# HOW COUPLES EXPERIENCE POSTPARTUM PSYCHOSIS

## Volume I

**By Laura Sian Porter**

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Department of Clinical Psychology
School of Psychology
The University of Birmingham
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# OVERVIEW

## Volume I

Volume I is comprised of three chapters. The first chapter is a meta-analysis of the reliability of the Calgary Depression Scale for Schizophrenia, focusing on its internal consistency and inter-rater reliability. The second chapter is an empirical paper exploring how couples experience an episode of postpartum psychosis in relation to the mother being admitted to a Mother and Baby Unit. The third chapter contains two publication dissemination documents, in the form of press releases.

## Volume II

Volume II contains four Clinical Practice Reports (CPRs) and a one-page summary of an orally presented CPR. To maintain client confidentiality and anonymity, names and personally identifiable information have been changed.

The first CPR formulates Tariq’s emotional difficulties from a cognitive-behavioural and systemic approach. The second CPR presents a service evaluation evaluating how young people and their carers experienced the transition to adult mental health services from a community learning disability team for young people.

The third and fourth CPRs report the assessment, formulation, intervention and evaluation of an individual client, primarily using a cognitive-behavioural approach. CPR three presents the case of Arthur, a 75-year-old male experiencing low mood and suicidal ideation. CPR four presents the case of James who was experiencing low self-esteem.

The fifth CPR summarises 10-year-old Lily's experiences of anxiety. The single-case design is outlined alongside the assessment, formulation, intervention and evaluation that was completed.

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# CHAPTER ONE: LITERATURE REVIEW

## A META-ANALYSIS OF THE RELIABILITY OF THE CALGARY DEPRESSION SCALE FOR SCHIZOPHRENIA

# ABSTRACT

**Background:**
Individuals with schizophrenia experience positive and negative symptoms. A challenge for clinicians is distinguishing depressive symptoms from negative symptoms of schizophrenia. The Calgary Depression Scale for Schizophrenia (CDSS) was developed for this purpose and is widely used within clinical practice and research. It is important to know the measure's reliability to establish its suitability for such contexts. No review has previously explored the CDSS' reliability across multiple studies using advanced statistical means.

**Objectives:**
This meta-analysis aimed to quantify the CDSS' internal consistency, inter-rater reliability (IRR) and test-retest reliability.

**Method:**
A systematic literature search was conducted across three databases (PsycINFO, Medline and PubMed) to find articles reporting on the CDSS' reliability. 1050 articles were identified in total, including 101 duplicates. Articles were screened against the inclusion and exclusion criteria, resulting in 910 being excluded. Data was extracted from the remaining 39 studies. Overall meta-analytic effects were calculated, and for internal consistency and IRR coefficients subsequent analyses explored between-study variation. The small test-retest reliability dataset limited analysis.

**Findings:**

The internal consistency meta-analytic effect was 0.83 (95% CI: 0.82-0.84). Higgins $I^2$ indicated an acceptable level of variation between the primary studies' alpha estimates. This suggests all items in the CDSS are measuring the same construct (i.e. symptoms of depression). The IRR meta-analytic effect was 0.88 (95% CI: 0.86-0.91), with Higgins $I^2$ indicating high levels of heterogeneity. This was not deemed problematic variance as it is within levels expected for psychometric measures and, therefore, considered acceptable for this literature. This reflects high level of agreement between different raters when using the CDSS on the same client.

**Conclusions:**

This review suggests the CDSS has good internal consistency and excellent IRR. It can, therefore, be used with confidence by clinicians and researchers. Further research regarding test-retest reliability would develop understanding of its psychometric properties.

# INTRODUCTION

## Schizophrenia

Schizophrenia is categorised as a psychotic mental illness and falls within the 'Schizophrenia Spectrum and Other Disorders' section of the Diagnostic and Statistical Manual of Mental Disorders (5th edition; APA, 2013). It is associated with a range of symptoms, typically separated into positive and negative symptoms. Positive symptoms are associated with the individual's perception or interpretation of stimuli being different from others, alongside difficulties distinguishing their thoughts and ideas from reality. They include hallucinations, delusional beliefs and disordered thinking; these are often accompanied by feelings of emotional distress. Negative symptoms include loss of motivation, apathy, impaired concentration, flattening of emotions and reduced speech (Cuesta, Basterra, Sanchez-Torres & Peralta, 2009).

## Controversy around schizophrenia as a diagnosis

Over the years, the diagnostic nature of schizophrenia has been the source of much debate (BPS, 2017). This has included consideration of the value of the concept of schizophrenia itself, particularly in terms of viewing it as an 'illness.' This relates to the occurrence of psychotic experiences in individuals who are not requiring help (i.e. 'not ill' or posed difficulties by such experiences) but also to the transitory nature of some individuals' psychotic experiences and the multiple causes of psychotic experiences (e.g. trauma or deprivation) (BPS, 2017). Two key areas of discussion regarding this controversy include how psychosis is best conceptualised and the value of the concept of negative symptoms, particularly when contrasted with depressive symptoms. Each will be discussed in turn.

The literature captures an ongoing debate as to whether it is more appropriate to understand symptoms of psychosis using categorical or dimensional approaches. A review of studies exploring a dimensional classification found four dimensions that occurred repeatedly and suggested these are best suited for describing the construct of psychosis (Potuzak, Ravichandran, Lewandowski, Ongür & Cohen, 2012). In addition to the positive and negative components traditionally represented in diagnostic frameworks of schizophrenia, affective and disorganisation dimensions were identified. There was some variation across the studies in the review regarding the affective dimension, in that some present it as one dimension inclusive of depressive and manic symptoms, whereas other studies propose depression and mania as separate factors. The notion of separate factors is in line with Boks, Leask, Vermunt and Kahn's (2007) factor analysis. There was, however, agreement across the studies that there is a significant mood component, regardless of co-occurring positive and/or negative symptoms (Potuzak et al., 2012). It is widely accepted within the literature that mood disturbances are often observed alongside a diagnosis of schizophrenia, with individual variation in the experience of negative symptoms (Rector, Beck & Stolar, 2005; van Os et al., 2000). This can include whether they are experienced concurrently or independently from the psychotic symptoms (Birchwood, Iqbal, Chadwick & Trower, 2000).

Although it has been acknowledged that affective symptoms may occur alongside psychotic experiences, there are different views of the causes (e.g. Hirsch, 1982; Siris et al., 1988). Birchwood (2003) proposed different pathways through which emotional dysregulation can arise in individuals with psychosis. This included low mood as a maladaptive response to the positive psychotic symptoms or resulting from using dysfunctional coping mechanisms and/or maladaptive schemas, in response to psychotic symptoms, due to early-life trauma. Research has also found that depressive symptoms can contribute to the on-going maintenance of negative symptoms (Sarkar, Hillner & Velligan, 2015).

There is also a body of evidence that suggests categorical and dimensional approaches are compatible and complementary (Peralta & Cuesta, 2007). This includes affective symptoms being found in individuals diagnosed with both affective and non-affective psychoses, but also considering the different stages of psychotic disorders and the importance of longitudinal assessments (Peralta & Cuesta, 2007). Using these approaches together is seen as helpful through capturing both the absence/presence of symptoms as well as symptom severity (van Os, Hanssen, Bijl & Ravelli, 2000). This combined approach is suggested as useful for acknowledging the presence of psychotic experiences as distributed throughout the population regardless of help-seeking status (BPS, 2017; van Os et al., 2000).

One key clinical aspect is the challenge of distinguishing between negative symptoms of schizophrenia (i.e. difficulties with motivational state) and depression (i.e. difficulties with pervasive low mood). A recent meta-analytic review found an association between higher rates of negative symptoms and higher rates of depressive symptoms (Edwards, Garety & Hardy, 2019). This is important given that the presence of depressive symptoms is associated with a poorer prognosis and an increased prevalence of suicide, compared to those with a diagnosis of schizophrenia not displaying depressive symptoms (Buckley, Miller, Lehrer & Castle, 2009; Conley, Ascher-Syanum, Zhu, Faries & Kinon, 2007; Upthegrove, Marwaha & Birchwood, 2017).

Regarding negative symptoms, they have been found to be associated with functional outcomes of those diagnosed with schizophrenia (Foussias & Remington, 2010). As mentioned previously, negative symptoms are considered a separate factor (i.e. distinct from positive symptoms, affective symptoms and disorganisation). There is, however, consideration within the literature as to whether negative symptoms are a unitary or multidimensional construct (Blanchard & Cohen, 2006). A growing body of evidence supports a two-factor structure, comprising diminished expression and amotivation (e.g. Blanchard & Cohen, 2006; Foussias & Remington, 2010; Messinger et al., 2011). Diminished expression is associated with affective flattening and poverty of speech. Amotivation is more widely debated, with research questioning whether the nature of symptom is best captured by the term anhedonia or amotivation. The literature tends towards amotivation, given the deficit observed is associated with impairments within anticipatory pleasure and goal-directed behaviour, with this considered to impact the individual’s capacity to express emotion (Foussias & Remington, 2010). Research outlines different types of negative symptoms including primary, persistent, and transient (Ahmed, Strauss, Buchanan, Kirkpatrick & Carpenter, 2015).

What is apparent from this literature, however, is that it is important to be able to identify signs of affective dysregulation (e.g. low mood) in individuals with a diagnosis of schizophrenia. This enables clinicians to distinguish between extrapyramidal, negative, and depressive symptoms, which can overlap. This distinction is considered important for various reasons. Blanchard and Cohen (2006) suggest that the approach to assessing individuals with a diagnosis of schizophrenia is influenced by whether negative symptoms are a unitary or multidimensional construct. Similarly, the conceptualisation and understanding of negative symptoms will inform the approach to intervention. For example, Upthegrove et al. (2017) suggest that being able to assess depressive symptoms accurately may enable affective symptoms to be targeted early which could reduce the occurrence of negative symptoms. In addition, Krynicki, Upthegrove, Deakin and Barnes (2018), note that enhancing the understanding of the underlying phenomenology through clearer assessment will also help identify treatment targets. This is in relation to their systematic review suggesting some symptoms relate more to depression (e.g. low mood, suicidal ideation and pessimism), some more to negative symptoms (e.g. alogia and blunted affect) and some as common to both (e.g. anhedonia, avolition and anergia).

## The Calgary Depression Scale for Schizophrenia (CDSS)

The Calgary Depression Scale for Schizophrenia was developed as a specific measure of depression in individuals with a diagnosis of schizophrenia (Addington, Addington and Schissel, 1990). It was developed as existing measures of depression were considered unsuitable for individuals with a diagnosis of schizophrenia. This was because existing measures were developed to assess depression in individuals diagnosed with non-psychotic illnesses (Addington, Addington & Maticka-Tyndale, 1993). These tools were, therefore, not developed for discriminating depressive symptoms from negative symptoms observed in schizophrenia. The lack of an appropriate measure contributed to difficulties in capturing depressive symptoms in these individuals.

The CDSS was developed by Addington et al. (1990) with consideration of two existing scales, namely the Hamilton Depression Rating Scale (Hamilton, 1960) and the Present State Examination (Wing, Cooper & Sartorious, 1974). The CDSS assesses the level of depression in individuals with a diagnosis of schizophrenia. It distinguishes between depression and the positive and negative symptoms present in schizophrenia (Addington, Addington & Maticka-Tyndale, 1994). The CDSS is suitable for individuals in the acute and residual stages of schizophrenia and is sensitive to change in presentation over time (Addington et al., 1993). The 9-item scale (see Appendix A) is completed by clinicians experienced in working with individuals diagnosed with schizophrenia. Items 1-8 are rated via interview to assess the presence of symptoms over the past two weeks. The final item's rating is dependent on the interviewer's observations throughout the interview (Addington et al., 1993). Since its development, the CDSS has been translated into different languages, with 44 language variants in existence.

## Reliability

Reliability of a measure refers to its level of consistency, with different types of reliability existing (Price, Jhangiani & Chang, 2015). A measure's reliability is important to know to establish the suitability of the tool for clinical and research purposes. Measures with poor reliability may produce unstable or confounded results. This can contribute to misleading study outcomes due to increasing the level of error variance, which can reduce the measure's statistical power and increase the potential of a type two error (Henson, 2001; Muller & Szegedi, 2002).

Several types of reliability can be considered when exploring a measure's psychometric properties. These enable consistency to be assessed across items, between raters and over time (Price et al., 2015). Internal consistency captures the level of consistency across the measure's items. This is related to the premise of all items on a measure aiming to relate to the same construct and, therefore, reflects the level of inter-correlation between the items (Price et al., 2015; Trajkovic et al., 2011). Cronbach's alpha is most often used to report a scale's internal consistency (Cronbach, 1951) and captures the scale's degree of homogeneity (Litwin, 1995). To support with interpreting alpha values, Streiner (2003) suggests values between .70 and .90 reflect tools considered internally consistent.

A second type of consistency is inter-rater reliability (IRR). This refers to the level of agreement between different raters on the same measure (Price et al., 2015). IRR values are commonly reported as Cohen’s Kappa or Intraclass Coefficient Correlations (ICC). Similarly to Cronbach’s alpha, there are guidelines for interpreting the values, with values between .60 and .74 considered good, and between .75 and 1 excellent (Cicchetti, 1994).

Test-retest reliability captures the scale’s ability to measure the same construct consistently over time (Price et al., 2015). It is assessed in terms of how stable responses are at two timepoints when the same person completes the scale (Litwin, 1995). The duration between the timepoints is determined form the rate of change expected in the variable being measured, as some variables are expected to change more quickly. Test-retest reliability coefficients are often reported as ICC values, with values between .75 and .90 considered to reflect good reliability and above .90 excellent test-retest reliability (Koo & Li, 2016).

### The Reliability of the CDSS

To establish the reliability of a measure, it is important to conduct multiple studies rather than basing reliability estimates on findings from one study. This ensures a measure’s reliability reflects the overall pattern of results (Price et al., 2015). This is important given estimates of reliability vary across studies due to differences in conditions (e.g. study setting) and sample characteristics (Henson, 2001; Sun, 2011). The CDSS is routinely used in clinical practice and research. Within clinical practice, it is used to identify individuals at increased risk of attempting suicide and those requiring intervention to address their symptoms of depression (Addington et al., 1993). NICE guidelines (NICE, 2014) recommend individuals with a diagnosis of schizophrenia are routinely assessed for depression. It is, therefore, important to understand the CDSS's reliability to establish its suitability for such purposes. The reliability of the CDSS, including original and translated versions, has been considered in several studies. Except for Lako et al's (2012) systematic review, the CDSS' reliability has largely been considered in single studies.

Lako et al's (2012) review focused on six measures of depression and considered their use with individuals diagnosed with schizophrenia. The CDSS was reported to have good reliability and validity, when compared to the other tools. The authors, therefore, recommended the CDSS for clinical practice and research. This review, however, combined results by taking a mean of the reliability values across individual studies rather than more advanced analytical means. Meta-analysis provides a means of synthesising quantitative findings from different studies using statistical methods (Rodriguez & Maeda, 2006). This enables results from single studies to be considered together, overcoming limitations associated with smaller sample sizes and individual study biases (Walker, Hernandez & Kattan, 2008). As a method, meta-analysis can better support clinicians in their decision about a measure's suitability for the intended purpose. This is particularly important for measures, like the CDSS, that have been translated into different languages and used with different diagnoses (Rodriguez & Maeda, 2006). There is currently no review providing a detailed numerical meta-analytic synthesis and comparison of the CDSS' psychometric properties. Given the CDSS is routinely used in clinical practice and research, it is important to fully understand its reliability. This is particularly important given it has been designed to assess depressive symptoms as separate from negative symptoms, with the presence of depressive symptoms in individuals with a diagnosis of schizophrenia associated with higher rates of suicide (e.g. Conley et al, 2007; Upthegrove et al., 2017).

### Objectives

The overall aim of this meta-analysis is to investigate the CDSS' reliability. Consideration will also be given to the version of the CDSS used and the nature of the sample. This is due to the CDSS having been translated into multiple different languages and the tool having been developed specifically for individuals with a diagnosis of schizophrenia.

## METHODS

### Search Strategy

A literature search of three databases was conducted in May 2019. The search included the following electronic databases: PsycINFO, Medline and PubMed. Reference lists and articles cited in full-text articles were also reviewed to identify additional studies, alongside reviewing the articles included in Lako et al's (2012) review. The aim of this search was to identify literature reporting the CDSS' reliability to assess the measure's reliability across studies. The following search terms were used to identify studies:

{“Calgary Depression Scale” or CDSS}

AND

{reliability OR “internal consistency” OR alpha OR “test-retest”}

AND

{“schizophrenia” OR “schizophrenic”}

**Eligibility Criteria**

The initial search of the databases identified 1015 records. A further 35 records were found through searching references of articles from the database search. After removing duplicate records, the remaining 949 records were screened for eligibility by applying the inclusion and exclusion criteria outlined in Table 1. The literature search and the search outcomes are presented in Figure 1, alongside an explanation for each criterion.

Table 1.

