having self-knowledge respected.
- Distrusting mental health professionals.
- Treatment decisions that do not appreciate the contexts of people's lives were received negatively by people (e.g., people may have dependents to look after or have other social or cultural needs).
- The effectiveness of treatment can be offset entirely by not including people in those decisions and not considering people's social contexts.
- Although some interviewees stated that coercive measures might be necessary for some instances and can be desirable for some people, others argued strongly against coercion. Coercion in this context included: being detained in the hospital, being forced to take medication or other treatment, not having any choice of treatments or alternatives to medical treatments, and not having opportunities to provide informed consent to treatment.
- Not having access to relational continuity of care. By relational continuity of care, I mean being able to see the same clinicians over a period of time. Many interviewees were frustrated by having to always see different people and having to repeat themselves to many people to receive help.

- Participants suggested that the clinical concept of insight means mere compliance with doctor’s advice or treatment.
- Side-effects of treatment also resulted in negative experiences.
- Everyday life stigma.

*Positive experiences of treatment were associated with:*

- Being able to participate in decision-making processes about treatment and having one’s input respected and valued.
- Receiving treatment that was effective in alleviating symptoms and provided in a way which respected one’s bodily integrity. However, effective treatment was also understood as encompassing needs other than medical needs. For instance, it was important for my participants that the treatment allowed them to feel and experience a variety of emotions appropriate to social situations.
- Having people’s life roles and life projects considered. For instance, when one of my participants was about to be sectioned, she explained to the doctor that she would be very worried about how this would impact her small child. The psychiatrist agreed not to section my participant and opted for home treatment. This resulted in a long-lasting supportive doctor-patient relationship and successful and positive treatment experiences.
- Access to various treatments: medications, therapies, and alternative treatments like hypnotherapies.
- Being supported in withdrawing from treatment and then restarting treatment. My participants generally agreed that they do not wish to take all treatments long-term, but only when needed. It is therefore important support is provided for withdrawing treatment and resuming it when needed.
- Having self-knowledge respected. Participants in this research suggested that they know well how they react to specific treatments, and this should form the basis of treatment decision-making.

## What did people think about Advance Consent?

Most people agreed that when well, they should be able to choose whether to make consent in advance to mental health treatment:

“I think it kind of [about] justice, but I would say that it’s more related to being free, being free to choose the treatment you want. ... there must be other ways to have it. So, I think that being included in your in your decision-making process is the most important thing because then you can think for yourself and say, I want this because I think it’s the best for me and not I want this because or and not the doctor is saying to you, this is the best. This is the best because it’s the best for most people. And you might not be most people. “

(Participant 3)

This was because of the following perceived benefits:

- It would enable people to exercise more autonomy.
- It would minimise the need for coercion. This is because advance consent could apply outside of the hospital setting and if followed some people may avoid hospitalisation.
- People would always be treated on their valid and informed consent.
- It would result in speedier access to treatment. People would not need to go through lengthy assessments, they would only be provided with the treatment they consented to and might be more likely to alert doctors (or others) when they need treatment knowing they would not be treated against their wishes. Interviewees also felt this would save resources.
- Advance consent could prevent deterioration of health.

To ensure that these benefits can materialize, interviewees suggested that advance consent should be legally binding so that it cannot be easily overridden. In addition, it was suggested by the majority that advance consent could only be made for treatment previously experienced by an individual. This is to ensure that the treatment is safe and appropriate and that the consent is fully informed. There were suggestions from others who thought advance consent could be made by people who have a family history of mental illness or those who have researched their options.

My participants thought that advance consent should not be limited to medical treatments and include psychological and alternative treatments that people found helpful. In any instance, it must always be voluntary.

Some interviewees suggested that people in mental health crises might need to have access to a safe place, but they should not be subjected to coercive interventions whilst in that safe place.

Sometimes the law allows for the detention of people in mental health crises in a “place of safety” for 72 hours, which can include police stations. Participants with such experiences stated that police stations are inappropriate for this purpose and that there should be a reconsideration of what counts as a “safe place”.