*Inclusion and exclusion criteria for inclusion within the review.*

| Inclusion Criteria | Exclusion Criteria | Rationale for Criteria |
|---|---|---|
| Articles published in the English language between 1990 and May 2019. | Article published in a foreign language (i.e. not in English). | This is due to time and resource constraints preventing non-English papers being translated. |
| Original articles reporting on primary studies. | Review articles, study protocols, critique papers and books/book chapters. Journal articles reporting reliability estimates from previous studies (i.e. not original data values). | The focus of this review is on studies that present original data, which is required for inclusion within a meta-analysis. Excluded formats reflect those that do not provide such data. |
| Articles for which the full-text version could be accessed. | Full-text articles unable to be accessed. Attempts were made to access full-texts via University and NHS Trust access, alongside directly accessing the Journals and contacting the corresponding author to request the full-text. | In order for studies to be included within the meta-analysis, certain information needs to be extracted. This requires access to the full article as opposed to just the abstract. |
| Study sample taken from a population reflecting the intended population for which the CDSS was designed. | The main diagnosis (i.e. <50%) within the sample was not schizophrenia. | The CDSS was developed for use specifically with individuals who have a diagnosis of schizophrenia. The sample was, therefore, required to have at least 50% of participants with a diagnosis of schizophrenia. |
| Use of the CDSS in its original form or a translated version which has been approved by the scale developer. | The CDSS, in either the original or a translated form, was not used. | The focus of this meta-analysis is on the CDSS. As such, only studies using an approved version of this measure were included. |
| Appropriate statistical reporting of at least one type of reliability for the CDSS. | Primary studies in which no reliability coefficients for the CDSS were reported. | The aim of this meta-analysis is to investigate the reliability of the CDSS. As such, appropriate reporting of reliability coefficients is a requirement for the study to be included within the analysis. |

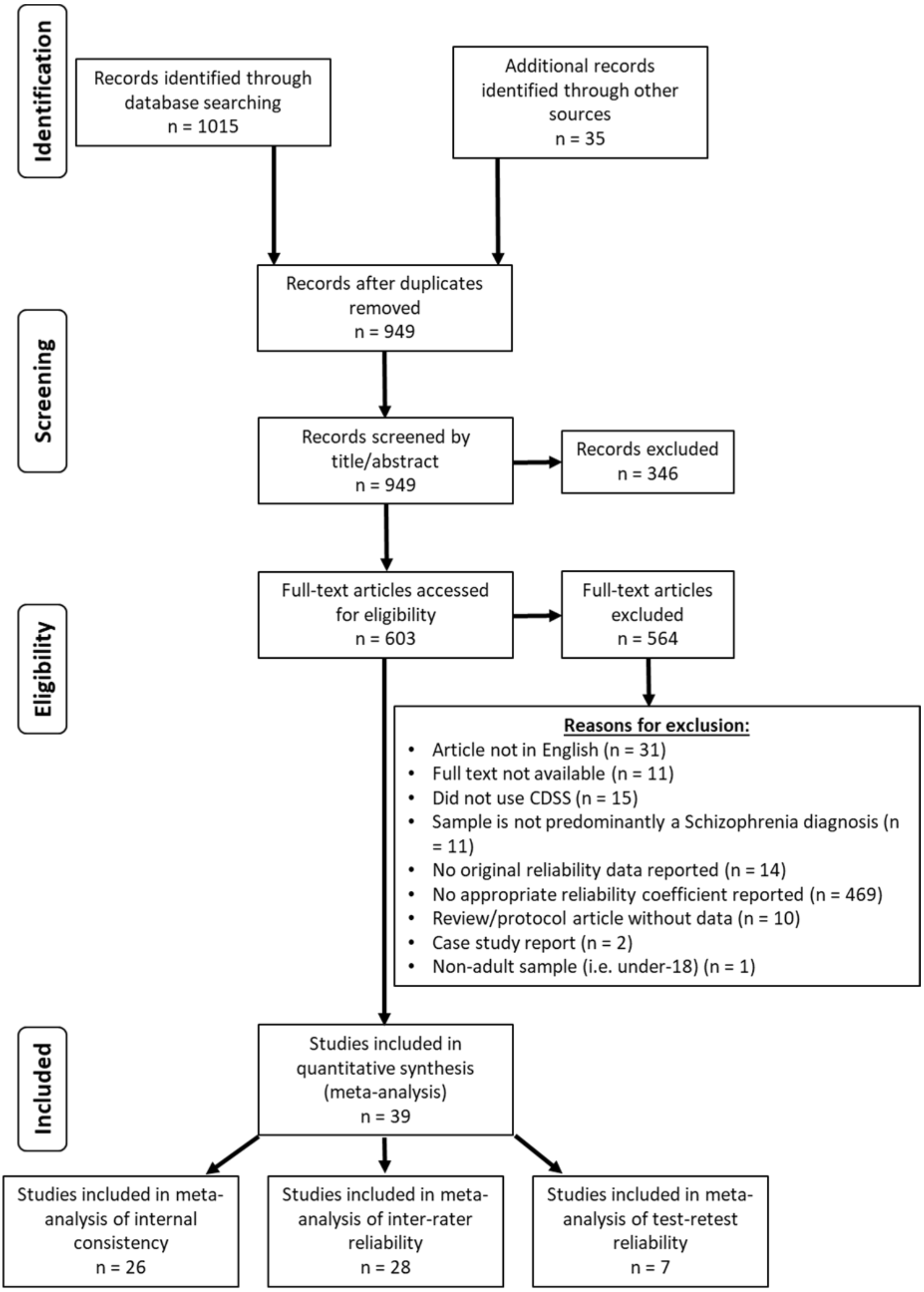

*Figure 1.* Flow chart of the search strategy and process of article selection for the meta-analysis[1].

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[1] Based on Moher, Liberati, Tetzlaff, Altman & The PRISMA Group's (2009) diagram.

## Study Characteristics

Table 2 presents the characteristics of the 39 studies included in the meta-analysis. Of the 39 studies, 26 were included for the CDSS' internal consistency and 28 were included for the IRR of the CDSS. Seven of these studies also reported test-retest reliability data, however, due to limitations within this dataset the analysis was restricted (*further information within results/discussion*).

Table 2.

*Overview of the included studies*[2].

| Study | Year | Internal Consistency | Inter-Rater Reliability (N) | Test-Retest Reliability (N) | N | Sample Diagnosis | Sample Type | Version of the CDSS | Country in which Study Conducted | Context of CDSS Use |
|---|---|---|---|---|---|---|---|---|---|---|
| Addington et al. | 1992 | 0.79 | 0.90 (10) | | 150 | 100% Schizophrenia | Inpatients & Outpatients | Original | Canada | Reliability and validity of CDSS |
| Addington et al. | 1994 | 0.84 | 0.96 (10) | | 150 | 100% Schizophrenia | Inpatients & Outpatients | Original | Canada | Establishing CDSS's specificity |
| Addington et al. | 1996 | 0.82 | 0.89 (10) | | 112 | 100% Schizophrenia | Inpatients & Outpatients | Original | Canada | Comparison of CDSS with another measure |
| Bernard et al. | 1998 | 0.79 | 0.98 (33) | 0.69 (16) | 70 | 100% Schizophrenia | Inpatients & Outpatients | Translated | France | Validation of CDSS |
| Bressan et al. | 1998 | 0.8 | | | 80 | 100% Schizophrenia | Outpatients | Translated | Brazil | Validation of CDSS |
| Lançon et al. | 1999 | 0.82 | | | 95 | 100% Schizophrenia | Inpatients & Outpatients | Translated | France | Reliability and validity of CDSS |
| Müller et al. | 1999 | | 0.97 (10) | | 10 | Mixed Psychotic Disorders | Inpatients | Translated | Germany | Reliability of CDSS |

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[2] Not all studies provided values for all types of reliability, so only reported values are included in this table. Some studies did not report whether the inter-rater reliability coefficients were calculated on the whole sample or a subset, as such where this information was reported it has been included in this table.

| Study | Year | Internal Consistency | Inter-Rater Reliability (N) | Test-Retest Reliability (N) | N | Sample Diagnosis | Sample Type | Version of the CDSS | Country in which Study Conducted | Context of CDSS Use |
|---|---|---|---|---|---|---|---|---|---|---|
| Kaneda et al. | 2000 | 0.82 | 0.84 (11) | 0.86 (28) | 47 | 100% Schizophrenia | Inpatients | Translated | Japan | Validation of CDSS |
| Kontaxakis et al. | 2000 | 0.87 | 0.78 (24) | 0.93 (24) | 24 | 100% Schizophrenia | Inpatients | Translated | Greece | Reliability and validity of CDSS |
| Schuetze et al. | 2001 | 0.76 | 0.93 (20) | | 20 | Mixed Psychotic Disorders | Inpatients | Translated | Denmark | Reliability and validity of CDSS |
| Maggini & Raballo | 2004 | | 0.83 (24) | | 84 | 100% Schizophrenia | Outpatients | Unknown | Italy | Measure of depression |
| Sarro et al. | 2004 | 0.83 | 0.97 (27) | 0.76 (14) | 93 | 100% Schizophrenia | Inpatients & Outpatients | Translated | Spain | Validation of CDSS |
| Kim et al. | 2006 | 0.86 | | | 84 | 100% Schizophrenia | Inpatients | Translated | Republic of Korea | Diagnostic validity of CDSS |
| Müller et al. | 2006 | | ≥0.87 (20) | | 119 | 100% Schizophrenia | Inpatients | Translated | Germany | Sensitivity and specificity of CDSS |
| Zisook et al. | 2006 | | ≥0.90 | | 165 | Mixed Psychotic Disorders | Outpatients | Original | USA | Measure of depression |
| Coulston et al. | 2007 | 0.81 | 0.87 | | 59 | Mixed Psychotic Disorders | Outpatients | Original | Australia | Measure of depression |
| Fitzgerald et al. | 2008 | | >0.90 (20) | | 20 | Mixed Psychotic Disorders | Outpatients | Original | Australia | Measure of depression |
| Jager et al. | 2008 | | >0.80 | | 288 | 100% Schizophrenia | Inpatients | Translated | Germany | Measure of depression |
| Liu et al. | 2009 | 0.8 | | | 101 | 100% Schizophrenia | Inpatients | Translated | China | Diagnostic validity of CDSS |
| Xiao et al. | 2009 | 0.8 | 0.88 (26) | 0.93 (26) | 26 | 100% Schizophrenia | Inpatients | Translated | China | Reliability and validity of CDSS |

| **Study** | **Year** | **Internal Consistency** | **Inter-Rater Reliability (N)** | **Test-Retest Reliability (N)** | **N** | **Sample Diagnosis** | **Sample Type** | **Version of the CDSS** | **Country in which Study Conducted** | **Context of CDSS Use** |
|---|---|---|---|---|---|---|---|---|---|---|
| Lincoln et al. | 2010 | | 0.92 | | 80 | Mixed Psychotic Disorders | Inpatients & Outpatients | Translated | Germany | Measure of depression |
| Chengappa et al. | 2012 | | ≥0.80 | | 70 | Mixed Psychotic Disorders | Outpatients | Original | USA | Measure of depression |
| Peleikis et al. | 2012 | 0.82 | | | 128 | Mixed Psychotic Disorders | Inpatients & Outpatients | Unknown | Norway | Measure of depression |
| Schennach et al. | 2012 | 0.78 | >0.80 | | 278 | Mixed Psychotic Disorders | Inpatients | Unknown | Germany | Comparison of CDSS with another measure |
| Moore et al. | 2013 | 0.83 | | | 72 | Mixed Psychotic Disorders | Outpatients | Original | USA | Measure of depression |
| Rabany et al. | 2013 | 0.83 | | | 184 | 100% Schizophrenia | Inpatients & Outpatients | Original | Israel | Measure of depression |
| Suttajit et al. | 2013 | 0.87 | 0.98 (10) | 0.86 | 60 | 100% Schizophrenia | Inpatients & Outpatients | Translated | Thailand | Reliability and validity of CDSS |
| Ucok et al. | 2013 | | 0.83 (20) | | 103 | 100% Schizophrenia | Outpatients | Translated | Turkey | Measure of depression |
| Bull et al. | 2016 | 0.82 | | | 148 | Mixed Psychotic Disorders | Outpatients | Unknown | Norway | Measure of depression |
| Garcia et al. | 2016 | 0.87 | | | 79 | Mixed Psychotic Disorders | Outpatients | Unknown | Spain | Measure of depression |
| Hani et al. | 2016 | 0.82 | 0.90 (21) | 0.85 (19) | 102 | 100% Schizophrenia | Inpatients | Translated | Qatar | Validation of CDSS |

| Study | Year | Internal Consistency | Inter-Rater Reliability (N) | Test-Retest Reliability (N) | N | Sample Diagnosis | Sample Type | Version of the CDSS | Country in which Study Conducted | Context of CDSS Use |
|---|---|---|---|---|---|---|---|---|---|---|
| Krupchanka & Katliar | 2016 | 0.88 | | | 96 | 100% Schizophrenia | Inpatients & Outpatients | Translated | Belarus | Measure of depression |
| Mingrone et al. | 2016 | | 0.85 (15) | | 147 | Mixed Psychotic Disorders | Outpatients | Unknown | Italy | Measure of depression |
| Pawelczyk et al. | 2016 | | >0.82 | | 71 | 100% Schizophrenia | Inpatients | Unknown | Poland | Measure of depression |
| Grover et al. | 2017 | 0.88 | 0.83 (42) | | 267 | 100% Schizophrenia | Inpatients & Outpatients | Translated | India | Factor analysis of CDSS |
| Jeon et al. | 2018 | | >0.75 | | 56 | 100% Schizophrenia | Outpatients | Unknown | Republic of Korea | Measure of depression |
| Xu et al. | 2018 | 0.83 | >0.85 | | 348 | 100% Schizophrenia | Inpatients | Translated | China | Measure of depression |
| Fathian et al. | 2019 | | 0.92 | | 208 | Mixed Psychotic Disorders | Inpatients | Original | Norway | Measure of depression |
| Richter et al. | 2019 | 0.79 | | | 55 | Mixed Psychotic Disorders | Outpatients | Unknown | Germany | Reliability and validity of another measure |

## Risk of Bias of Individual Studies

Higgins et al. (2011) reported that findings of meta-analyses can be impacted by including poor quality studies. Quality captures how appropriate the study is for answering its research question, considering design, delivery and analysis. There are various tools for assessing risk of bias. Higgins et al. (2011), however, advocate using a set of criteria specific to methodological issues pertinent to the literature and question under review. Assessment of risk of bias was, therefore, completed using a framework developed for this review, presented in Table 3. Existing tools and information on the types of bias guided the development of this framework (e.g. Higgins et al., 2011; Smith & Noble, 2014).

Table 3.

*Quality framework used to assess risk of bias.*

| Area | Brief Description | Risk of Bias |
|---|---|---|
| **Selection bias** | The study sample is representative of that for which the CDSS was designed. The CDSS is specifically designed for adults with a diagnosis of Schizophrenia. It is suitable for individuals in both the acute and residual stages of the illness. | **Low risk:** The characteristics of the study population are clearly described and are representative of the population for which the scale was developed. 100% of participants have a diagnosis of Schizophrenia.<br>**Unclear risk:** The characteristics of the study population are not clearly reported so it is unclear the proportion of the sample with a diagnosis of Schizophrenia, or the percentage of the sample with a diagnosis of Schizophrenia is less than 100% but greater than 50%.<br>**High risk:** The sample characteristics are not representative for the scale's target population with less than 50% having a diagnosis of Schizophrenia. |
| **Performance bias** | Takes into consideration any alterations made to the original measure and the use of the scale. The following is outlined for use of the CDSS: the rater should have experience with individuals with Schizophrenia; it is to be administered as an interview with the 9th question based on rater observation; IRR with another rater experienced in using structured assessments should be developed; adequate IRR should be established within 5-10 practice interviews. | **Low risk:** The full version of the scale is used, either the original version or a version approved by the scale's developer (e.g. language variant). The measure was used in accordance with the scale protocol around training and administration.<br>**Unclear risk:** It is unclear whether the full scale was administered, or it is unclear whether it is an approved version; or it is unclear whether the administration protocol was followed.<br>**High risk:** Only selected items of the scale were administered; the scale’s developer had not approved the version; or the administration protocol was not adhered to. |

| Area | Brief Description | Risk of Bias |
|---|---|---|
| **Reporting bias** | Captures the completeness of the reporting within the study, around descriptive statistics and outcomes. | **Low risk:** There is a complete account of the descriptive statistics, with all results reported in full and appropriately.<br>**Unclear risk:** Descriptive statistics are reported but are only partially reported.<br>**High risk:** There are either no descriptive statistics or important data is missing within the reported dataset (e.g. data they said they were going to report has not been included). |
| **Detection bias** | Consideration of the detection of depression, as guided by the reported IRR. For this purpose, the acceptability of IRR coefficient values was determined using Koo & Li's (2016) guidelines. | **Low risk:** IRR coefficient was reported and is an acceptable value (>0.75).<br>**Unclear risk:** IRR coefficient is not reported.<br>**High risk:** IRR coefficient is reported and falls below the level considered acceptable (i.e. <0.75). |
| **Statistical bias** | The reporting of statistical information, relating to the reliability coefficient. Considers the information reported in terms of its completeness and accuracy. | **Low risk:** Exact reliability coefficient is reported, and it is clear how this was calculated (i.e. no missing data).<br>**Unclear risk:** Non-exact reliability coefficient is reported; or some data is missing (i.e. unclear whether the full sample was used to provide this value or just a subset of the sample).<br>**High risk:** No information is provided as to how the reliability coefficient has been calculated. |
| **Generalisability** | Capturing the size of the sample and the ability to transfer findings to the wider population. | **Low risk:** The sample contains more than 40 participants.<br>**Unclear risk:** The sample contains between 20 and 40 participants.<br>**High risk:** The sample contains fewer than 20 participants. |

Each study was assessed for its risk of bias across these six areas, with ratings depicted in Table 4. Low risk is indicated in green, unclear risk in orange and high risk in red. Assessment of study quality was initially completed by the reviewer for all studies. After rating each study for each bias, an overall quality index score was computed for each study. This was calculated using a total score obtained from summing the ratings across the six dimensions (2 points for low risk, 1 point for unclear risk and 0 points for high risk). Table 4 presents these scores, with the score provided for each type of reliability to capture any differences. Such differences emerged due to variation in proportion of the sample used to calculate the estimate of reliability, in accuracy of the reliability estimate provided (i.e. exact or non-exact value) and completeness of reporting (e.g. the extent to which it was clear how the value had been calculated). Quality index scores were used in the analysis as a weighting factor to assess the impact of methodological variation within the primary studies.

Table 4.

*Risk of bias ratings and quality index scores for each study.*

| **Study** | **Year** | **Selection Bias** | **Performance Bias** | **Reporting Bias** | **Detection Bias** | **Statistical Bias** | **Generalisability** | **Quality Index Score (%)** |
|---|---|---|---|---|---|---|---|---|
| Addington et al. (internal consistency) | 1992 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Addington et al. (IRR) | 1992 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Addington et al. (internal consistency) | 1994 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Addington et al. (IRR) | 1994 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Addington et al. (internal consistency) | 1996 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Addington et al. (IRR) | 1996 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Bernard et al. (internal consistency) | 1998 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Bernard et al. (IRR) | 1998 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 79 |
| Bernard et al. (test-retest) | 1998 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Bressan et al. (internal consistency) | 1998 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 | 79 |
| Lançon et al. (internal consistency) | 1999 | 🟩 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 71 |
| Müller et al. (IRR) | 1999 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 🟥 | 57 |
| Kaneda et al. (internal consistency) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 79 |
| Kaneda et al. (IRR) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟨 | 🟥 | 57 |
| Kaneda et al. (test-retest) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟨 | 🟨 | 64 |
| Kontaxakis et al. (internal consistency) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟨 | 71 |
| Kontaxakis et al. (IRR) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟨 | 🟨 | 64 |
| Kontaxakis et al. (test-retest) | 2000 | 🟩 | 🟨 | 🟩 | 🟩 | 🟨 | 🟨 | 64 |

| Study | Year | Selection Bias | Performance Bias | Reporting Bias | Detection Bias | Statistical Bias | Generalisability | Quality Index Score (%) |
|---|---|---|---|---|---|---|---|---|
| Schuetze et al. (internal consistency) | 2001 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | 57 |
| Schuetze et al. (IRR) | 2001 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | 57 |
| Maggini & Raballo (IRR) | 2004 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 79 |
| Sarro et al. (internal consistency) | 2004 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Sarro et al. (IRR) | 2004 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 79 |
| Sarro et al. (test-retest) | 2004 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Kim et al. (internal consistency) | 2006 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 | 79 |
| Müller et al. (IRR) | 2006 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟨 | 71 |
| Zisook et al. (IRR) | 2006 | 🟨 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 71 |
| Coulston et al. (internal consistency) | 2007 | 🟨 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 71 |
| Coulston et al. (IRR) | 2007 | 🟨 | 🟨 | 🟩 | 🟩 | 🟨 | 🟩 | 64 |
| Fitzgerald et al. (IRR) | 2008 | 🟨 | 🟩 | 🟩 | 🟩 | 🟨 | 🟨 | 64 |
| Jager et al. (IRR) | 2008 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 79 |
| Liu et al. (internal consistency) | 2009 | 🟩 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 71 |
| Xiao et al. (internal consistency) | 2009 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 79 |
| Xiao et al. (IRR) | 2009 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟨 | 71 |
| Xiao et al. (test-retest) | 2009 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟨 | 71 |
| Lincoln et al. (IRR) | 2010 | 🟨 | 🟨 | 🟩 | 🟩 | 🟨 | 🟩 | 64 |
| Chengappa et al. (IRR) | 2012 | 🟨 | 🟨 | 🟩 | 🟩 | 🟨 | 🟩 | 64 |
| Peleikis et al. (internal consistency) | 2012 | 🟨 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 64 |
| Schennach et al. (internal consistency) | 2012 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 79 |
| Schennach et al. (IRR) | 2012 | 🟨 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 71 |

| **Study** | **Year** | **Selection Bias** | **Performance Bias** | **Reporting Bias** | **Detection Bias** | **Statistical Bias** | **Generalisability** | **Quality Index Score (%)** |
|---|---|---|---|---|---|---|---|---|
| Moore et al. (internal consistency) | 2013 | 🟨 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 64 |
| Rabany et al. (internal consistency) | 2013 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 | 79 |
| Suttajit et al. (internal consistency) | 2013 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 79 |
| Suttajit et al. (IRR) | 2013 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟥 | 64 |
| Suttajit et al. (test-retest) | 2013 | 🟩 | 🟨 | 🟩 | 🟩 | 🟨 | 🟩 | 71 |
| Ucok et al. (IRR) | 2013 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 79 |
| Bull et al. (internal consistency) | 2016 | 🟨 | 🟨 | 🟨 | 🟨 | 🟩 | 🟩 | 57 |
| Garcia et al. (internal consistency) | 2016 | 🟨 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 64 |
| Hani et al. (internal consistency) | 2016 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Hani et al. (IRR) | 2016 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 79 |
| Hani et al. (test-rest) | 2016 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 71 |
| Krupchanka & Katliar (internal consistency) | 2016 | 🟩 | 🟥 | 🟩 | 🟨 | 🟩 | 🟩 | 64 |
| Mingrone et al. (IRR) | 2016 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 64 |
| Pawelczyk et al. (IRR) | 2016 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 79 |
| Grover et al. (internal consistency) | 2017 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Grover et al. (IRR) | 2017 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Jeon et al. (IRR) | 2018 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 79 |
| Xu et al. (internal consistency) | 2018 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 86 |
| Xu et al. (IRR) | 2018 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 79 |
| Fathian et al. (IRR) | 2019 | 🟨 | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 71 |
| Richter et al. (internal consistency) | 2019 | 🟨 | 🟨 | 🟩 | 🟨 | 🟩 | 🟩 | 64 |

### *Selection Bias*

Overall, selection bias was mixed, with 24 rated low risk and 15 rated unclear risk. For those rated unclear, this was due to including participants who were not diagnosed with schizophrenia. These were papers where the sample contained a mixture of psychotic diagnoses whereby less than 100% but more than 50% of the sample had a diagnosis of schizophrenia (i.e. the diagnosis for which the CDSS is designed).

### *Performance Bias*

There was variation in performance bias across the studies, with 24 rated low risk, 14 unclear risk and one high risk. Krupchanka & Katliar (2016) was rated high risk of bias due to the raters not having been trained to use the measure, opposing the protocol for the CDSS, and it being unclear whether the translated version being used had been approved by the scale's author. For the 14 studies considered unclear risk, this was because it was unclear whether raters were trained according to Addington et al's (1990) protocol.

### *Reporting Bias*

Reporting bias was generally low within the primary studies, with 36 rated low risk, two unclear risk and one high risk. Schuetze et al. (2001) was considered high risk of bias given data reported on the measures used was limited. For example, no participant scores were reported for each measure, such as mean, with only psychometric properties data provided. The two studies deemed unclear risk were due to partial reporting of descriptive statistics (Bull et al., 2016; Müller et al., 1999). In Müller et al's. (1999) study, there was limited demographic information (only age and diagnosis) and CDSS scores were not reported. Bull et al (2016) indicated participants had been separated into two groups, but the number per group was not reported, impacting data interpretation.

### *Detection Bias*

Depending on the nature of the reliability assessed, ratings of detection bias varied within the primary studies. For IRR and test-retest reliability, all primary studies were rated low in risk. This was due to clear reporting on reliability coefficients of the measure used as applied to their study participants. For internal consistency, however, detection bias was mixed within the primary studies, with 28 rated low risk and 11 unclear risk. For the 11 studies considered to have an unclear risk, this was due to authors not reporting the IRR of the CDSS for their study.

### *Statistical Bias*[3]

Depending on the reliability being assessed, there was some variation in statistical bias ratings across the primary studies. For all studies reporting internal consistency coefficients (N=26), statistical bias was considered low risk. Within these studies, there were 15 also providing IRR coefficients. Of these, six were rated unclear risk for statistical bias (Coulston et al., 2007; Kaneda et al., 2000*; Kontaxakis et al., 2000*; Schennach et al., 2012; Xiao et al., 2009*; Xu et al., 2018). Unclear risk for IRR data was due to non-exact reliability coefficients being reported and/or uncertainty over the percentage of the population used to calculate IRR. For one paper no overall IRR was reported, meaning it

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[3] Studies marked with an * reflect studies which were also assigned an unclear risk rating for the test-retest reliability data for the same reason.

had to be calculated from individual item reliability coefficients (Xiao et al., 2009). Of the studies only reporting IRR coefficients (N=13), nine were considered unclear risk of statistical bias (Chengappa et al., 2012; Fathian et al., 2019; Fitzgerald et al., 2008; Jager et al., 2008; Jeon et al., 2018; Lincoln et al., 2010; Müller et al., 2006; Pawelczyk et al., 2016; Zisook et al., 2006). These ratings related to uncertainty about how IRR had been calculated (i.e. on a subset of the sample or the whole sample).

### *Generalisability*

Depending on the nature of the reliability being assessed, ratings of generalisability varied across the primary studies. Regarding the internal consistency dataset, 23 were considered low risk of generalisability, whereas three primary studies were rated as unclear risk. The studies rated unclear (Kontaxakis et al., 2000; Schuetze et al., 2001; Xiao et al., 2009) were due to the sample size being between 20 and 40 participants.

For the IRR data, there was greater variation in risk ratings for generalisability. There were 12 studies rated low risk, nine studies unclear risk and seven studies high risk of generalisability. Unclear risk was assigned to studies using a sample of 20 to 40 participants. This included: Bernard et al. (1998), Fitzgerald et al. (2008), Hani et al. (2016), Kontaxakis et al. (2000), Maggini and Raballo (2004), Müller et al. (2006), Sarro et al. (2004), Schuetze et al. (2001) and Xiao et al. (2009). High risk studies were those with a sample size less than 20 participants (Addington et al., 1992, 1994, 1996; Kaneda et al., 2000; Müller et al., 1999; Mingrone et al., 2016; Suttajit et al., 2013).

For the test-retest reliability data, risk ratings for generalisability varied. One study was rated low risk, three unclear risk and three high risk of generalisability. The following studies were assigned an unclear risk rating due to having sample sizes between 20 and 40: Kaneda et al. (2000), Kontaxakis et al. (2000) and Xiao et al. (2009). The following studies had sample sizes less than 20 and were assigned high risk ratings: Bernard et al. (1998), Hani et al. (2016) and Sarro et al. (2004).

## Data Extraction

All data were extracted by one reviewer, who had completed the literature search and assessed papers for inclusion against the eligibility criteria (Table 1). From each paper, descriptive data was extracted regarding author, study setting, sample size, sample demographics (e.g. age, gender, diagnosis and onset of illness) and CDSS version used (i.e. original or translated). Data were also extracted for synthesis, including reliability coefficients and number of items. For studies reporting IRR coefficients, the type of coefficient (e.g. Kappa or ICC) was also noted. Regarding IRR, of the included studies, two reported the % agreement between raters. For these two studies[4], this value was converted into a Kappa coefficient using the following formula:

$$\kappa = \frac{p_o - p_e}{1 - p_e} = 1 - \frac{1 - p_o}{1 - p_e},$$

where:
$P_o$ = the relative observed agreement among raters.
$P_e$ = the hypothetical probability of chance agreement

(Statistics How To, 2014)

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[4] Mingrone et al. (2015) and Pawelczyk et al. (2016)

There were two studies[5] where individual item ICC values were reported but an overall ICC was not provided. In these cases, an overall value was calculated by taking the average of Fisher's (1921) z transformed kappa values.

## DATA ANALYSIS STRATEGY

The data analysis strategy used within this review follows the guidelines for the Centre for Applied Psychology (University of Birmingham). This strategy is paraphrased below.

### Process of and Reasons for Transformation and Back-transformation of Data

Before numerical synthesis was computed, alpha estimates and IRR coefficients from the primary studies were transformed into a Fisher's (1921) Z value. This transformation is often recommended as it functions to normalise the distribution of effects and stabilises the variance of the estimates due to the non-linearity in the correlational values (Silver & Dunlap, 1987). Unless otherwise indicated, values presented within tables and figures have been back-transformed to their original format for clarity of presenting the data interpretation.

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[5] Kaneda et al. (2000) and Xiao et al. (2009)

### Normalisation and Variance Stabilisation

The DerSimonian-Laird method is the simplest and most commonly used method for calculating the between studies variation (tau) for fitting the random-effects model (DerSimonian & Laird, 1986). The DerSimonian-Laird method, however, assumes that the population has a normally distributed random effect. As such, the effect sizes provided by primary studies should tend towards a normal distribution. The assumption of normality will be assessed using a QQ plot. If marked non-normality is observed, then the restricted maximum likelihood estimator, which has been shown as robust to non-normality (Banks, Mao & Walter, 1985), will be used in preference to the DerSimonian-Laird method.

### Random- Versus Fixed-Effects Models

When calculating a meta-analytic synthesis (i.e. the omnibus test) it is possible to use either fixed-effects (FEM) or random-effects (REM) models. The FEM assumes only one true effect size exists, with all studies measuring the effect with equal efficacy and with any variation simply reflecting sampling error (Borenstein, Hedges, Higgins & Rothstein, 2009). This means, when assigning weights to the individual studies, information from smaller studies can largely be ignored given we have better information about the same effect size from larger studies. When the data have come from multiple studies with different methodological strengths and limitations, it is unlikely that the studies are equally efficient at detecting the effect.

The REM, however, accounts for individual study differences which are likely to impact on the measurement of the effect. This model assumes there is a distribution of observed effects resulting from differences in the primary studies. These differences can include participant characteristics, measurement error and factors associated with idiosyncratic interpretation of the test items (Borenstein et al., 2009). One common effect size should not, therefore, be assumed and the REM estimates the mean of a distribution of possible effects representing individual differences in inter-rater interpretation of the measure.

The REM also differs from the FEM in how it assigns weights to the different studies. The FEM only uses sample size as an indicator of study precision, whereas the REM uses both sample size and heterogeneity to estimate study precision. In the REM, study precision is a function of sample size and the degree to which the study's psychometric parameter corresponds with the rest of the literature. This ensures within-study error and between-study variation in true effect are accounted for (Brockwell & Gordon, 2001). The studies included within this review were conducted across different samples, by different researchers and in different settings. A REM is, therefore, more easily justified as is the case for most meta-analyses of psychological research (Schmidt, Oh & Hayes, 2009).

### Testing for Heterogeneity

Heterogeneity refers to the variation observed between the outcomes of individual studies that is not attributable to variation in the true effect size (Higgins, 2008). This can be considered as nuisance or noise variation. For meta-analyses, heterogeneity is expected to exist given the approach of collating multiple studies to aggregate effect sizes. To ascertain the generalisability of findings from a meta-analysis, it is important to know the degree of consistency across the results (Higgins, Thompson, Deeks & Altman, 2003). It is, therefore, important to assess the size and impact of heterogeneity, alongside establishing what is deemed an appropriate level of heterogeneity (Higgins, 2008).

An effect is considered heterogeneous if it presents with variation that cannot be attributed to true individual differences underlying rating of the items on the CDSS (i.e., the distribution of the true alpha coefficient). Heterogeneity can result from methodological variation in the studies, measurement error or uncontrolled individual difference factors within the body of literature. Higgins $I^2$ is a commonly used measure of heterogeneity, with greater values of $I^2$ indicating variation in effect that cannot be attributed to true variation in the psychometric parameters (Higgins et al., 2003). Other measures of heterogeneity exist, including Cochran's Q. Higgins $I^2$, however, is considered advantageous given it captures the level of heterogeneity as opposed to simply whether heterogeneity is absent or present, as is the case with Cochran's Q[6] (Huedo-Medina, Sánchez-Meca, Marin-Martinez & Botella, 2006). The amount of heterogeneity can be used to decide whether to proceed with subgroup analyses, with further analyses recommended for higher $I^2$ values (Borenstein et al., 2009). Higgins et al. (2003) suggested that $I^2$ values between 0-50% reflect low, 50-75% moderate and 75-100% high heterogeneity. As there is considerable

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[6] Higgins et al. (2003) also note that $I^2$ enables comparison across different meta-analyses because its computation does not rely on the number of studies in the meta-analysis. This further presents $I^2$ as advantageous given that Cochran's Q has limited or excessive power in calculating true heterogeneity for meta-analyses involving, respectively, a small or large number of studies (Huedo-Medina et al., 2006).

variation in the use of the CDSS and the methodologies used within the primary studies, problematic heterogeneity was defined as a Higgins $I^2$ value greater than 75%.

### Assessing Methodological Variation

The quality effects model (QEM; Doi & Thalib, 2008) builds upon the REM by explicitly including rating of methodological quality in addition to weighting studies by sample size and heterogeneity in the estimation of precision. In addition, a quality index from the six risk of bias criteria outlined in 'Risk of Bias of Individual Studies' is derived. This QEM weights against studies with greater risk of bias. It can, therefore, be interpreted as the meta-analytic synthesis that would have been obtained had all the primary studies been of the same methodological quality as the best study within the current review. The impact of methodological variation can be assessed by comparing the REM and the QEM. Any substantial differences between the REM and the QEM would suggest attenuation in estimated effect due to methodological variation in the primary studies.

### Estimation of Unexplained Variance due to Methodological Factors and Uncontrolled Covariates

If problematic heterogeneity is observed, then a leave-one-out analysis will be conducted to identify primary studies that exert a disproportionately influential effect on the meta-analytic synthesis. Any such study will be reviewed to consider possible exclusion due to risk of bias. Subgroup analyses will also be used to attempt to identify the source or sources of problematic heterogeneity and the attenuated estimate of the synthesis will be reported.

### Identifying Influential Studies

To examine whether any study or studies are exerting a disproportionately high influence on the overall meta-analytic effect, a one-left-out procedure will be conducted. This procedure identifies individual studies with a disproportionate influence on the quantitative synthesis, by observing the impact of removing each study in turn. If omitting a study results in an effect that lies outside of the 95% Confidence Intervals (CI) for the complete meta-analysis, then that study is deemed to have a disproportionate influence and will be removed from the omnibus test.

### Identifying Publication Bias and Small Study Effects

Where there is a sufficient number of primary studies, publication bias and small study effects will be identified through visual and statistical inspection of the funnel plot. A funnel plot is a scatterplot of the effect size plotted against a measure of study precision. It is used primarily as a visual aid for detecting systematic heterogeneity.

Where publication bias is not present, it is assumed that studies with high precision will be plotted near the average (i.e., the meta analytic synthesis), and studies with low precision will be spread evenly on both sides of the average. This results in a roughly funnel-shaped distribution where the distance from the average is inversely proportionate to the precision of the study. A symmetric inverted funnel shape arises from a 'well-behaved' data set, in which publication bias is unlikely whereas deviation from this shape can indicate publication bias. The absence of primary studies in the regions associated with small sample sizes and non-significant effects is particularly indicative of publication bias. If publication bias is identified a trim and fill procedure (Duval & Tweedie, 2000a; 2000b) will be undertaken. This is based upon the assumption that publication bias would produce an asymmetrical funnel plot[7].

In addition, the fail-safe N will be calculated using Orwin's method (Orwin, 1983). This method has been selected as it is based on a threshold as opposed to significance, and is, therefore, considered more appropriate for reliability data. The fail-safe N is an estimation of the number of missing studies that would need to be retrieved for the effect to reduce to some criterion value (i.e., 0.7 for internal consistency data and 0.6 for IRR coefficients). If this number is large, relative to the number of primary studies in the meta-analysis, then the omnibus test can be considered robust to the effects of publication bias.

**Planned Contrasts**

For categorical moderators, summary effects and associated heterogeneity measures will be calculated for each of the sub-groups. The significance of the difference between the sub-groups will be evaluated by comparison of their 95% CI. Given the CDSS was developed for use with individuals with schizophrenia, a sub-group analysis will be conducted to compare reliability estimates across studies using such a sample and those with a sample comprising various psychotic disorder diagnoses. As mentioned previously,

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[7] The trim and fill procedure removes the most extreme small studies from the side of the funnel plot associated with positive effects using an iterative algorithm. The effect size at each iteration is then re-computed at each iteration until the funnel plot is symmetric about the (corrected) effect size. In theory, this will yield an unbiased estimate of the effect size, however, this process also reduces the variance of the effects which yields a too narrow CI. The algorithm, therefore, adds the primary studies back into the analysis and, for each study, inputs a mirror image on the negative effects side of the funnel plot.

the CDSS has been translated into different languages since its development. This has the potential to impact on reliability estimates, such that a sub-group analysis will be conducted to compare primary studies using the original version of the CDSS and those using a language-variant.

# RESULTS

## Internal Consistency

There were 26 studies reporting alpha coefficients in a total sample size of 2929 participants. Sample sizes in the primary studies ranged from 20 (Schuetze et al., 2001) to 349 (Xu et al., 2018). The distribution of the study level estimates of Fisher's (1921) transformation of internal reliability coefficients conformed to normal expectations, as shown in the QQ plot below (Figure 2). The DerSimonian-Laird estimate is, therefore, appropriate to use as a measure of between studies variation.

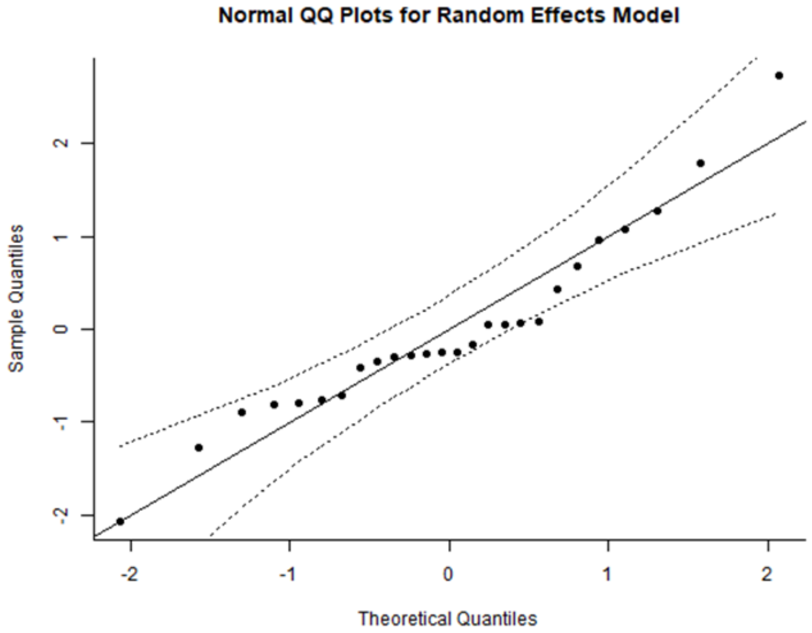

*Figure 2.* QQ plot indicating normal distribution of study level effects for internal reliability coefficients.

Figure 3 reports the random effects synthesis of these 26 studies, with an estimated internal consistency of alpha = 0.83 (95% CI: 0.82-0.84). There was an acceptable level of agreement between the primary studies' alpha estimates (Higgins $I^2$ = 11.00%). The normal distribution of primary effects and acceptable heterogeneity is also evident in the forest plot depicted in Figure 3.