However, others did not agree that advance consent is a good idea. One participant thought that instead of advance consent, they should always retain their decision-making ability in all circumstances, therefore did not support the idea. Another participant did not think that advance consent would be a good idea because they have not experienced an effective treatment or intervention.

### When should advance consent come into effect?

This question did not provide straightforward findings. Some interviewees felt that it should come into effect as soon as an individual is sectioned. Others thought it should come into effect as soon as people begin to relapse. Participants suggested that everyone knows their triggers, and these could also be specified within their/an advance consent document.

Some participants brought up the concept of mental capacity. Mental capacity is a legal test which assesses people's decision-making ability. You have mental capacity if you can:

- Understand the information given
- Retain that information
- Use or weigh it to make a decision
- Communicate your decision

In the context of physical health, advance decisions come into effect when a person loses their mental capacity. However, participants suggested (in line with research in this area) that people with mental health treatment needs retain their mental capacity in most situations. Therefore, if advance consent came into effect when people lose their mental capacity, that would limit its scope. For advance consent to be empowering it needs to apply before the loss of mental capacity.

### Should advance consent preclude changes of mind?

Much of the debate on advance consent relates to what I call the "changes of mind dilemma". A change of mind dilemma is a situation whereby someone makes an advance consent and later, at the time when it is supposed to come into effect, attempts to revoke it. In the follow-up interviews, I asked my participants whether such revocation should be allowed.

My participants thought that changes of mind in such a situation should not be permitted. There was a range of reasons for this:

- Some participants felt that the entire point of making an advance consent is so that you cannot change your mind at the time it is supposed to apply. Below are some quotes from my participants on the changes of mind dilemma:

> "Of course, people with mental health problems get paranoid. They might think someone wants to poison them, for instance. I think, that if I had made a living will and then I got paranoid and delusional and ended up in a hospital and said "well, I don't want it anymore, I've changed my mind" and they [doctors] listened to me, I think I would be really cross. I think I would turn around and say "look, we agreed in advance when I was in my right mind, when I spent all this time considering this decision ... that you would treat me and you didn't". ... Yes, I'd be cross. I would be really cross that nobody respected what I agreed when I was in my right mind."

(Participant 10)

"The whole idea I think of advance consent is that you've made the advance consent so we can't change it. So that's the whole idea of doing it. So no, that's it. If you can refuse it, then what's the point of having advance consent in the first place?"

(Participant 12)

Therefore, advance consent which precludes changes of mind seen as better in ensuring that people's choices are followed. Moreover, some people suggested that they may wish to make advance consent specifically in anticipation of themselves changing their minds later.

• Participant felt it would still be better to be treated in accordance with their advance consent than to be subjected to coercive measures or treatment they never consented to or experienced previously.

### When should advance consent be revoked?

Interviewees felt that they should be able to revoke their advance consent at any time outside of situations when it is supposed to apply.

Some participants recognized that it may not always be desirable to follow advance consent because there might be a change in a person's medical history. If such change exists, then advance consent should not be valid.

Some participants also suggested that when changes of mind arise at a material time, a nominated trusted person should be consulted about those to help decide whether advance

consent should be revoked. Suggestions included family members or independent advocates. However, it was also important for others that such persons are not involved in advance consent at any point.

### What kinds of treatment decisions should advance consent involve?

- Medications
- Psychological treatments
- Alternative treatments/therapies
- There was a suggestion that advance consent might include consent to the hospitalisation in situations where people may need access to a "safe place".

## Findings: Concluding Summary

Overall, advance consent to mental health treatment appears to be a desirable legal instrument, provided it is voluntary and that people's wishes are well safeguarded. There is more research needed to explore what safeguards are appropriate. For instance, more work is needed to understand the nominated trusted person framework for supporting an individual's advance consent. Finally, future legal research should also investigate how to develop advance consent in line with all relevant human rights considerations.

As some participants suggested that how decisions are made in a psychiatric context has a lot to do with "insight", it is important that more research is conducted to investigate whether insight is used to deny people's legal rights.