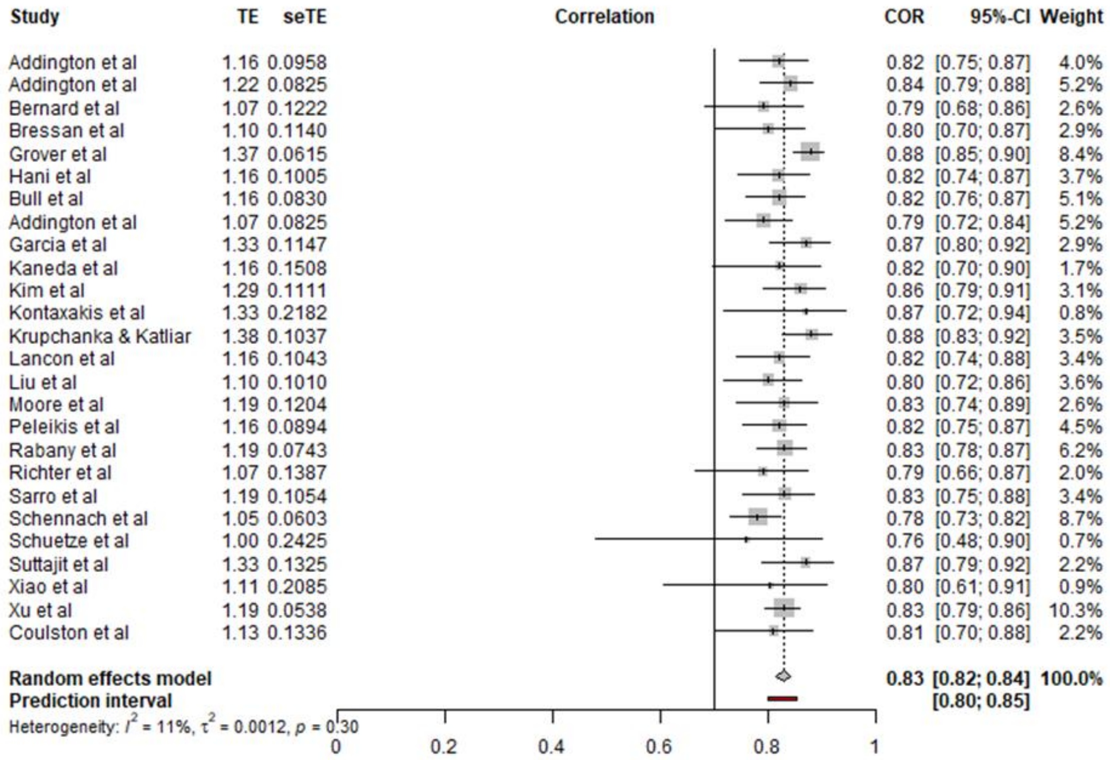

*Figure 3.* Forest plot of the omnibus test of the internal reliability coefficients.

### ***Attenuation due to Influential Studies***

The Baujat, Mahe, Pignon and Hill (2002) scatterplot in Figure 4 portrays the contribution of each study to overall heterogeneity on the y-axis and to the overall synthesis on the x-axis. Any studies placed in the upper right-hand corner of this chart are exerting a substantial effect on the overall analysis and are also discrepant from the rest of the literature.

Figure 4 reveals two studies as potentially exerting a disproportionate influence over the meta-analytic synthesis, namely Grover et al. (2017) and Schennach et al. (2012). The study conducted by Schennach et al. (2012) utilised a large sample size as part of a multi-centre programme, with the authors noting they had “liberal” (pp. 284) inclusion and exclusion criteria. From the reported information it was also unclear what proportion of the sample had a diagnosis of Schizophrenia, as opposed to another psychotic disorder. This suggests there may be a substantial amount of variation amongst the sample, potentially contributing to findings discrepant from the main body of literature. Grover et al.’s (2017) study was the only study to be completed in India and to use the Hindu version of the CDSS. Research has highlighted cultural differences in how depression presents, with variation between Eastern and Western cultures (Raguram, Weiss, Keval & Channabasavanna, 2001). As such, it may be that the questions within the CDSS are less applicable to this population.

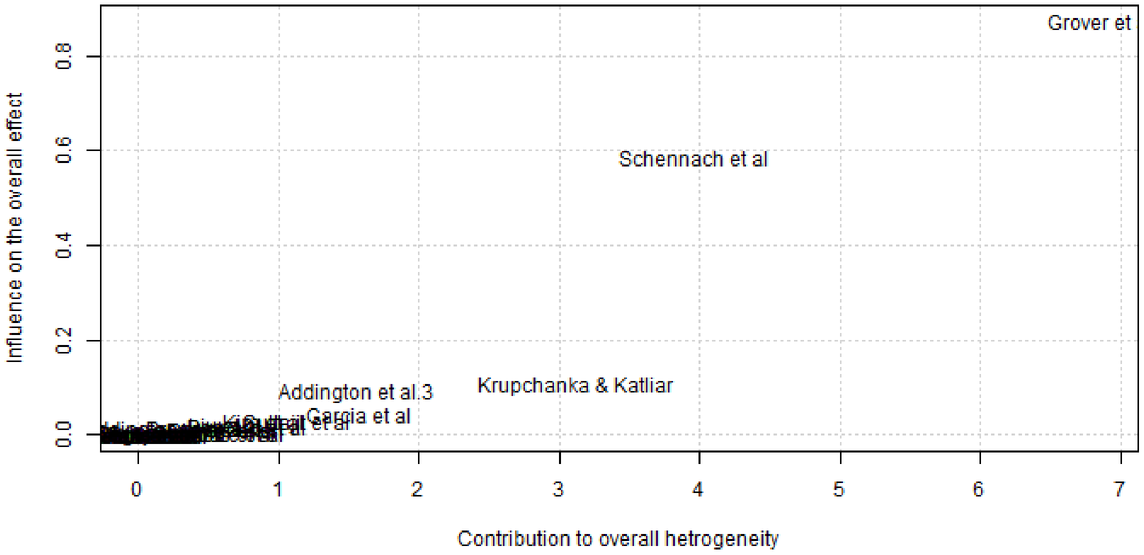

*Figure 4.* Baujat scatterplot representing heterogeneity in estimates of internal consistency.

The overall meta-analytic effect, therefore, was estimated with these two studies removed, through a 'leave-one-out' analysis. This resulted in a negligible difference (estimated internal consistency of alpha = 0.83 (95% CI: 0.81 to 0.84)), and their exclusion did not change the overall conclusion of the analysis. As such, these studies were retained in the overall meta-analytic effect and these data are considered robust to the effects of disproportionately influential studies.

### ***Attenuation due to Risk of Bias***

The QEM was calculated using the risk of bias ratings reported in Table 4. This model reported a meta-analytic effect (0.83, 95% CI: 0.81-0.84) comparable to that of the non-weighted estimate, with heterogeneity remaining below the level indicating problematic variance ($I^2$ = 10.99%). This indicates that consideration of the methodological quality of the studies does not have a substantive change on the conclusion drawn from these studies. These data are, therefore, robust to the effects of methodological bias.

### ***Publication Bias and Small Study Effects***

The funnel plot in Figure 5 illustrates the correlation between Fisher's z transformed correlation coefficient and standard error.

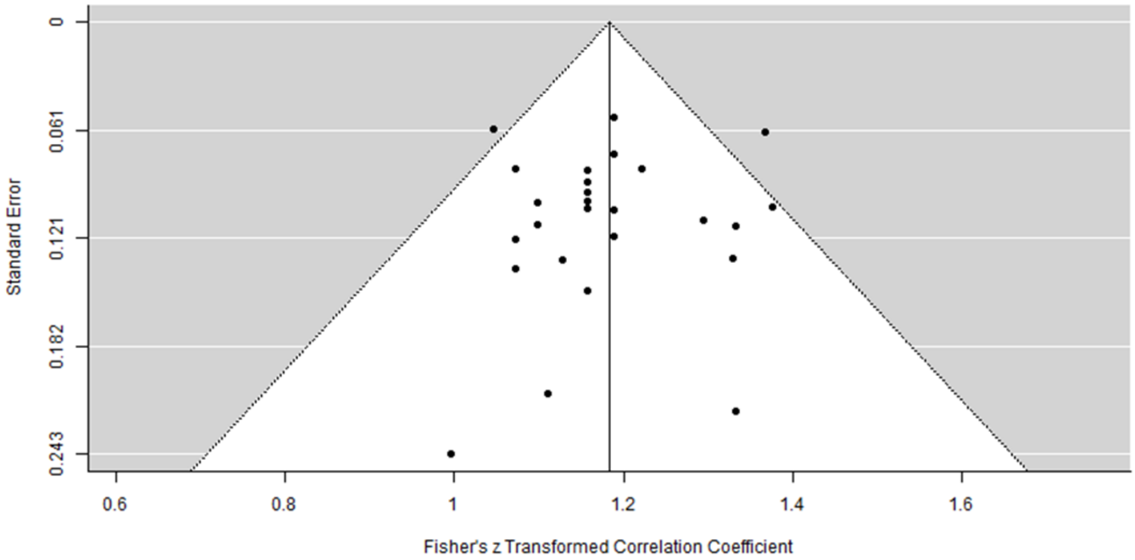

*Figure 5.* Funnel plot of the correlation between Fisher's z transformed correlation coefficient and standard error (internal reliability coefficients).

Figure 5 does not suggest any obvious evidence of publication bias given the individual data points are symmetrical around the meta-analytic effect value. In addition, use of Orwin's (1983) method indicates 19 null studies (i.e. 73% of the existing literature) would be required to reduce this effect below an alpha value of 0.7. These data can, therefore, be considered as robust to the effects of publication bias.

### ***Attenuation due to Diagnosis***

To explore whether there was any influence of the sample's diagnosis on the distribution of alpha coefficients resulting from rating of the CDSS items, a subgroup analysis was conducted. This analysis grouped the primary studies into two groups: Pure and Mixed. 'Pure' refers to primary studies in which the entire sample had a reported diagnosis of paranoid schizophrenia. 'Mixed' refers to studies involving samples with a mixture of psychotic disorder diagnoses, including schizophrenia and schizoaffective disorder. The results of this analysis are presented in Table 5. The non-significant difference reflects a lack of a substantive difference in the estimates of reliability between both groups, such that it is unlikely that meaningful differences exist.

Table 5.

*Subgroup analysis by composition of sample diagnosis.*

| **Sub-group analysis** | | **Number of studies** | **Random Effects Model** | | **Heterogeneity** | | | **Between groups comparison** |
|---|---|---|---|---|---|---|---|---|
| | | | **Reliability** | **95% CI** | **Higgins $I^2$** | **Tau$^2$** | **Cochran's Q** | |
| **Nature of diagnosis of the study sample** | Pure | 18 | 0.83 | 0.82-0.85 | 8.20 | 0.0008 | 18.51 | Q = 3.31, *p = 0.069* |
| | Mixed | 8 | 0.81 | 0.79-0.83 | 0.00 | 0.00 | 6.01 | |

### *Attenuation due to Version of Measure*

To explore whether there was any influence of the version of the CDSS used on the distribution of alpha coefficients resulting from rating of the CDSS items, a subgroup analysis was conducted. This analysis grouped the primary studies into two groups: Original and Translated. 'Original' includes primary studies that utilised the original version of the CDSS developed by Addington et al. (1990). 'Translated' refers to all primary studies utilising a version of the CDSS that has been translated into another language. The results of this analysis are presented in Table 6. The non-significant difference reflects consistency in the effect across the groups.

Table 6.

*Subgroup analysis by version of CDSS used.*

| **Sub-group analysis** | | **Number of studies** | **Random Effects Model** | | **Heterogeneity** | | | **Between groups comparison** |
|---|---|---|---|---|---|---|---|---|
| | | | **Reliability** | **95% CI** | **Higgins $I^2$** | **$Tau^2$** | **Cochran's Q** | |
| **Version of CDSS used** | Original | 6 | 0.82 | 0.80-0.84 | 0.00 | 0.00 | 1.96 | Q = 1.41, *p* = 0.235 |
| | Translated | 15 | 0.84 | 0.82-0.86 | 12.00 | 0.002 | 15.91 | |

### Inter-Rater Reliability

There were 28 studies reporting IRR coefficients. These were reported as either kappa or ICC values, with the exception of two papers as explained previously in Data Extraction. For the purposes of analysis, IRR values were in the form of kappa or ICC values with these being treated equivocally. The data arises from a total sample size of 1976 participants[8]. Sample sizes in the primary studies ranged from 10, accounting for five of the studies, to 349 (Xu et al., 2018). The distribution of the study level estimates of Fisher's (1921) transformation of IRR coefficients conformed to normal expectations, as shown in the QQ plot in Figure 6. Given the normal distribution, the DerSimonian-Laird estimate is appropriate to use as the measure of between-studies variation.

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[8] It is of note that for 11 of the primary studies it was unclear whether the whole sample or a subset of the entire sample was used to calculate the inter-rater reliability value. For those studies for which it was unclear, the total sample has been used for the value of N.

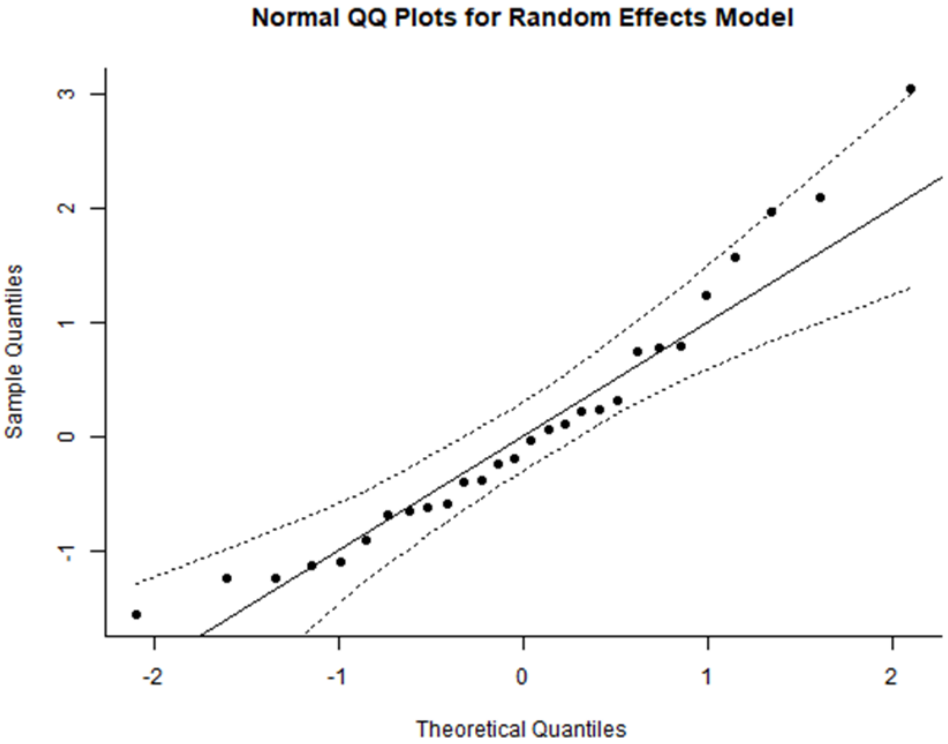

*Figure 6.* QQ plot indicating normal distribution of study level effects for IRR coefficients.

The random effects synthesis of these 28 studies had an estimated IRR of 0.88 (95% CI: 0.86-0.91). This appeared to estimate a high level of IRR for the CDSS. A high level of heterogeneity was found within the data (Higgins $I^2 = 78\%$, $\tau^2 = 0.06$, $p < 0.01$), as depicted in Figure 7. This level of heterogeneity can be problematic in suggesting that the estimates provided by the primary studies are biased by the presence of either uncontrolled or confounding variables. For this data, however, the high value for Higgins $I^2$ can be attributed to the narrow 95% CI. The observed variability is also what would be expected for a psychometric measure and not reflective of uncontrolled or confounding variables. As such, the level of heterogeneity is not considered to relate to inconsistency amongst the primary studies, such that the provided IRR estimates have an acceptable level of variance.

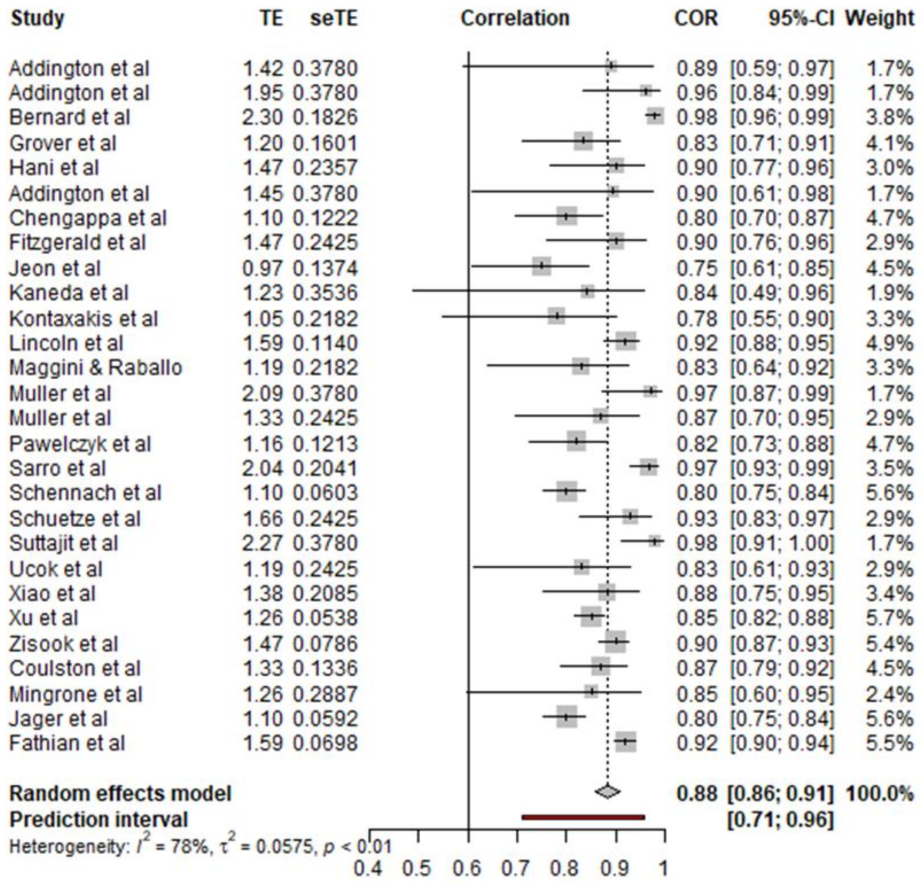

*Figure 7.* Forest plot of the omnibus test of the IRR coefficients.

### *Attenuation due to Influential Studies*

The Baujat et al. (2002) scatterplot in Figure 8 indicates there is one study that is potentially exerting a disproportionate influence over the meta-analytic synthesis. This study was conducted by Bernard et al. (1998) with its placement in the upper right-hand corner of the scatterplot reflecting a large influence on both the estimated meta-analytic effect and the overall level of heterogeneity. Bernard et al's (1998) was the only study to utilise the French variant of the CDSS and the authors also note that some participants had very low scores on the CDSS (mean: 6.97, range: 0-22). In addition, several measures of depression were used, with two members of the research team completing these, such that contamination effects across the assessments cannot be ruled out. These factors may have contributed to these findings being discrepant from the other literature. To explore whether exclusion of this study impacted upon the overall conclusion of the analysis, the meta-analytic effect was estimated with Bernard et al's (1998) study removed. This resulted in a non-substantive difference (estimated IRR = 0.87; 95% CI: 0.85-0.90). As such, this study remained in the dataset for calculating the overall effect, whereby the data are considered robust to the effects of disproportionately influential studies.

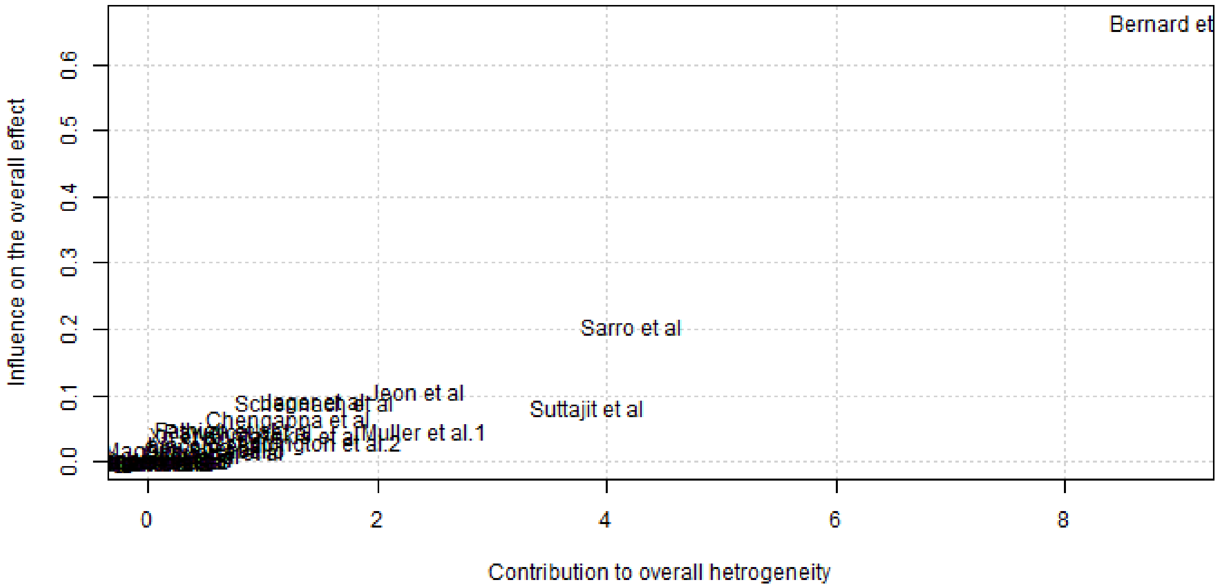

*Figure 8.* Baujat scatterplot depicting heterogeneity in estimates of IRR.

### ***Attenuation due to Risk of Bias***

The QEM was calculated using the risk of bias ratings provided in Table 4. The effect estimated by this model suggested studies of a better methodological quality report slightly better estimates. The meta-analytic effect reported by the QEM (0.89, 95% CI: 0.87-0.92). This is comparable to that of the non-weighted estimate, such that any difference due to variation in methodological quality is negligible. These data are, therefore, considered robust to the effects of methodological bias.

### ***Publication Bias and Small Study Effects***

The correlation between Fisher's (1921) z transformed correlation coefficient and the standard error for IRR data is depicted in Figure 9. The distribution of the data about the meta-analytic effect value suggests publication bias may be present. This is due to the lack of primary studies within the bottom left-hand corner of the funnel. It is of note, however, that use of Duval and Tweedle's (2000a; 2000b) trim and fill procedure did not result in any corrections for publication bias. Literature also highlights the potential limitations of relying on funnel plots alone for determining publication bias. For example, Terrin, Schmid and Lau's (2005) studied revealed difficulties in correctly identifying publication bias from visual inspection of the funnel plot alone. They also noted that other factors, besides publication bias, can contribute to asymmetry within a funnel plot, including heterogeneity. As such, Orwin's (1983) method was used alongside the funnel plot. The use of Orwin's (1983) method indicated that 41 null studies (i.e. 146% of the existing literature) would be required to reduce the effect below an IRR value of 0.60. These data can, therefore, be considered robust to the effects of publication bias.

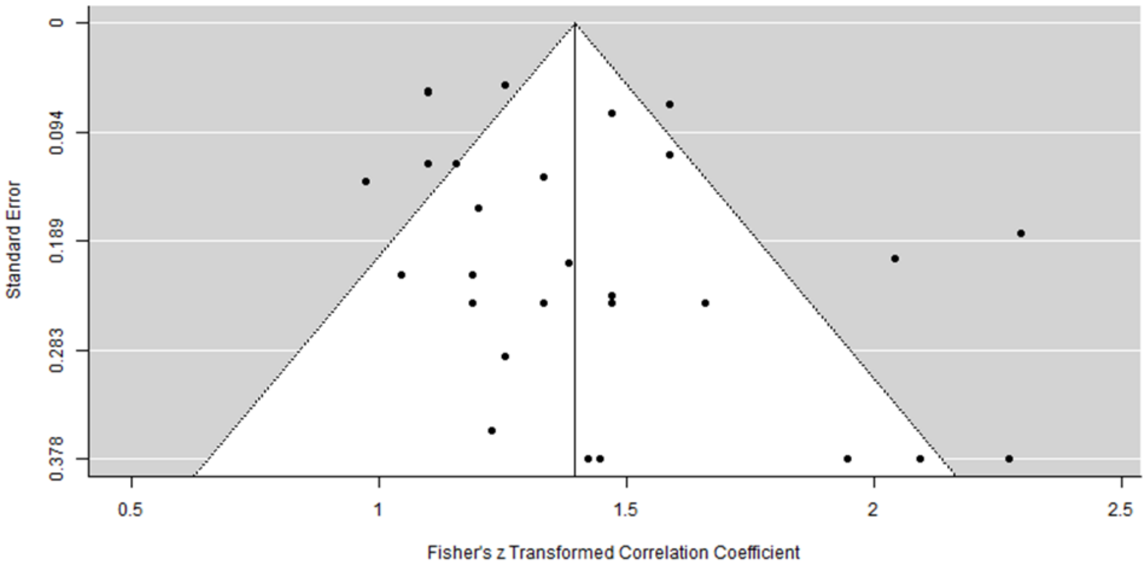

*Figure 9.* Funnel plot of the correlation between Fisher's z transformed correlation coefficient and standard error (IRR coefficients).

### *Attenuation due to Diagnosis*

To consider whether the composition of the sample's diagnosis had any influence on the distribution of IRR coefficients for the CDSS ratings, a subgroup analysis was conducted. The primary studies were categorised into two groups: Pure and Mixed, as occurred with the internal consistency data. The results of this analysis can be seen in Table 7. A non-significant and negligible difference was observed between the groups.

Table 7.

*Subgroup analysis regarding sample diagnosis.*

| **Sub-group analysis** | | **Number of studies** | **Random Effects Model** | | **Heterogeneity** | | | **Between groups comparison** |
|---|---|---|---|---|---|---|---|---|
| | | | **Reliability** | **95% CI** | **Higgins $I^2$** | **Tau$^2$** | **Cochran's Q** | |
| **Nature of diagnosis of the study sample** | Pure | 18 | 0.88 | 0.84-0.91 | 76.70 | 0.07 | 72.98 | Q = 0.05, *p* = 0.821 |
| | Mixed | 10 | 0.89 | 0.87-0.92 | 80.40 | 0.05 | 45.84 | |

### *Attenuation due to Version of Measure*

To consider whether the version of the CDSS used had any influence on the distribution of IRR coefficients for the CDSS ratings, a subgroup analysis was conducted. The primary studies were categorised into two groups: Original and Translated, as occurred with the internal consistency data. The results of this analysis are summarised in Table 8, which indicates there was a non-significant difference in the effect when analysed by the version of the CDSS used. As with the previous sub-group analysis (Table 7), this indicates consistency in the effect across the groups.

Table 8.

*Subgroup analysis for variant of the CDSS conducted.*

| Sub-group analysis | | Number of studies | Random Effects Model | | Heterogeneity | | | Between groups comparison |
|---|---|---|---|---|---|---|---|---|
| | | | Reliability | 95% CI | Higgins $I^2$ | Tau$^2$ | Cochran's Q | |
| Version of CDSS used | Original | 8 | 0.89 | 0.85-0.92 | 52.60 | 0.02 | 14.76 | Q = 0.34, *p* = 0.558 |
| | Translated | 15 | 0.91 | 0.87-0.93 | 82.00 | 0.09 | 77.61 | |

## Test-Retest Reliability

There were seven studies reporting test-retest reliability coefficients. These were reported as intraclass correlation values. The data arises from a total sample of 187[9], with sample sizes ranging from 14 (Sarro et al., 2004) to 60 (Suttajit et al., 2013). All studies had a maximum test-retest period of three days, apart from Kaneda et al's (2000) study whose

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[9] It is of note that for two of the primary studies it was unclear whether the whole sample or a subset of the entire sample was used to calculate the test-retest reliability coefficient. For those studies for which it was unclear, the total sample has been used as the N value.

maximum test-retest period was eight days. The distribution of the study level estimates of Fisher's (1921) transformation of the test-retest reliability coefficients is shown in the QQ plot in Figure 10. Despite the small number of studies, the data appears to approximate a normal distribution, such that the DerSimonian-Laird estimate is appropriate to use as the measure of between-studies variation. Using this estimate, the random effects synthesis of these seven studies had an estimated test-retest reliability of 0.87 (95% CI: 0.81-0.91), as shown in Figure 11. Given the limited sample of studies no further analysis has been computed.

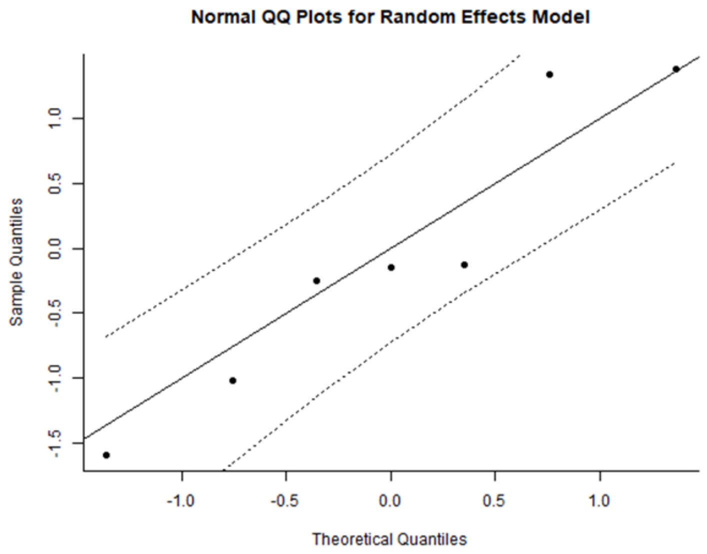

*Figure 10.* QQ plot indicating distribution of study level effects for test-retest reliability coefficients.

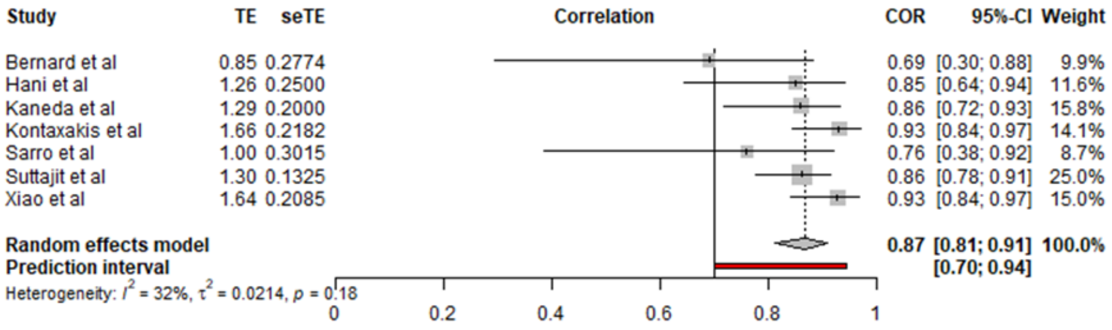

*Figure 11.* Forest plot of the omnibus test of the test-retest reliability coefficients.

# DISCUSSION

## Summary of Evidence

This meta-analytic review aimed to quantify the reliability of the CDSS, which is a widely used measure of symptoms of depression in individuals with a diagnosis of schizophrenia. There were some difficulties in performing this meta-analysis, related to the available body of literature. Of the 588 studies identified as using the CDSS, 469 were excluded due to not reporting reliability data. There was also a limited number of studies reporting on the CDSS' test-retest reliability within their study (N=7). Given the small number of studies, alongside the limitations of this literature (e.g. presence of heterogeneity and three studies having a small sample size (<20)), an in-depth analysis of test-retest reliability coefficients was not computed.

The review, therefore, focused on the CDSS' internal consistency and IRR. The search process identified 39 eligible studies, with 26 included within the meta-analysis of alpha coefficients and 28 used to meta-analyse IRR coefficients. The alpha coefficient meta-analysis (0.83, CI: 0.82-0.84) suggests the CDSS has a good degree of internal consistency, in accordance with Streiner's (2003) guidelines for interpreting alpha coefficients. Meta-analysing the ICC and kappa coefficients indicates the IRR of the CDSS is excellent (0.88; CI: 0.86-0.91), when considered in relation to Cicchetti's (1994) guidelines. The current review highlighted non-significant differences in estimates of both internal consistency (Q=1.41, p=0.235) and IRR (Q=0.34, p=0.58) between the original version of the CDSS and translated versions. Despite the CDSS being developed specifically for use with individuals diagnosed with schizophrenia, rather than other psychotic disorders, this meta-analysis found consistency in the estimates of internal consistency and IRR between differently comprised samples (i.e. 100% vs. >50% had a diagnosis of schizophrenia). This emphasises the importance of commonalities between different psychotic disorders over and above aspects that distinguish between different diagnostic groups. As such, this may suggest that the CDSS is detecting common aspects of symptoms across diagnoses. This could be considered more consistent with a dimensional approach to understanding symptoms of psychosis, in which they fall on a continuum (i.e. more or less present) rather than into discrete diagnoses as advocated for within the categorical approach.

A previous review by Lako et al. (2012) concluded the CDSS outperformed, in terms of reliability and validity, five other tools for assessing the presence of depressive symptoms in individuals with a diagnosis of schizophrenia. Their review reported that the CDSS has good internal consistency (0.82; CI: 0.76-0.88) and good IRR (0.86; CI: 0.73-0.98). These values are comparable to those of the current meta-analysis, albeit with larger CI, potentially reflecting the smaller number of studies upon which the estimates of Lako et al. (2012) are based. Lako et al's (2012) review, however, calculated reliability estimates using the mean of individual study coefficients, rather than the weighted means as used in the current review. The simple arithmetic mean is subject to multiple biases, principle amongst which is the failure of the arithmetic mean to consider the precision of the individual estimates. This means poorer quality evidence is weighted as highly as better quality evidence. Regarding the reliability data, Lako et al's (2012) outcomes were based upon analysis conducted on a smaller body of literature (N=14). The current review can, therefore, be considered the first of its kind to quantitatively synthesise both the CDSS' internal consistency and IRR across numerous studies. Further, this review has highlighted the CDSS to have good internal consistency and excellent IRR for multiple languages.

## Implications of the Findings

### *Service Users*

When considering the impact of this meta-analysis on service users, the findings present the CDSS as a psychometrically-sound tool. Service users can, therefore, be reassured that, as an assessment tool for screening individuals with schizophrenia for depressive symptoms, it is fit for purpose. It is important to note, however, that the CDSS is a clinician-administered measure. This means that the exact reliability is dependent upon the assessor, with Cella et al. (2015) highlighting limitations of this format of administration. For example, there is the potential for interviewer bias, which may reflect the assessor's rapport with the client, their familiarity with the measure, their interviewing skills and their beliefs about the diagnosis of schizophrenia. Some of this variation is addressed within the protocol for using the CDSS, as outlined within the *Introduction,* but as noted it was not always clear whether the assessors had receiving training in-line with this protocol *(as captured within the Risk of Bias criteria shown in Tables 3 and 4).* It is also important to consider that the reliability of the measure could be affected by the client's engagement in the interview process. The client's engagement is likely to be influenced by their ability and willingness to engage in the assessment process, which may reflect their mental state and rapport with the assessor. This review also highlighted that language variants of the CDSS are reliable with respect to internal consistency and IRR. This may enable service users to be assessed using a measure in their first language or, for bilingual service users to select the language version with which they are more confident.

### ***Clinicians***

Regarding the impact of this review on clinical practice, for both internal consistency and IRR, the meta-analytic effect is greater than the threshold recommended (i.e. >.70 and >.60 respectively). As such, clinicians can be confident in using the CDSS to screen for symptoms of depression in individuals with schizophrenia, and subsequently acting upon the findings. Given the findings regarding the translated versions of the CDSS, it may be beneficial for clinicians to consider which version may be best (i.e. more reliable) when working with bilingual service users.

For clinicians, it is important to consider whether an individual's change in score on a measure reflects a clinically significant difference. This is important when evaluating an individual's progress in therapy, with consideration of the change observed in CDSS score between the start and end of therapy. The Reliable Change Index (RCI) provides a means of determining the degree of change required for an individual's presentation to be considered a reliable change (i.e. above that expected of measurement error) in their mental wellbeing (Ferguson, Robinson & Splaine, 2002). That is to say an observed difference is due to real change rather than error arising from the measure's imprecision. Table 9 reports the cut-offs for reliable change for inpatient and outpatient respondents using the standard deviations reported by Addington et al. (1994) and the alpha coefficients from the current review. Reliable change was calculated using the procedures described by Jacobson and Truax (1991). This indicates that, for an alpha coefficient of 0.83, a change of 5.14 (inpatients) or 4.64 (outpatients) to an individual's CDSS score is required for clinicians to be sufficiently confident (i.e. within 95% CI) that the individual is showing a clinically reliable change in the extent to which they experience depressive symptoms.

Table 9.

*Reliable change indices at varying levels of confidence.*

| | **Inpatient** | **Outpatient** |
|---|---|---|
| Reliable Change at 51% Confidence | ±1.73 | ±1.56 |
| Reliable Change at 66% Confidence | ±2.62 | ±2.37 |
| Reliable Change at 95% Confidence | ±5.14 | ±4.64 |
| Reliable Change at 99% Confidence | ±5.25 | ±4.73 |

### ***Researchers***

The impact of this meta-analysis on researchers can be considered in terms of outstanding research needs and recommendations for data reporting. Regarding future research, this review suggested comparable reliability estimates across the language variants of the CDSS. This was via a subgroup analysis of studies using the original measure against those using a translated version. Within the evidence included in this review, several of the translated versions were only used in one primary study. To develop understanding of the psychometric properties of these versions, further research may be beneficial. This may include consideration of whether there are different norms for different populations (e.g. by age or by nature of diagnosis).

In terms of recommendations, these have been identified in relation to challenges experienced in completing this meta-analysis, primarily during data extraction. Future reviews of this nature would benefit from authors reporting reliability coefficients for assessment tools used within their study, regardless of the study's aims. This would expand the range of literature incorporated within such reviews. The ability to synthesise results from individual researchers would also be improved by clearly documenting how reliability coefficients were calculated. For example, data extraction in the current review was compromised by various studies not detailing how IRR had been computed (i.e. on what proportion of the overall sample and the number of raters used). Together, improved data reporting will provide further opportunities to quantify the internal consistency and IRR of the CDSS and enable the CDSS' test-retest reliability to be quantified.

## Limitations

This meta-analysis focused upon the CDSS' internal consistency and IRR. Another area of importance is the tool's stability across time (i.e. test-retest reliability). As previously mentioned, seven studies were identified that reported test-retest coefficients. The quality of the data, however, alongside the small body of literature, was considered unsuitable for a meta-analytic review. The current review would, therefore, be complemented by a review quantifying the CDSS' test-retest reliability.

Regarding methodology, the literature search, identification of studies for inclusion and data extraction were completed by one researcher. There is, therefore, the potential for errors to have occurred during these processes. Within the literature, it is recommended that data extraction involves multiple researchers where feasible (Kitchenham, 2004). For this meta-analysis, resource and time constraints prevented this. The extraction process for this analysis, however, was considered reasonably simple given the nature of the data being extracted (i.e. reliability coefficients, sample size and number of items). In addition, any queries about data extraction or study inclusion were discussed with the researcher’s supervisors.