Advance consent could potentially improve people's experiences of mental health treatment but so much more is needed to fully achieve that. It requires a commitment to change from those who provide mental health treatment and an allocation of appropriate resources to facilitate this change. The change is about a shift towards better recognition of people's needs that are likely to extend between immediate medical responses. Finally, it is important that changes in mental health care are underpinned by people's experiences of it as it is their wellbeing that is at the very heart of these discussions and considerations.

## RECOMMENDATIONS

1. Advance consent should be limited to treatments that people have previously experienced to ensure their consent is fully informed.
2. The law should recognise legally binding advance consent to mental health treatment and ensure that it is properly safeguarded. Advance consent must always be voluntary and be entirely a decision of an individual.
3. Advance consent should come into effect at a time that an individual specified when they were making their advance consent ('a material time'). It should preclude changes of mind at that time. An individual should be able to revoke their advance consent at any time other than the material time.
4. Any framework for advance consent should also recognise people's right to make advance refusals of treatment.
5. Police stations should not be used as a "place of safety" for people who experience mental health crises.
6. I do not recommend for the law introduce Advance Consent to Confinement (which is to hospitalisation only without being able to safeguard treatment preferences) if it means that people can still be treated without their consent while in a hospital.
7. There is much to learn from jurisdictions which allow for some form of advance consent. These should be considered when thinking about introducing advance consent into English law.

## Acknowledgements

I want to thank all my participants for candidly sharing their stories with me. Thank you for welcoming me into your homes or coming out to meet with me, for cups of tea/coffee, cakes and most importantly, for your time, patience, and honesty.

Thank you.

# APPENDIX 8: CONSENT FORM – NARRATIVE INTERVIEW

**Title of project: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law.**
**Name of researcher:** Magdalena Furgalska, [redacted]

Please tick box:

| | | Yes | No |
|---|---|---|---|
| 1 | I confirm that I have read and understand the information sheet for the above study entitled ‘Narrative Interview Information Sheet’ and have had the opportunity to ask questions. | ☐ | ☐ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time up to 12 weeks after this interview. | ☐ | ☐ |
| 3 | I agree to take part in this study. | ☐ | ☐ |
| 4 | I understand that I can refuse to answer any question or omit anything from my story I am not happy to share. | ☐ | ☐ |
| 5 | I agree to my interview being digitally audio recorded. | ☐ | ☐ |
| 6 | I understand that data collected will be treated confidentially. | ☐ | ☐ |
| 7 | I understand that the data collected about me during this study will be anonymised before it is used in conference presentations or publications. | ☐ | ☐ |
| 8 | I agree that anonymous quotes from my interview can be used in conference presentations and publications. | ☐ | ☐ |
| 9 | I agree to allow the data collected to be used in future research projects. | ☐ | ☐ |
| 10 | I agree that audio recordings may be confidentially stored until the end of this project (approx. March 2023). | ☐ | ☐ |
| 11 | I agree that an anonymised transcript of the interview may be confidentially stored for 10 years. | ☐ | ☐ |
| 12 | I agree that an anonymised transcript of the interview may be offered to the UK Data Service for archiving. | ☐ | ☐ |

| | | |
|---|---|---|
| ____________________ | ____________________ | ____________________ |
| Name of participant | Date | Signature |
| ____________________ | ____________________ | ____________________ |
| Researcher | Date | Signature |

1 for Participant, 1 for Researcher

# APPENDIX 9: CONSENT FORM – PHOTO-ELICITATION INTERVIEW

**Title of project: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law.**
**Name of researcher:** Magdalena Furgalska, [redacted]