One of the exclusion criteria involved filtering out primary studies in a non-English language. This was due to constraints around resources required to translate such articles. This resulted in 31 studies being excluded, although it was unclear whether these papers provided the required data for inclusion. As translated versions of the CDSS may be published in non-English journals, there is potentially a number of relevant articles not included within this review. This, therefore, limits the claims that can be made when comparing the reliability of the original CDSS and translated versions. A future review would benefit from including non-English studies to provide a more comprehensive insight into the reliability of translated versions of the CDSS.

## Conclusions

In summary, this meta-analysis provides an important contribution to the existent literature on the CDSS. Using advanced statistical techniques, this review has quantified the internal consistency and the IRR of the CDSS. The findings suggest the CDSS is a reliable tool for assessing for symptoms of depression in individuals with schizophrenia. This provides reassurance to clinicians and service users that the CDSS is an appropriate measure to use within clinical practice.

This review has also provided several recommendations that will contribute to on-going research on the CDSS and its reliability. This will develop the existing understanding of the measure's reliability, particularly its reliability over time (i.e. test-retest reliability). It is hoped that the research resulting from such recommendations will support researchers and clinicians to utilise the CDSS effectively and with confidence.

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# CHAPTER TWO: EMPIRICAL RESEARCH PAPER

# HOW DO COUPLES EXPERIENCE THE RECOVERY FROM POSTPARTUM PSYCHOSIS IN THE CONTEXT OF A MBU?

# ABSTRACT

**Background**

Perinatal Mental Illnesses (PMI) are experienced by about 10% of women. Postpartum Psychosis (PP), one of the most severe PMI, is associated with high risk to the mother and baby. Treatment within a Mother and Baby Unit (MBU) is recommended. At present, research is limited on how couples experience an episode of PP, with no studies focusing on treatment setting. This study, therefore, aimed to explore how couples experience PP when the mother is treated in a MBU.

**Methods**

This qualitative study used purposive sampling to recruit couples who had experienced an episode of PP. Individual interviews were conducted with two mothers and their partners, and analysed using multi-perspectival Interpretative Phenomenological Analysis.

**Findings**

The final analysis considered each dyad individually. Four superordinate themes were identified for each dyad. Themes captured shared and unique individual aspects of their experience. Overarching ideas, albeit different for each dyad, included: PP as not known about, a process of figuring out what was going on, valuing the MBU and recovery being gradual and on-going. Systemic ideas were also emphasised, including the couple experiencing PP together and PP impacting the wider system.

## Conclusion

The study’s findings highlight the widespread effects of an episode of PP, illustrating the direct and indirect experiences of the illness. It provides insight into the benefits and challenges associated for the couple in the mother being in a MBU. This develops understanding of this population’s needs, indicating areas of importance for services to consider.

# INTRODUCTION

## Perinatal Mental Illness

The perinatal period covers pregnancy and the first year following the birth. Perinatal Mental Illnesses (PMI) are estimated to affect 10% of women, including onset of new difficulties and recurrence of pre-existing mental health conditions (NHS, 2015). The range of difficulties is akin to those outside the perinatal period, including anxiety, depression, psychosis, and adjustment difficulties (JCPMH, 2012). There are different considerations, however, due to the need to tease apart normal mood and behavioural changes associated with pregnancy from changes reflecting mental illness (NICE, 2014).

## Postpartum Psychosis

Postpartum psychosis (PP) is defined as *"psychosis often with mania and/or depressive symptoms in the immediate postnatal period, which can become very severe extremely quickly"* (NICE, 2014, pp. 14). It is estimated to affect two women per 1000 who give birth, occurring in women with and without a history of mental illness, although individuals with type one bipolar disorder are at an increased risk (NICE, 2014). PP is one of the most severe forms of PMI, with elevated risk of suicide, often requiring hospitalisation (Kohl, 2004; Lewis, 2007). Symptoms typically emerge two to four weeks after childbirth, with onset very rapid (Higgins, 2011). Brockington (1996, pp. 200) described a typical presentation as *"an odd affect, withdrawn, distracted by auditory hallucinations, incompetent, confused, catatonic; or alternatively, elated, labile, rambling in speech, agitated or excessively active."* Table 10 outlines other symptoms commonly observed.

Table 10.

*Commonly observed symptoms of PP**.

| |
|---|
| Delusions of a paranoid, grandiose, persecutory, or jealous nature |
| Variable mood, including periods of irritability |
| Confusion of thought and racing thoughts |
| Disorganised behaviour, considered a significant variation from the person’s typical presentation |
| Hallucinations (including tactile, visual, and olfactory) |
| Sleep difficulties (e.g. insomnia) |
| Restlessness |

* Heron, Craddock & Jones, 2005; Lewis, 2007; Seyfried & Marcus, 2003; Sit, Rothschild & Wisner, 2006; Wisner, Peindl & Hanusa, 1994

The understanding of the causes of PP continues to be explored. The existing evidence has focused upon biological and hormonal factors, with less clear understanding of psychological and environmental factors. In terms of psychological factors, Dowlatshahi and Paykel’s (1990) study did not find an association between social stress and occurrence of PP, with the authors suggesting this reflected PP having largely biological causes. Similarly, Marks, Wieck, Checkley and Kumar’s (1991) research provided support for an association between significant life stressors and non-psychotic postpartum illnesses but not psychotic PMI. Regarding obstetric factors, PP has been found to be more prevalent in women experiencing obstetric complications, such as pre-eclampsia (Bergink et al., 2015). PP has also been suggested to reflect abnormal sensitivity to endocrinological disturbances (i.e. significant decreases in oestrogen levels following placenta removal), with support for this theory gained from oestrogen supplementation ameliorating symptoms (Balaraman & Schmetzer, 2011).

Despite this lack of clarity around psychological factors, such factors are typically considered when discussing the etiology of PP. In general, models of PMI present these disorders as the result of interaction between biological, psychological, and socio-environmental factors. For example, the biopsychosocial model of perinatal distress suggests that PMI, such as PP, arise from bidirectional interplay of different vulnerabilities which are mediated by life stressors (Wenzel & Kleiman, 2015). This model considered biological, neurochemical, and psychological vulnerabilities, with the complexity of PMI reflected in how these vulnerabilities influence one another rather than functioning in isolation. The complexity of PMI is also reflected in life stressors capturing both general stressors (e.g. work pressures) and perinatal specific stresses (e.g. pregnancy complications or practical pressures around the baby's arrival). This interplay of factors is also seen within Davies' (2017) model, in which PP is presented as a product of the interplay of biological (e.g. endocrine organ dysfunction and/or placental dysfunction), genetic (e.g. family or personal history of bipolar affective disorder and/or altered CCN gene function) and psychological (e.g. psychosocial stressors and/or sleep disturbance) vulnerabilities. The range of factors highlighted within these models reflects the current approach to treating PP, which incorporates both pharmacological and psychological interventions (NICE, 2014).

## Mother and Baby Units

Current guidelines, covering England and Wales, regarding PP indicate treatment should occur in Mother and Baby Units (MBUs) rather than general psychiatric wards (NICE, 2014). MBUs are part of an integrated care model, in which they work alongside maternity services, health visitors and perinatal mental health teams (BPS, 2016). MBUs currently provide specialist care from the third trimester of pregnancy through to the baby's first birthday. This approach to treating PMI reflects acknowledgement of the need for specific knowledge and expertise due to complexities inherent to the timing of the presenting mental health difficulties (JCPMH, 2012). In addition, MBUs (unlike general psychiatric wards) enable mother and baby to remain together when admission is required postnatally. This is important as separation during the first 12-months can significantly disrupt their bonding and nature of attachment (Bowlby, 1969; 1973), which may impact the baby further, given this attachment provides the template for future relationships (Hogg, 2013).

Untreated or inadequately managed PMI can contribute to poor maternal self-esteem, disruption to relationships, impaired child development and maternal suicide (JCPMH, 2012). A priority of perinatal mental health services is, therefore, to ensure timely access to the most appropriate support (NCCMH, 2018). This is particularly important given the cost of poor detection of PMI, which prevents fast and effective treatment, amounts to £8.1 billion per year (Bauer, Parsonage, Knapp, Iemmi & Adelaja, 2014). There are several different perinatal mental healthcare pathways within the integrated model, with the potential for women's care to traverse the different pathways. MBUs fall within Pathway Five, with women accessing this pathway having complex needs and requiring specialist inpatient care (NCCMH, 2018). Admission to MBUs can be planned, with referrals typically made by secondary and tertiary services (e.g. Home Treatment Teams, Community Mental

Health Teams or acute inpatient wards), or emergency, with such admissions often resulting from urgent assessments conducted as part of Pathway Three (NCCMH, 2018).

MBUs aim to treat PMI symptoms, care for mothers, and support the mother-baby relationship to develop (NHS, 2018). This can facilitate stronger attachments and better parenting as reflected by the extent to which the child's needs are met (NHS, 2018). MBUs operate using a multi-disciplinary approach and offer a range of interventions from pharmacological treatment, psychological therapy and occupational therapy alongside nursery nurses providing advice and support for new mothers (RCP, 2018). Regarding psychological input, Clinical Psychologists promote the team's psychological thinking to support understanding of clinical presentations through offering consultancy around diagnosis and formulation and providing supervision and reflective practice forums. Additionally, Clinical Psychologists work with mothers individually to address mental health difficulties and also support the mother-baby relationship to develop through intervening in cases of bonding, attachment, or parenting difficulties (BPS, 2016).

Existing guidelines highlight the importance of considering family needs, given their role in supporting the mother (NICE, 2014). Research acknowledges partners can find the mother's experience of PP frightening and stress-provoking (Higgins, 2011; Muchena, 2007). Given increasing awareness of PMI in fathers (Wong et al., 2015) and acknowledgement of the family's pivotal role, a systemic approach is essential. Current

MBU service standards reflect this approach in suggesting partners are well-informed, involved in care planning and have their needs considered (Flewett, 2016).

### Existing Literature

PP has a limited but growing body of research. An early study explored how mothers understood their illness and how it impacted their relationships (Robertson & Lyons, 2003). PP was considered a distinct mental illness caused by having a child, therefore, different from other mental illnesses. This view was shared by mothers in Glover, Jomeen, Urquhart and Martin's (2014) research, where PP was considered the result of biological changes within pregnancy. Robertson and Lyons (2003) identified a theme of 'loss' about participant's role as a mother, which was associated with feelings of guilt and lacking control. Mothers typically felt their partners were under-supported, given pressures they faced (e.g. an acutely unwell partner, separation from their baby and multiple responsibilities). Subsequent research has focused on a theoretical understanding of PP (McGrath, Peters, Wieck & Wittkowski; 2013). Accounts from mothers suggested a multi-stage recovery, progressing from initial crisis management to moving forward. A narrative also captured by Heron et al (2012) when exploring mothers' views of recovering from PP.

Admission to a MBU involves fathers being separated from their partner and new-born. This can be traumatic, stressful, and frightening for fathers (Higgins, 2011). Recent research explored how fathers experienced their partner's admission to a MBU due to PP (Boddy, Gordon, MacCallum & McGuiness, 2016). Fathers expressed not knowing what was happening and feeling excluded by professionals, contributing to embarrassment and confusion. This reflects Glover et al’s (2014) findings whereby mothers felt unsupported as their support network could neither understand nor cope with the PP. Fathers also spoke about role changes, relationships and identity, including PP delaying them becoming a father and being a family. This parallels research indicating an episode of PP is an uncertain time because expectations of becoming a father do not materialise (Muchena, 2007), and is overwhelming and traumatic because it unexpectedly takes the place of an anticipated joyous event (Heron et al., 2012). These findings suggest fathers have their own needs and have a supportive role for their partner.

Wyatt, Murray, Davies and Jomeen (2015) considered PP in the context of relationships by interviewing dyads. PP was experienced as both contributing to difficulties and positively strengthening relationships. Negative effects related to changes observed in mothers, experiences of loss and partners experiencing guilt due to hospitalisation being required. Positive elements centred around increased trust and respect, alongside pre-existing positive relationship qualities being strengthened. The authors suggested relationships with significant others can facilitate recovery by providing mothers containment during their illness.

There are study limitations to consider when interpreting these findings. Samples typically displayed high levels of heterogeneity (Glover et al., 2014; Heron et al., 2012; McGrath et al., 2013; Robertson & Lyons, 2003; Wyatt et al., 2015), including between-participant differences in presence of subsequent episodes of mental illness and duration since PP episode. More problematic heterogeneity is variation in setting, with treatment received in general psychiatric wards, maternity wards, MBUs and at home. Different treatment settings mean aspects unique to MBUs may be missed, including access to specialist professionals and remaining with their baby. This limits understanding of how the MBU involvement impacted perception of PP and the recovery. This is important given how mother-child interactions can influence recovery (Plunkett, Peters, Wieck & Wittkowski, 2015).

Other limitations relate to couples being interviewed jointly (Wyatt et al., 2015) and interviews occurring pre-discharge (Boddy et al., 2016). This limits understanding of PP's longer-term impact and the adjustment process and does not reflect experiences individuals feel uncomfortable discussing with their partner.

### Study Rationale

Existing literature is particularly limited in accessing couples' views of experiencing PP when treated in a MBU. This knowledge is important given recent developments in perinatal mental healthcare provision across England, including more MBUs, additional beds in existing MBUs and forming specialist perinatal teams (NHS, 2017). These aim to decrease admissions to general psychiatric wards for PMI to reduce the likelihood of risk to mother (self-harm or suicide) and baby (neglect or physical harm) (Bauer et al., 2014; Flewett, 2016).

Experiencing PMI can be viewed as disrupting the transition to parenthood. It is, therefore, important to develop the limited body of evidence on PP, particularly given guidelines recommend a family approach (Flewett, 2016). Research has begun to explore these areas, although guidelines indicate recommendations are based upon *"the best available evidence"* which has *"significant limitations"* (NICE, 2014, pp. 7). For example, the recommendation for MBU treatment comes from research on women treated in different settings due to national variation in perinatal services. Combining experiences across settings poses difficulties for relating the understanding to aspects of care specific to the hospital environment, impacting the ability to use findings to inform future provision of perinatal services. Studies have predominantly included White-British females. This limited diversity affects generalisability of findings given cross-cultural variation in how PP presents, beliefs about the causes and treatment attitudes (Cox, 1979; Nakigudde et al., 2010).

### Aims

This research aims to explore the experience of PP for mothers and their partners when treatment occurred in a MBU, with consideration of the couple's joint experience. This will increase understanding of the needs and nature of support required by this population, in light of new perinatal service developments.

# METHOD

## Study Design

A qualitative study design was selected, using Interpretative Phenomenological Analysis (IPA). According to Smith, Flowers and Larkin (2009), IPA seeks to understand how individuals experience life events and the meaning they attach. It is a phenomenological approach, meaning specific situations are focused on to consider the individual's experience within the wider context of their life. IPA was chosen as it has been identified as a useful methodology for exploring topics with a limited evidence base (Olson, Young & Schultz, 2015). IPA was also considered appropriate given an episode of PP is likely to be a significant life event for mothers and partners, with dyads as the unit of study.

Despite focusing on understanding individual experiences, IPA is acknowledged as amenable for gathering multiple perspectives, termed multiperspectival IPA. This approach considers events experienced by individuals are based in their wider context, capturing more systemic aspects. For example, mental illnesses such as PP, are not only experienced by the individual with the diagnosis but also those within their *"lived world,"* including partners and family members (Larkin, Shaw & Flowers, 2019; pp. 182). IPA takes the Heideggerian view of individuals as 'person-in-context' with their interactions with the world central to who they are and their interpretation of experiences (Larkin, Watts & Clifton, 2006; Smith et al., 2009). Multiperspectival IPA, therefore, captures shared and relational aspects of an individual's sense-making.

**Participants**

Participants were recruited via purposive sampling, as IPA requires a homogeneous sample (Pietkiewicz & Smith, 2014). For the purposes of this study, the desired homogeneity related primarily to the woman's diagnosis and treatment setting. As such, the focus was on identifying women who had received a diagnosis of PP and been treated on a MBU. Given the aforementioned differences regarding the presentation and beliefs about PP seen cross-culturally (e.g. Cox, 1979; Nakigudde et al., 2010), a culturally homogenous sample was also desired. Recruitment was from one NHS Foundation Trust in England. Participants were recruited as couples, with first contact made with mothers. Couples meeting the inclusion criteria in Table 11 were eligible.

Table 11.

*Inclusion criteria.*

| **Inclusion Criteria** |
|---|
| - The mother experienced an episode of psychosis after giving birth, and had received a diagnosis of PP.<br>- The mother received treatment in a MBU and was discharged in the past four years.<br>- Neither the mother nor their partner had previously received a diagnosis of a psychotic illness.<br>- The mother and their partner remained together as a couple (i.e. in a relationship).<br>- Both the mother and their partner were fluent in English (i.e. able to provide informed consent and participate in an interview in English). |

Recruitment occurred between August 2019 and March 2020. Ten mothers were identified; of these, six could not be contacted via the details available and three consented to receive further information. The target sample size, six couples, was based upon guidelines regarding that considered appropriate for obtaining sufficient information and feasible for achieving a thorough analysis within time constraints of a professional doctoral thesis (Thompson, Larkin & Smith, 2011).

The final sample comprised two couples, limited due to the COVID-19 pandemic and associated restrictions impacting recruitment. To ensure external anonymity, participants were assigned a pseudonym. Table 12 presents demographic information for each couple.

Table 12.

*Participant demographic information.*

| | **Dyad One** | | **Dyad Two** | |
|---|---|---|---|---|
| **Pseudonym** | Priya | Dhanesh | Ellie | Mark |
| **Age** | 28 | 29 | 29 | 39 |
| **Ethnicity** | Indian | Indian | White-British | White-British |
| **Number of Children** | 1<br>Aditi | 1<br>Aditi | 2<br>Lily & Harry | 2<br>Lily & Harry |
| **Nature of Delivery** | Vaginal with forceps | Vaginal with forceps | Vaginal – no complications | Vaginal – no complications |
| **Time between birth and diagnosis of PP** | 2 weeks | 2 weeks | 8 weeks | 8 weeks |
| **Time since discharge from MBU** | 10 months | 10 months | 4 months | 4 months |
| **Previous Mental Health Difficulties** | No | No | No | Self-reported depression, no formal diagnosis or contact with services |

### Procedure

A local NHS Foundation Trust's clinical team was contacted to discuss the study. They identified potential participants and contacted mothers by phone to inform them about the study. Interested individuals were sent two 'consent to be contacted' forms (one each for the mother and partner) (Appendix B). Completing these indicated they consented to their personal information being passed onto the researcher (the Trainee Clinical Psychologist). The researcher then posted out information sheets (Appendix C) before calling to discuss the study and answer any questions. Participants completed a screening questionnaire (Appendix D) by telephone, with interviews scheduled for those eligible to participate. Informed written consent (Appendix E) was obtained before interviewing. Interview location varied due to COVID-19. The first couple were interviewed face-to-face at their home and the second via video because non-essential face-to-face contact was prohibited. Semi-structured interviews were conducted with participants individually, guided by an interview schedule (Appendix F). This incorporated open questions, encouraging individuals to share and reflect on their experiences, whilst enabling matters important to participants to be explored further in line with the IPA approach (Smith et al., 2009). All interviews were recorded digitally and transcribed verbatim by the researcher.

### Ethical Considerations

Ethical approval was received from the Health Research Authority, including approval from the Leicester Central Research Ethics Committee (Appendix G). The researcher adhered to the British Psychological Society research guidelines (BPS, 2014), the Data Protection Act (Gov.uk, 2018), General Data Protection Regulations and the NHS

Trust’s data protection policies. This ensured participants’ right to anonymity and secure storage of personally-identifiable information.

The nature of the topic was considered to have the potential to elicit short-term distress by discussing emotive information and experiences, however, no long-term harm was anticipated. During interviews, the researcher monitored for potential indicators of distress, ensuring participant wellbeing was maintained. Participants were aware of their right to withdraw from the study with no impact on any on-going care.

The study’s dyadic nature presented ethical considerations. Mothers and partners were contacted separately, providing an opportunity to discuss the research alone and decide individually about participating. Interviews were conducted separately and guided by the interview schedule, ensuring information from one interview was not discussed during their partner’s interview. Before consenting, participants were informed the researcher would not provide therapy or crisis management but could signpost to third-party organisations if they wished to seek additional support.

Before interview, participants were informed of the limits of confidentiality. This included the researcher’s duty of care to inform the participant’s clinical team or local safeguarding body if any matters involving risk of harm to the participant or others were disclosed. Participants were debriefed post-interview and given the opportunity to discuss any concerns or issues.

Participants were told their interview transcript would be anonymised and identifiable information removed. Participants had the opportunity to receive their transcript with a two-week timeframe to inform the researcher of aspects they wanted excluding from analysis and/or dissemination documents. Access to this research was restricted to protect participants' identity, given the sample size and in-depth analysis. Summary documents for participants provided an overview of findings, without quotations to maintain participant confidentiality. This is important as dyadic qualitative research has an increased likelihood of individuals identifying their partner from the presented extracts (Larkin et al., 2019).

### Data Analysis

Interviews lasted between 43 minutes and 67 minutes (mean length: 53 minutes 25 seconds). Larkin et al.'s (2019) approach to multi-perspective data analysis was followed. This involved focusing on individual accounts before considering each dyad and how each partner's experience related to one other. During analysis, the researcher considered both emic and etic perspectives (Reid, Flowers & Larkin, 2005; Smith & Pietkiewicz, 2014). The emic stance involves developing a psychological understanding of participant experiences by applying psychological concepts and theories to the data. The etic approach seeks to provide additional understanding, capturing insight about which the participant themselves may be unaware.

Smith et al (2009) provide guidelines for analysis allowing an iterative cycle between raw data and interpretation of the data. The guidelines in Table 13 informed the analysis process.

Table 13.

*Description of the analysis stages undertaken (Smith et al., 2009).*

| **Stage Number** | **Stage Name** | **Stage Overview** |
|---|---|---|
| 1 | Reading and re-reading the transcript | By reading and re-reading the interview transcript, the researcher becomes immersed within the data. This ensures that the analysis is focused upon the participant and their experience through the researcher actively engaging with the participant's account. |
| 2 | Initial noting | A detailed step within the analysis that explores the transcript at a minute level to capture the content and the participant's language. This supports the researcher in understanding how the participant describes, understands and reflects on their experience. This is achieved by identifying what matters to the participant and the meaning they attach. The aim is to annotate the transcript using descriptive, linguistic and conceptual codes.<br>An example of this stage is presented in Appendix H. |

| Stage Number | Stage Name | Stage Overview |
|---|---|---|
| 3 | Developing prototype themes | The aim of this step is to collate the initial codes, gathered in the previous stage, into preliminary themes of related ideas. This is achieved by making connections between initial codes. This functions to condense the data without reducing the complexity or losing the detail within the data. The prototype themes capture the participant's view alongside a level of interpretation from the researcher.<br>An example of this stage is presented in Appendix I. |
| 4 | Searching for links across prototype themes | This stage involves the researcher considering how the prototype themes relate to one another. This process, of joining together initial themes, functions to capture the most important elements of the participant's experience. During this process, the researcher generates an overall understanding of the data, through the development of superordinate themes and subthemes.<br>An example of this stage is presented in Appendix J. |
| 5 | Moving to the next participant | Having completed the first four stages for participant one, this process is repeated for the next participant and so on. When completing subsequent analyses, it is important for the researcher to immerse themselves in the new data. This can be helped by bracketing their ideas from the previous analysis. |
| 6 | Exploring patterns across participants | Once each participant's transcript has been analysed in line with the first four stages, the final stage is to explore patterns across participants. This stage was adapted to capture additional guidelines regarding analysis of complex data (i.e. multi-perspective). In line with Larkin et al's (2019) strategies, shared elements and differences in individual experiences within the dyad were considered. This enabled themes to be identified that were shared across the partners whilst also capturing idiosyncratic aspects.<br>An example of this stage is presented in Appendix K. |

Stage 6, considering the multiperspectival level, aimed to make sense of the individual analyses in the context of the couple. Larkin et al. (2019) outline areas to develop this narrative, offering insight into the relationship and interaction between their experiences. This includes identifying overlaps (shared elements) and conflicts (differences), which can relate to concerns and/or the meaning attributed to experiences (Larkin et al., 2019). Eisikovits and Koren (2010) suggest this can be descriptive or interpretive.

Across the stages, the iterative process was followed ensuring analysis remained grounded in the data. Interview extracts were selected for illustrative purposes, increasing the transparency of the analysis whilst capturing both the participants' experiences and the researcher's interpretation (Hefferon & Gil-Rodriguez, 2011). This reflects IPA's double hermeneutic approach, acknowledging the researcher's own experiences influence how they access and understand participant narratives (Smith & Eatough, 2015).

## The Researcher's Epistemological Position and Reflexivity

The researcher's active role in IPA means it is important to consider personal experiences (Alase, 2017). The researcher completed this study during their Doctor of Clinical Psychology. They had a strong interest in the systemic model, particularly on understanding mental health difficulties in the wider familial context. This included how one person's diagnosis impacts the system around them.

The researcher had no clinical experience with individuals experiencing PMI, nor did they know anyone personally who had experienced PP. They were, however, interested in this area, informed of the literature and undertaking their final placement within a community perinatal team.

During analysis steps were taken to enhance its credibility and reliability. This included discussing themes and associated quotations in supervision and IPA peer-support groups, at the ideographic and dyadic level. The researcher also kept a reflective diary to monitor biases, helping ‘bracket’ personal experiences from participant experiences (Alase, 2017). This assisted in minimising the influence of any preconceptions, which is important for maintaining focus on the lived experience and, therefore, on the participants’ sense-making (Elliott, Fischer & Rennie, 1999).

With regards to epistemological position, the researcher adopted a critical realist approach. This was considered appropriate given the relatively young literature base and the focus on the individual experiences as opposed to seeking to extend findings to a reality independent of the participants. This position enabled ideas and views about PP within the context of a MBU to be obtained from those with lived experience in an exploratory manner. This was appropriate in light of the lack of research around how couples experience PP as previously highlighted, meaning theoretical understanding is currently limited.

# ANALYSIS

The following narrative presents the superordinate themes identified for each dyad. Given the small sample size and between-dyad variation (i.e. demographic and experiential differences), across-dyad analysis was not conducted. This reflects ideas underpinning multi-perspective IPA:

> *the overarching aim here is to produce an account that capitalises on multiplicity and offers a plausible interpretative perspective on how the participants' lifeworlds interact and overlap. This need not involve the loss of idiography, the artificial construction of consensus, or the denial of difference, but the analyst should be sensitive to these risks* (Larkin et al., 2019; pp. 192).

Each theme considers shared elements and differences, representing unique understanding and shared insight of their PP experiences.

## Dyad One: Priya and Dhanesh

Priya and Dhanesh had a new-born daughter, Aditi. Table 14 presents an overview of their themes, with all illustrative quotations included in Appendix L. Each theme will be described in turn.

Table 14.

*Overview of Priya and Dhanesh's themes.*

| Theme | Shared Elements | Differences |
|---|---|---|
| 1. Something's not right: is this normal? | - It's not what we expected<br>- Noticing symptoms and questioning *"what's going on"* | - Priya: mismatch with others in level of awareness<br>- Priya: focus on difference from her usual self |
| 2. Finding out it's psychosis and we're not on our own | - Discovering it's a mental illness<br>- There are others like us | - Dhanesh: focus on the process followed<br>- Priya: greater input from others for realisation and acceptance |
| 3. We're facing it together | - Impact of separation<br>- Keeping everyone in mind | - Dhanesh: focus on impact on him and his needs<br>- Priya: considering the impact on the couple's relationship |
| 4. We're getting the right help and becoming a family | - Importance of the MBU<br>- Getting better and becoming a family<br>- Returning home | - Priya: focus on regaining her identity<br>- Priya: considering positive changes |

### 1. *'Something's not right: is this normal?'*

The first superordinate theme focuses upon how the couple came to realise something was wrong. It represents the gradual process and reflects them trying to make sense of Priya's experiences in relation to expectations around childbirth. The fact it was their first child appeared central in how they responded to the situation.

<u>*Shared Elements:*</u>

a. *It's not what we expected*

Priya and Dhanesh initially did not identify changes they noticed as problematic. Dhanesh noticed Priya *"couldn't sleep for, err, a couple of days"* but felt this was *"just normal."* Similarly, Priya expressed *"initially I didn't think anything was wrong."* This links to it being their first child and a new experience, which is how they made sense of the situation:

> Priya: *I was just on the go. Initially, I didn't think anything was wrong, I just thought you know, maybe, because I've just had a baby girl I'm excited about it…it was all new to me, so thought nothing of it…like it's getting used to being a mother, it's all new.*

> Dhanesh: *after five days Priya couldn't sleep for, err, a couple of days and we thought it's just normal, like me, my mum and mother-in-law; because at that time my mother and mother-in-law they come to help us and to support because it's our first baby…I didn't know about the psychosis stuff, and thought this was just normal because my mother-in-law says [having a baby] takes time for it to become a routine life.*

This was further reflected in Priya saying *"after giving birth I mean you'd expect me to be exhausted, but I wasn't."* The couple did not know about PP, Dhanesh recalled: *"before we went to the MBU I don't know about the psychosis;"* and Priya stated: *"I'd never heard of psychosis and how it's linked to giving birth."* Overall, suggesting their reality did not match their expectations of childbirth.

### b. *Noticing symptoms and questioning "what's going on"*

Their lack of knowledge led the couple to question what they were noticing. Priya questioned *"what is going on in my head?"* and Dhanesh thought *"what's going on with her? I don't know."*

The first indicator of a problem noticed was Priya's on-going inability to sleep. Dhanesh said this started *"after five days"* and she *"couldn't sleep for next couple days as well."* Priya described *"I wasn't able to sleep, just wasn't able to switch off."* Both accounts reflected lack of sleep, with Priya describing a manic nature to her behaviour, having *"tremendous amounts of energy,"* explaining why she could not sleep.

Their concerns grew as the symptoms persisted, leaving them *"confused."* Dhanesh worried about them becoming a family, expressing *"I worried about Priya, because it's Priya, if she's not there, how can we bring up our little one?"* Priya worried about her symptoms, finding them *"very, very confusing,"* and even questioned her role asking, *"was that me…did I do that?"*

They also worried about Priya's behaviour which seemed odd. This was elicited from the behaviours they described, their thoughts on the behaviours and their emotional reactions:

> Dhanesh: *after 2am I woke up and Priya wasn't there. I look around upstairs and she wasn't there, and then the light was on downstairs and I come downstairs. And Priya was like drawing on the paper, she put a candle everywhere, outside as well, outside were lit candles but inside were real ones. And I was shocked, and wondered what was going on?*

> Priya: *I was like doing weird stuff in the middle of the night, like sorting out paperwork, folding clothes, coming downstairs and you know tidying up…I kept repeating words over and over again, like a sentence or a word…and my husband was like 'okay, what's going on here?'*

This illustrates a shared sense of Priya's behaviour being unusual. Dhanesh seemed more concerned, potentially reflecting variation in awareness discussed within 'Differences.'

<u>*Differences:*</u>

When Priya acknowledged *"something was wrong,"* her account reflected a mismatch in awareness with others. She reflected when she *"didn't think anything was wrong,"* not only was her husband suggesting it was *"not normal"* but *"everyone is saying this isn't normal."* Priya described herself, on reflection, as *"totally out of it,"* indicating a lack of awareness regarding her actions at the time.

Priya's awareness of symptoms related to how her experiences differed from her usual self. This mismatch was captured in her language and repeatedly saying *"I've never:"*

> Priya: *totally out of character…I was just up and, on the go, constantly doing stuff…my heart was like beating fast, I've never been so anxious. I've never been*

> *repeating my words. I've never been confused about anything…my behaviour just wasn't right.*

Dhanesh did not capture this mismatch but focused on specific behaviours he considered strange or feeling her presentation was unusual due to having given birth, as discussed previously.

Priya and Dhanesh's understanding of what they noticed was 'something is not right.' They had no other way of understanding how Priya was behaving (e.g. as an illness), so were left confused about what was happening at the time. Further understanding emerged with input from others, as theme two captures.

### 2. 'Finding out it's psychosis and we're not on our own'

This theme considers how the couple came to understand that the *"something is wrong"* was a mental illness. It illustrates how they found out it was called PP, their relief when realising other couples experience it and their different focuses.

*Shared Elements:*

a. *Discovering it's a mental illness*

After recognising *"something was wrong,"* there was a process to discovering that what Priya was experiencing was PP. They both felt her experience was a mental health concern, which professionals also voiced, suggesting it was an important distinction to make. Dhanesh thought it was something mental during the onset, recalling, *"it's been like six or seven days continuously where she hasn't like slept, so it's mentally health problem"* but Priya only thought this after being admitted, reflecting the mismatch in awareness between herself and others.

They both deemed the situation *"serious,"* but the idea of mental illness concerned Dhanesh more. This was captured in content and linguistically through repeatedly describing mental health difficulties as *"very bad," "very dangerous"* and *"very scary."* This potentially reflects differences in directly and indirectly experiencing psychosis.

The process of discovering it was PP involved professionals explaining what PP is and how it develops:

> Dhanesh: *when I saw the doctor he explained to me about the psychosis and that psychosis does not just come like flu but that you can build up in your mind and that if you don't share or are hiding something that it's very bad.*

> Priya: *the doctors came to see me, and they were like you know this is what we think you've got, you know … we believe you've got postpartum psychosis … there's imbalance in your hormones and that's why you're acting like this.*

Following the diagnosis, they both sought more information. Dhanesh used *"leaflets and some YouTube videos,"* which he found *"helpful."* Priya asked more questions:

> Priya: *I was obviously confused and wanting to know answers…like I said I've never heard of psychosis and how it's linked to giving birth…yeh, like not really heard of, like obviously postnatal depression and antenatal depression and all that has been heard of, but psychosis is quite you know never heard of, first time I heard of it, first*

> *time I came across it. So, initially I was like, okay, so what is psychosis? That was my first question I asked, like what is it? Umm, what are the symptoms of it and what does someone experience when they do have psychosis? Umm so these were all my questions and then I was like okay yeh this is me, yeh what you're saying is making sense.*

This suggests the diagnosis elicited a desire to know more about PP with additional information aiding their understanding. The information they received, therefore, can be considered as relieving their confusion and the associated concern previously discussed.

b. *There are others like us*

The couple experienced relief upon realising other new mothers experience PP:

> Priya: *I didn't feel like I was on my own. I felt like that there were other people who were experiencing similar things…my symptoms didn't seem so abnormal as such, like I didn't feel I was on my own, and that there were other people with me in this, kind of that are experiencing the same thing.*
>
> Dhanesh: *I less worry about her because when we came to the MBU I thought we were only one case but then I saw a few women, a few, so I feel ah it's not just us, there are others as well, so it's not only a problem for Priya.*

This reflects the importance for them in knowing others experience *"similar things,"* which reduced their sense of being *"abnormal"* and the only ones who experience this. This appeared helpful in reducing their worries.

*Differences:*

Dhanesh and Priya's accounts of gaining understanding differed in focus. Dhanesh focused on the process and input from professionals. He said doctors wanted to know about Priya's past *"like when she was a child and growing-up"* and the present by *"[observing] everything."* This appeared related to Dhanesh's uncertainty, with a sense he was guided by and reliant on professionals. This may be a particularly important source of knowledge for Dhanesh due to not having direct access to the experience of the episode, unlike Priya, which may be why this featured as particularly salient in his sense-making.

In contrast, Priya focused upon requiring input from others to acknowledge being unwell, as captured in an interaction with her observing nurse:

> Priya: *one day I totally lost it, I was like 'you don't need to be here, I'm totally fine' but [observing nurse] didn't argue back…but was like 'look you're a patient here and it's my duty to take care of you, that's why I'm here, I'm not here to judge you.'*

The progression in her understanding was also evident in how she described not identifying as *"a patient"* initially, before *"[realising], okay I'm a patient."*

Overall, this theme captures how the couple came to understand Priya was experiencing PP. It presents a gradual process, with the couple jointly valuing the MBU staff and being with others experiencing something similar, which provided them with relief.

### 3. ‘We’re facing it together’

The third superordinate theme considers how PP impacted the couple and the system around them, with the idea of everyone having needs. It reflects the couple’s perception they were facing and managing it together, despite also having unique experiences and challenges.

<u>*Shared Elements:*</u>

a. *Impact of separation*

Priya’s admission and the resulting separation affected Priya and Dhanesh. Priya reflected on the challenges she experienced:

> Priya: *I stayed in there for quite a long period of time. I was, umm, sort of getting a bit, umm homesick and I wanted to be around my family quite a lot. I was feeling really, really homesick and it was a shame I couldn’t spend a lot of time with my family.*

Dhanesh described the separation as *“very worrying, very difficult,”* acknowledging he *“missed baby as well.”* He also reflected his impatience to have Priya home:

> Dhanesh: *I tried to bring her back as soon as possible, after 28 days, but they said that she wasn’t ready to be released…I just tried to, I want to see Priya and see her stay at home, but after a couple of weeks I became patient and I want to see her better.*

These experiences highlight the impact of hospitalisation, suggesting it was difficult for Priya and Dhanesh, albeit differently.

Despite being separated, they both considered Dhanesh important for Priya. She described turning to him when confused, *"I remember calling my husband and asking 'why am I here? What's going on?'"* Similarly, Dhanesh described managing Priya's concerns:

> Dhanesh: *she say 'I feel very bad because I'm not looking after my baby,' and then after a few weeks she can recognise that she was not looking after her baby because I say 'you have to look after yourself first and then worry about your baby.'*

Priya also shared how Dhanesh helped reassure her when she was confused by saying: *"'look, trust me, you're in the right place, there are professionals there to help you.'"* Dhanesh expressed a similar idea:

> Dhanesh: *I tried to explain that Priya was dreaming, and it'll stop. Then next day I took the picture of me at home to show her and try and explain that I was at home [not at the hospital as she thought]…next couple of days I just tried to explain…but it was difficult to explain to her…it was difficult but I was trying to explain to her every day, and think about six or seven days she asked me and I explained to her. I explained that over a few days and then she was understanding.*

Here, the partner seems to play a central role, with Dhanesh providing reassurance and support alongside helping Priya understand her situation, emphasising PP as a shared experience.

### b. *Keeping everyone in mind*

For Priya and Dhanesh, there was a real sense of the widespread impact of PP on them becoming a family and on the wider family. The effect on their baby was a shared concern but at different stages. Dhanesh considered any possible impact on Aditi before Priya's admission:

> Dhanesh: *doctor advised don't take a tablet, you know like a sleeping tablet. They say just don't take a tablet because it's, err, too high a dose and because if Priya is feeding the baby it can have an effect on the baby too.*

Priya's thoughts about Aditi arose later and related to her role as a mother and to others meeting Aditi. First, she questioned her parenting ability, asking Dhanesh *"'am I a good Mum? Do I look after Aditi well?'"* Second, she considered how her admission impacted their families seeing Aditi:

> Priya: *it was quite soon after my daughter was born that I, err, went to the MBU, so it's kind of like everybody probably wants to see my daughter and that kind of thing…I just want to be home with my family like sort of celebrating her birth.*

Dhanesh also considered this, saying he wanted Aditi *"to be bonding with both of [them]"* but understood the importance of Aditi and Priya being together, despite wanting to be a father:

> Dhanesh: *I want to look after our baby but I want to see if Priya can look after our baby … as after one week we dropped Aditi off with Priya because they want to know mother and baby are bonding.*

These ideas reiterate that, although mothers experience the symptoms, PP also impacts partners and their families.