Please tick box:

| | | Yes | No |
|---|---|---|---|
| 1 | I confirm that I have read and understand the information sheet for the Above study entitled 'Photo-elicitation Interview Information Sheet' and have had the opportunity to ask questions. | ☐ | ☐ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time up to 12 weeks after this interview. | ☐ | ☐ |
| 3 | I agree to take part in this study. | ☐ | ☐ |
| 4 | I understand that I can refuse to answer any question or omit any Information. | ☐ | ☐ |
| 5 | I understand that I can refuse to share any photographs I am not comfortable to share. | ☐ | ☐ |
| 6 | I agree to my interview being digitally audio recorded. | ☐ | ☐ |
| 7 | I understand that data collected will be treated confidentially. | ☐ | ☐ |
| 8 | I understand that the data collected about me during this study will be anonymised before it is used in conference presentations, publications. | ☐ | ☐ |
| 9 | I agree that anonymous quotes from my interview can be used in conference presentations and publications. | ☐ | ☐ |
| 10 | I agree to allow the data collected to be used in future project.<br>. | ☐ | ☐ |
| 11 | I agree that audio recordings may be confidentially stored until the end of this project (Approx. March 2023). | ☐ | ☐ |
| 12 | I agree that an anonymised transcript of the interview may be confidentially stored for 10 years. | ☐ | ☐ |
| 13 | I agree that an anonymised transcript of the interview may be offered to the UK Data Service for Archiving. | ☐ | ☐ |

| | | |
|---|---|---|
| Name of participant | Date | Signature |
| Researcher | Date | Signature |

1 for Participant, 1 for Researcher

# APPENDIX 10: PARTICIPANT INFORMATION SHEET – NARRATIVE INTERVIEW

**Project title: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law**
**Researcher**: Magdalena Furgalska (PhD Student), [redacted]
Supervisors: Professor Rosie Harding, [redacted] Dr Emma Oakley, [redacted]

*This research has been approved by the University of Birmingham Humanities and Social sciences ethics committee.*

Invitation

You are being invited to take part in this research because you self-identify as a psychiatric survivor. Before you decide to do so, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The aim of this research is to explore:

> *How desirable is advance consent to mental health treatment based on the lived experiences of psychiatric survivors?*

People with mental health problems have the right to equal treatment under the law. This includes the right to make your own decisions. This research is interested in finding out whether psychiatric survivors would like the law to provide them with an option to decide what mental health treatments they would like to undergo to in the future. I refer to this mechanism as Advance Consent to Mental Health Treatment. The data gathered will therefore be analysed to identify what people with experiences of mental health treatment think about advance consent to mental health treatment. Learning from the information gathered, I will be aiming to propose policy and law reform recommendation in the area of mental health law. This research forms the basis of my PhD in Law and is a response to the growing interest into increasing choice and treatment options for people who require mental health treatment. I am simply interested in finding out what your experiences say about mental health treatment in England and Wales and how these experiences could be improved in the future for people like yourself.

**Who can take part?**

**Anyone aged 18 or over who has an experience of receiving treatment for mental health in England and/or Wales. You may have received treatment for (but not limited to) any**

**of the following: anxiety, bipolar disorder, borderline personality disorder, depression, eating disorders, episode of psychosis, schizophrenia.**

Do I have to take part?

No. It is your choice whether to take part or not.

What will happen if I take part?

You will be asked to meet with the researcher at your preferred location (your home, local café, University of Birmingham), date and time. I will record each interview using a small recording device. I am likely to take some notes whilst you are speaking. This is nothing to worry about – these might be questions that I may wish to ask you later. Once the recording has taken place it will be transcribed and then analysed to find any themes, patterns or useful information that will inform the outcomes of my project.
A narrative interview means that I will ask you to tell me your story of mental health. This interview should take about an hour. It is okay if you need more time to tell me your story as long as this is also okay with you.

What are the benefits of taking part?

**Help me understand experiences of mental health**

- **Help me make recommendations about how to better help people like you to make decisions**
- **Tell your story**

What are the risks of taking part?

Sometimes, talking about things that are difficult can make people upset. If you feel upset, you can stop at any time. I will make sure that you know how to seek support to feel better.
If you say anything that makes me think that you or somebody else might be in serious danger, I will need to report it to relevant bodies. If this happens, I will talk to you first.

What if I change my mind about taking part?

If you would like to withdraw from the study you may do so any time during the interview or up to 12 weeks after the interview. If you wish for your data to be removed from the study and not used for the research you can email me at: [redacted] You do not need to state why you wish to withdraw. I will send you confirmation by email that I have destroyed all of your data (deleting all electronic copies and shredding any paper forms). If you do not have access to email you may contact me via telephone on: XXX-XXXX.
Nothing will happen to you if you change your mind.

How will information about me be used?

The interview will be audio recorded using a digital recorder. This allows me to listen to the interview later and transcribe it. The transcribed interview will be anonymised. This means that you and any people you mention will be given pseudonyms. This might also be the case with places and organisations if these include information that could potentially identify you. The purpose of anynomisation is to protect you and ensure nobody will be able to tell that you took part.

I will analyse your transcript to inform my thesis. Examples from the story you tell me will be used as evidence of lived experiences of mental health and mental health treatment. The findings from this research may also be published in journal articles, books, internet publications and through conference presentations and talks.
At the end of the project, I will send you an executive summary of my findings. If you wish to read the thesis you full, you will also be given access to it.

### Who will have access to my data?

Only the research team will have access to the original data. The research team includes myself and my supervisors.

### How will you protect my confidentiality and anonymity?

In addition to anonymising transcripts, the recordings will be stored on a password protected laptop, University server and University owned cloud system. These will be disposed of at the end of the project (approximately September 2022).
All signed consent forms and participant information sheets will be scanned and stored digitally in an encrypted folder on a password protected laptop.
In accordance with University guidelines, anonymised transcripts will be stored securely and kept for 10 years after the research has concluded for use in the future. If you agree to it, the data will also be offered to the UK Data Service.  All confidentiality and anonymity rules will continue to apply to the data.
Data collected may be shared in an anonymised form to allow reuse by the research team and other third parties. These anonymised data will not allow any individuals to be identified or identifiable.

### Who is funding and organising this research?

The Economic and Social Research Council Midlands Graduate School Doctoral Training Partnership fund this research project. The research is being carried out and organised by researchers at Birmingham Law School, University of Birmingham.

### What is there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to me and I will do my best to answer your questions. Please contact me by Email: [redacted] If you are unable to contact me by email then you may call me on XXXX-XXXX. Alternatively, if you do not wish to contact me you may contact Professor Rosie Harding using the email: [redacted] or telephone: XXXX-XXXX, or contact via post at: Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance officer, Head of Research Governance and Ethics, via post at Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

If you have any questions, you can contact me by phone on XXXX-XXXX or by email on [redacted]

# APPENDIX 11: PARTICIPANT INFORMATION SHEET – PHOTO-ELICITATION INTERVIEW

**Project title: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law**
**Researcher**: Magdalena Furgalska (PhD Student), [redacted]
Supervisors: Professor Rosie Harding, [redacted], Dr Emma Oakley, [redacted]

*This research has been approved by the University of Birmingham Humanities and Social sciences ethics committee.*

Invitation

You are being invited to take part in this interview because you have taken part in the narrative interview with me. Before you decide to do so, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The aim of this research is to explore:

> *How desirable is advance consent to mental health treatment based on the lived experiences of psychiatric survivors?*

People with mental health problems have the right to equal treatment under the law. This includes the right to make your own decisions. This research is interested in seeing whether psychiatric survivors would like the law to provide them with an option to decide what mental health treatments they would like to undergo to in the future. I refer to this mechanism as Advance Consent to Mental Health Treatment. The data gathered will therefore be analysed to identify what people with experiences of mental health treatment think about advance consent to mental health treatment. Learning from the information gathered, I will be aiming to propose policy and law reform recommendations in the area of mental health law.
This research forms the basis of my PhD in Law and is a response to the growing interest into increasing choice and treatment options for people who require mental health treatment. I am simply interested in finding out what your experiences say about mental health treatment in England and Wales and how these experiences could be improved in the future for people like yourself.

**Who can take part?**
**Anyone who already took part in a narrative interview for this research project.**

Do I have to take part?
No. It is your choice whether to take part or not.

What will happen if I take part?

You will be asked to meet with the researcher again at your preferred location (your home, local café, University of Birmingham), date and time. I will record each interview using a small recording device. I am likely to take some notes whilst you are speaking. This is nothing to worry about – these might be questions that I may wish to ask you later. Once the recording has taken place it will be transcribed and then analysed to find any themes, patterns or useful information that will inform the outcomes of my project.

Prior to the interview, I will ask you to prepare a few photographs (3-8) which help you communicate your experiences and feelings about your mental health journey further. These can be physical or digital photographs. You can use any photographs you already have or you are welcome to take some photographs for the purpose of this interview. Below is a guide which may help you identify photographs you may wish to share:

- Photographs which represent your experiences/feelings about mental health treatment
- Photographs which represent your experiences/feelings about treatment without consent
- Photographs which represent anything that you find helpful in your mental health journey
- Photographs which represent aspects of your journey that could be improved upon
- Photographs which represent important relationships in your mental health journey
- Anything you wish to expand on from what you told me during narrative interview
- Anything that represents something of importance to you and your mental health

The main purpose of using photographs is to allow you to communicate your experiences at a deeper level and for me to understand these experiences better and from your perspective. I may also ask you some follow up questions from the narrative interview. With your permission, I will scan your photographs or take photographs of these using a camera. These photographs might be used in my thesis, publications, or conference talks. However, you can choose to agree to some of these only, or not agree to any of these additional uses of photographs. I will discuss these options with you prior to the interview and immediately after so that you can decide which uses of a particular photograph you agree/disagree to. If you allow me to use your photographs in various ways, any identifying information (like faces, street names, locations etc) will be blurred to protect your privacy.
This interview will take about an hour. It is okay if you need more as long as this is also okay with you.

What are the benefits of taking part?

- **Help me understand experiences of mental health**
- **Help me make recommendations about how to better help people like you to make decisions**
- **Tell your story**

### What are the risks of taking part?

Sometimes, talking about things that are difficult can make people upset. If you feel upset, you can stop at any time. I will make sure that you know how to seek support to feel better.
If you say anything that makes me think that you or somebody else might be in serious danger, I will need to report it to relevant bodies. If this happens, I will talk to you first.

### What if I change my mind about tasking part?

If you would like to withdraw from the study you may do so any time during the interview or up to 12 weeks after the interview. If you wish for your data to be removed from the study and not used for the research you can email me at: [redacted]. You do not need to state why you wish to withdraw and I will send you confirmation by email that I have destroyed all of your data (deleting all electronic copies and shredding any paper forms). If you do not have access to email you may contact me via telephone on: XXX-XXXX.
Nothing will happen to you if you change your mind.

### How will information about me be used?

The interview will be audio recorded using a digital recorder. This allows me to listen to the interview later and transcribe it. The transcribed interview will be anonymised. This means that you and any people you mention will be given pseudonyms. This might also be the case with places and organisations if these are information that could potentially identify you. The purpose of anynomisation is to protect you and ensure nobody will be able to tell that you took part.

Examples from your answers and the story you tell me will be used as evidence of lived experiences of mental health and mental health treatment. The findings from this research may also be published in journal articles, books, internet and through conference presentations and talks.

We will discuss prior to the interview and after the interview ways in which you allow me / not allow me to use your photographs.

At the end of the project, I will send you an executive summary of my findings. If you wish to read the thesis you full, you will also be given access to it.

### Who will have access to my data?

Only the research team will have access to the original data. The research team includes myself and my supervisors.

### How will you protect my confindentiality and anonymity?

In addition to anonymising transcripts, the recordings will be securely stored on a password protected laptop, University server and University owned cloud system. These will be disposed of at the end of the project (approximately September 2022).

All signed consent forms and participant information sheets will be scanned and stored digitally in an encrypted folder on a password protected laptop.

In accordance with University guidelines, anonymised transcripts and photographs will be stored securely and kept for 10 years after the research has concluded for use in the future.
If you agree to it, the data will also be offered to the UK Data Service. All confidentiality and anonymity rules will continue to apply to the data. Archived data collected may be shared in an anonymised form to allow reuse by the research team and other third parties. These anonymised data will not allow any individuals to be identified or identifiable.

Who is funding and organising this research?

The Economic and Social Research Council Midlands Graduate School Doctoral Training Partnership fund this research project.
The research is organised and carried out by researchers from Birmingham Law School, University of Birmingham.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the me and I will do my best to answer your questions. Please contact me by Email: [redacted]
If you are unable to contact me by email then you may call me on XXXXX. Alternatively, if you do not wish to contact me you may contact Professor Rosie Harding using the email: [redacted] or telephone: XXXXXX, or contact via post at: Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance officer, Head of Research Governance and Ethics, via post at Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

# APPENDIX 12: SUPPORT INFORMATION SHEET

If you feel that you need mental health support following this interview, here is a list of some helplines which can offer this help for free:

Call NHS on 111. If you urgently need medical help or advice but it is not a life-threatening situation. It is free to call.
Call Samaritans on 116 223: If you are thinking about ending your life or are concerned about someone who may be, you can call for help any time of day or night. It's a free call.

Anxiety UK: Charity providing support if you have been diagnosed with an anxiety condition.
Phone: 03444 775 774 (Monday to Friday, 9.30am to 5.30pm)
Website: www.anxietyuk.org.uk

Bipolar UK: A charity helping people living with manic depression or bipolar disorder.
Website: www.bipolaruk.org.uk

Men's Health Forum: 24/7 stress support for men by text, chat and email.
Website: www.menshealthforum.org.uk

Mental Health Foundaiton: Provides information and support for anyone with mental health problems or learning disabilities.
Website: www.mentalhealth.org.uk

Mind: Promotes the views and needs of people with mental health problems.
Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)
Website: www.mind.org.uk

No Panic: Voluntary charity offering support for sufferers of panic attacks and obsessive compulsive disorder (OCD). Offers a course to help overcome your phobia or OCD.
Phone: 0844 967 4848 (daily, 10am to 10pm)
Website: www.nopanic.org.uk

Hearing Voices Network: Information about strategies to cope with hearing voices and local support groups.
0114 271 8210
hearing-voices.org
Beat Eating Disorders: Information and helpline about eating disorders.
Beateatingdisorders.org.uk
08088010677

# APPENDIX 13: CONSENT FORM – INDIVIDUAL PHOTOGRAPHS

**Title of project: Achieving Social Justice for Psychiatric Survivors: Capabilities and Advance Consent in Mental Health Law.**
**Name of researcher:** Magdalena Furgalska, [redacted]

CONSENT FORM FOR PHOTOGRAPH NUMBER …

Please tick box:

| | | Yes | No |
|---|---|---|---|
| 1 | I confirm that I understand that the main purpose of using this photograph is to elicit my experiences and stories. | ☐ | ☐ |
| 2 | I have chosen this photograph because I am comfortable to share it. | ☐ | ☐ |
| 3 | I understand that I can refuse to use this photograph during an interview if I am no longer comfortable with sharing it. | ☐ | ☐ |
| 4 | I agree for the researcher to scan this photograph using a camera. | ☐ | ☐ |
| 5 | I agree for this photograph to be used in presentations. | ☐ | ☐ |
| 6 | I agree for this photograph to be used in publications. | ☐ | ☐ |
| 7 | I agree for this photograph to be used in the researcher's PhD thesis. | ☐ | ☐ |
| 8 | I agree for this photograph to be used in future research projects. | ☐ | ☐ |
| 9 | I understand that if I agree to any of the statements 5-8 that identifying information will be blurred (faces, signs, location etc). | ☐ | ☐ |
| 10 | I understand that I can withdraw my consent to any of the above uses for this photograph up to 12 weeks after this interview. | ☐ | ☐ |
| 12 | I agree to this photograph being securely stored for 10 years after the research is completed. | ☐ | ☐ |

Any other consent issues/requests (such as if you said no to no.12 when would you like your photograph to be destroyed)

Name of participant　　Date　　Signature

| | | |
|---|---|---|
| ______________________ | ____________________ | ______________________ |
| Researcher | Date | Signature |

1 for Participant, 1 for Researcher