The differences in when they thought about Aditi, potentially reflects variation in awareness, which was apparent when discussing Priya's ability to attend to Aditi. Dhanesh recalled *"she doesn't care about Aditi at that time because she doesn't know what's, err, going on"* and Priya described the moment in the MBU when she realised *"oh my god, my* *daughter is here."* Priya's role as a mum is considered further in theme four as an indicator of recovery.

*Differences:*

When considering how the couple managed this experience, they differed in areas they felt were impacted, highlighting unique aspects of their experiences. Priya reflected on PP affecting their relationship, saying it *"impacted a lot"* in the early stages, perceiving the onset as *"intense, really intense"* for them. She also felt her symptomatic experience affected interactions with Dhanesh:

> Priya: *I remember kind of lashing out on him at times as well, not wanting to see him, and sometimes I was like 'why are you here?' you know? Like 'you're a rubbish husband, you're not taking care of me, you're not engaging in our daughter.'*

This was not captured by Dhanesh as he did not perceive their relationship as affected, stating *"no"* when asked about any effect on their relationship. Dhanesh did, however, describe Priya's discharge as *"very good"* and expressed having *"waited a long time,"* suggesting he was glad they were reunited.

A focus of Dhanesh's experience, less acknowledged by Priya, was the illness' emotional impact on him. Dhanesh found it a *"very confusing"* time, adding he was *"shocked and worried,"* which appeared related to the situation being unfamiliar. Through her reflective diary, the researcher also noted Dhanesh's frequent use of the word *"trying."* This language was considered when exploring his transcript to understand his sense-making process, perhaps reflecting a state of not knowing what to do but trying his best.

Dhanesh, therefore, described his family as invaluable, saying he needed *"support from mum and dad, and Priya's mum."* This included during the first week of her admission when *"it was difficult because the little one was here [i.e. with him]."* Dhanesh also acknowledged turning to others when finding it hard to manage his confusion and when Priya's condition was deteriorating:

> Dhanesh: *I ask my Mum 'what's going on?' and then I was crying, so just very sad … one day I lose my confidence because every day it was getting worse and worse, but after I admit this to a few people they gave me the confidence that things will get better.*

This captured his positive view of the emotional support others provided. This seemed particularly important given he found it a *"very busy"* time when Priya was hospitalised:

> Dhanesh: *at that time I had two months paternity leave and one-month holiday so I could ignore the work … [at a later stage in their experience] I have to go to work and then straight after I go to the hospital because my father and mum here too so lots of responsibilities here too…it's Priya, and my mother, and my father, they came over [from where they live] so it felt like it was 24 hours.*

This provides valuable insight into demands and responsibilities partners can experience. It also indicates specific needs requiring consideration as emphasised by Dhanesh expressing: *"if I was on my own, maybe I would have been admitted somewhere."*

Overall, this theme captures the complexities of PP when treated in a MBU. It indicates the widespread impact, reiterating that although mothers experience the symptoms, PP also impacts partners and their families. The differences suggest, although the couple face it together, they also have individual experiences. The final theme changes focus from the system to the recovery process.

### 4. ‘We’re getting the right help and becoming a family’

This superordinate theme reflects the couple’s experience of recovery. It encompasses convergences relating to symptomatic recovery, the context of the MBU and discharge, including the importance of post-discharge support. Aspects of recovery Priya viewed as prominent that Dhanesh did not address are considered, therefore acknowledging shared and individual elements in how couples move beyond PP.

#### Shared Elements:

a. *Importance of the MBU*

The MBU was considered highly important, with them both describing it as *“the right place*.*”* There was a sense that arriving at the MBU was a key moment. Dhanesh described their journey through different hospitals, with a sense of relief upon arriving at the MBU: *“and after one night they transferred to MBU – finally!”* Similarly, Priya shared, *“I wasn’t as such worried because I knew I was in the right place.”* This suggests they recognised the MBU as where Priya needed to be.

The couple described feeling relieved Priya was in a MBU, related to the approach to care. Dhanesh considered it being a *“family ward”* a positive *“surprise,”* with Priya also valuing family involvement:

> Priya: *the information was there for, umm, my husband as well to read. That was really, really helpful. In leaflets, even with a member of staff talking to my husband like about what was going on with me. That was really good, like the fact he could come to my ward reviews, that was really nice.*

The couple viewed the MBU staff positively. Priya described helpful interactions where she felt supported and reassured when staff said, *"it's not your fault, this is what happens, it's one of those things, but you're doing the best you can."* She also felt able to *"rely on [staff] if something was to go wrong."* For Dhanesh, nurses being with Priya *"24 hours"* was *"a relief,"* providing reassurance given he *"wasn't allowed to stay with her 24-hours."* Staff, therefore, seemed central in helping the couple manage their experience.

### b. *Getting better and becoming a family*

Following her admission, Dhanesh and Priya recognised signs indicating she was improving. These captured an individual recovery and a desire to care for Aditi.

Regarding her role as a mother, they described Priya gradually becoming interested in caring for Aditi. Priya also recalled feeling she was meeting expectations of being a mother:

> Priya: *I was starting to take care of my daughter, I'm doing stuff that I should be doing…you know, being the best mother I can be in that environment, providing all that I can provide for her…I was looking after her, sterilising bottles, picking her up when she's crying and reassuring her, bonding with her as well.*

> Dhanesh: *she asked about Aditi and I clicked that she can remember, that she can worry about Aditi…she asked 'did you change the nappy?' and now I had confidence that she can look after [Aditi]…after a couple of days Priya started to ask, 'can I do, can I do it?' She wanted to do more with Aditi by herself.*

Being a mother seemed important to them in Priya's recovery, further highlighting the MBU's importance by keeping Priya and Aditi together.

The couple shared their sense that as Priya improved and could *"look after"* Aditi, they were becoming a family, reflecting how an episode of PP can delay this transition (Glover et al., 2014). Dhanesh discussed the discharge process and how *"after a few weeks [of leave] it was just [him], Priya and baby; just the three of us"* (i.e. no observing nurse). Priya described *"enjoying being parents"* and *"doing stuff as a family."*

### c. *Returning home*

Another convergence considered managing the return home, with this transition helped by discharge being gradual. This began with periods of leave, with the first trip home appearing important given they both discussed it. Dhanesh recalled the doctor saying, *"Priya could come for two or three hours with a nurse."* Support from the nurse appeared helpful for Priya: "*it was quite nice to have that person and have that open and honest sort of conversation,"* which related to their sense she was *"not fully recovered."* Dhanesh focused on this leave more, potentially reflecting his desire to have Priya home and how difficult he found the separation:

> Dhanesh: *it was very difficult at that time…I request to the doctor can we, can I take her with us, if I like, but they don't allow it until she is getting better…so I tried to bring her back as soon as possible, but they said that she wasn't ready to be released.*

They valued this gradual process, with Priya saying it was *"really nice"* and emphasised this adding, *"I wasn't kind of just thrown in the boat, like get out."* Despite his previously mentioned impatience to have her home, Dhanesh recalled being *"worried"* about Priya's discharge and acknowledged *"the gradual process was helpful"* in managing these concerns.

They both felt Priya was not completely better upon returning home. Dhanesh recalled *"she didn't have full confidence about the baby"* and Priya stated she was "*not fully recovered yet."* They, therefore, realised Priya still required support. Dhanesh described his role as *"to give her confidence and positive thoughts,"* and Priya recalled needing *"somebody just to be there,"* contrasting the MBU with home to highlight this need:

> Priya: *in the MBU I had kind of a member of staff that I'd rely on if something was to go wrong, umm and [at home] it was just me and my baby…I was like this is overwhelming, like I'm on my own. My husband has gone back to work, my [in-laws] have returned home and I was literally on my own, me and Aditi. I remember ringing my mum, like 'Mum, she's crying, like can you come over? Can you help me out?'*

They also spoke about what helped them beyond the illness. Dhanesh acknowledged following advice from the doctor who *"told [him] not to talk about her previous life but to move forward."* Priya took a more reflective approach:

> Priya: *I could look back and sort of laugh about everything and not take it too seriously. Umm, and that's what the good thing about the whole experience was, cos if I had taken it too seriously, like, I don't think would have been able to improve. Like I didn't dwell upon things too much at the time.*

*__Differences:__*

Regarding recovery, there were ideas only Priya discussed. The first related to feeling she gradually returned to her usual self. This links to the 'Differences' within theme one, where Priya focused upon the mismatch with her usual self when unwell. Priya described *"gradually coming back to being myself from what I was,"* and experiencing a gradual reduction in her symptoms:

> Priya: *my speech it slowed down quite a bit. Not having any weird dreams, the confusion had gone, like I knew when I was dreaming and knew what reality was … I felt like gradually I was getting back to myself.*

Unlike Priya, Dhanesh acknowledged noticing improvements *"day by day,"* but didn't detail these changes, beyond saying her sleep was *"going up each day."*

The second divergence was the sense of gaining from a difficult experience. Priya considered this across several areas of her life, including how she felt being in the MBU had *"made [her] stronger"* and *"made [her] have a stronger bond with [her] daughter."* Priya also felt her relationship with Dhanesh had grown stronger:

> Priya: *we overcame that and as like I got better and my mood had improved, I wasn't like lashing out on him and I was thinking before speaking … it's made our communication a lot stronger. We've just grown closer as well after the psychosis. We're more considerate now and about how each other feels now as well, so yeh that's a positive.*

Dhanesh did not mention this, possibly reflecting his sense that PP did not affect their relationship. He did agree there had been *"a lot of change,"* but for him this centred around having had their *"first baby."*

In summary, this theme highlights the elements in the recovery process, presenting this as something the mother and couple experience, whilst acknowledging the value of gradual discharge for everyone.

### Dyad Two: Ellie and Mark

Ellie and Mark had a baby, Harry, and a four-year-old daughter, Lily.

Table *15* presents an overview of their themes, with all illustrative quotations included in Appendix M. Each theme will be discussed in turn.

Table 15.

*Overview of Ellie and Mark's superordinate themes.*

| Theme | Shared Elements | Differences |
|---|---|---|
| Mum's not herself: we don't know why but we need help | • Affected thoughts, emotions, and behaviours<br>• Trying to *"battle through"* but needing more help<br>• Changes to Mum's sense of self | • Ellie: focus on her symptomatic experience<br>• Mark: a sense of acceptance and feeling powerless |
| Being in the right place | • The contribution of professionals<br>• MBU as *"the right place"* | • Ellie: importance of being with other mums experiencing the same thing<br>• Ellie: her experience as a hidden story |
| Different challenges: It was hard for us both | • Responsibilities and needs<br>• Impact on their relationship<br>• Needing to manage the system's input | • Ellie: strong feelings of guilt<br>• Mark: impact on him and meeting his own needs |
| Mum's getting better and we're becoming closer | • Starting to get better<br>• Returning home: life after the MBU | • Mark: what's done is done<br>• Ellie: wanting to understand<br>• Ellie: personal growth |

### 1. *'Mum's not herself: we don't know why but we need help'*

Theme one represents the couple's shared understanding that Ellie's illness emerged gradually but deteriorated rapidly. It captures the changing nature of PP and how they came to realise they needed help. Also reflected is the experience of Ellie's sense of self being affected, featuring convergences and divergences, and Mark's unique experience of feeling powerless.

*Shared Elements:*

a. *Affected thoughts, emotions, and behaviours*

Ellie and Mark initially understood something was wrong from noticing gradual changes in Ellie's thoughts, emotions, and behaviours. Ellie perceived it began with *"the baby blues,"* and Mark recalled:

> Mark: *[referring to the period before her admission] the week before, maybe the fortnight before, I saw it creeping up on her just from the way she was acting, erm, the emotion she was showing. She was, she was struggling.*

Relating to the struggle Mark described, they both recollected Ellie having negative thoughts:

> Ellie: *I didn't want to be here anymore. Yeh, just basically that. I didn't want him. I resented him … I don't want to be here. I don't want Harry. Umm [Mark] had gone out and I was thinking I'm going to wait till Harry's asleep and then I'm just going to go.*

> Mark: *there were thoughts of wanting to harm herself or just walk away from it all. Just leave the house, leave Harry just lying in his cot and just going. They were starting to creep into her head more and more.*

Mark found these thoughts *"difficult to hear"* but made sense of them as *"the mind"* being *"a mysterious thing."* Similarly, Ellie referred to them as *"horrible,"* capturing their unpleasant presence.

There was a shared awareness of Ellie's behaviour being affected. Mark described how she *"couldn't concentrate…couldn't stand still,"* suggesting restlessness. Ellie recalled a manic-like nature to her behaviour:

> Ellie: *I was like massively on a high, like, I just felt like I was on top of the world basically. I just felt like, umm, I'm super mum. I can do this, I can do that, I'm capable of this. I'm going to go home and make tea.*

Their sense of Ellie's presentation, including the range of symptoms, suggests PP is complex. This is considered further through its changing nature and the impact on Ellie's sense of self.

### b. *Trying to "battle through" but needing help*

Given the gradual onset, they tried to continue with daily life, with their language suggesting this was difficult. Mark described Ellie *"trying to battle through"* and Ellie illustrated this battle in an experience of the school run:

> Ellie: *I was still doing the school run and stuff, and like I absolutely hated doing it and I kind of, as soon as I got out the car at school I felt like a wave of someone else's face came over me. So, like I would be so, so down and then as soon as I got out the car this smiley, happy Ellie was back, but it was such a false, and then as soon as I got back in the car I'd just go like [*makes crying sound*].*

They also tried to comprehend the situation, sharing their belief Ellie had *"postnatal depression:"*

> Mark: *there was no apparent reason why, but obviously she knew, well, well cos she'd had a baby, we knew, well thought that chances were that it was postnatal*

> *depression. So, she was trying to battle through it herself, but it just got more and more difficult.*

Following a GP appointment, Ellie recalled *"they put me on antidepressants"* due to *"most likely experiencing postnatal depression."* Their accounts both report the diagnosis tentatively, however, suggesting uncertainty.

Over time, the couple experienced the situation deteriorating and becoming harder to manage:

> Ellie: *on the Tuesday I definitely thought things were going downhill. I spoke to my health visitor and I said I'm having suicidal thoughts. I just really don't want to be here anymore…by the Wednesday, Mark had now been advised by the health visitor that he needed to be at home with me.*

> Mark: *I worried when I went to work each day that she was going to be alright on her own with him [new baby] towards her being admitted … I actually got a phone call from Katie, the health visitor, that was on the Wednesday before the Friday that she got admitted, asking me to come home from work cos she was in a pretty bad way.*

Here, they jointly reflected on input from the Health Visitor, Katie, and her support for each of them. This illustrates PP as a joint experience for the couple, and depicts the complexity of PMI in there being risk to mother and baby, which Ellie also acknowledged:

> Ellie: *Thursday I said to [Mark], 'I don't feel like home's my safe space anymore' … by the Thursday night I was actually contemplating killing the children…it was all so quick, umm, I remember getting into bed with Mark cos Harry was in his cot and*

> *Mark was in bed. I then got into bed with Lily cos she shouted me, and had fallen asleep and then woke up and there was something just telling me I needed to suffocate Lily.*

Related to this growing risk, they recalled feeling unable to manage on their own anymore:

> Mark: *I came home from work that Wednesday and she was, she was just sat crying on the sofa, umm, she just said, 'I can't, I can't handle it on my own anymore. I need help.' And err, she realised that she needed help.*

> Ellie: *my worry was that actually, although I wanted to kill the kids, I probably would have done something to myself first. Cos I always knew that although that was my strong feeling that there was something in my head saying suffocate the kids, kill the kids; I would have always tried to do something to myself first.*

This indicates their awareness of the severity of Ellie's illness, with Katie contributing to this understanding in saying *"'it's gone beyond me now.'"* The couple also experienced this need for additional help; Mark recalled *"when she got admitted, I could see how bad she was"* and Ellie stated, *"I know I need help."*

c. *Changes to Mum's sense of self*

The couple jointly felt Ellie's symptomatic experience affected her sense of self. Mark described *"she wasn't herself when she was at her worse,"* and Ellie recalled thinking *"who am I? I don't know who I am anymore.'"* Despite the shared understanding Ellie discussed this more, perhaps illustrating differences between experiencing and observing psychosis. The following, therefore, captures convergences and divergences.

Mark shared his understanding that Ellie was not herself because she *"was suffering mentally."* This reflects how he objectified the experience and linked it to *"the mind."* Ellie described a flow of confusing experiences where she *"was constantly battling,"* feeling she had *"been taken over."* Ellie found her psychotic experience difficult to comprehend:

> Ellie: *I can remember feeling like somebody else was living in my body…whoever it was in my head just saying to me 'just kill yourself and kill everybody else, nobody is going to miss you' … I don't know who she was, oh, but it is just awful. It is literally like somebody is inside of your skin and you're trying so desperately to do what's right but almost like the devil on your shoulder is inside of you and I can't really explain.*

This reflects how psychosis can cause a disconnect from reality and contribute to a fragmented sense of self (Lysaker et al., 2020). Ellie also experienced this disconnect with Harry, reflecting the complexity of psychosis related to childbirth:

> Ellie: *I said to Mark, I almost wanted to feel like I just didn't want him ever, like that would almost have been easier for me, but I was constantly battling between 'I do want him nobody else is touching him' and 'I don't want him.'*

### *Differences:*

Another divergence was their initial response to the situation. When reflecting on the early days, Ellie focused upon her symptomatic experience and feeling she *"needed help."* Mark described having to accept the situation, indicating feelings of powerlessness:

> Mark: *I just had to go along with everything that was happening. I didn't really think about me at the time. Umm, all I was concerned for was her and her mental health … I just had to accept it I guess and get her help; help get her the help that she needed.*

This indicates how PP affects partners when symptoms are emerging, presenting the situation as beyond their control and something they *"have to deal with."*

In summary, this theme highlights the couple's early experience of PP and how it quickly became too difficult to manage alone. It captures the complexities of experiencing psychotic symptoms and how psychosis is understood differently by sufferers and observers. The next theme considers their experience of receiving additional help.

### 2. *'Being in the right place'*

Theme two encompasses the couple's perception that the MBU was *"the right place"* for managing Ellie's illness, despite some unhelpful interactions with staff. It presents the unspoken nature of PMI, helping highlight the importance of being with others experiencing something similar.

#### *Shared Elements:*

#### a. *The contribution of professionals*

Mark and Ellie appeared to value input from professionals throughout their experience. This was reflected before Ellie's admission, where they valued Katie's support:

> Mark: *Katie was very good with her. She'd always give her some advice about, umm, making lists – to do lists. So if you get up in the morning and you don't feel so clever, like 'oh I'm not going to bother today,' then you've got to force yourself that I'm going to have a shower, and write yourself a little list of what you're going to do to help the day.*

> Ellie: *the Health Visitor was with me near enough every day, erm, and she took me to the doctors…she tried to obviously hold onto me for as long as she could but I can always remember her saying, umm, 'it's gone beyond me now, like you need, you need help' … when Katie had rung the ambulance, she's said that when they arrived, she said to them that we needed somewhere for me to be safe for that night.*

This highlights Katie's role in Ellie getting further help and, as the next section captures, being in *"the right place."* The importance of specialist input for Ellie's recovery was jointly acknowledged. Ellie found it *"helpful that the perinatal team were involved"* and Mark felt Ellie had *"tools to deal with it"* from being in the MBU.

Despite valuing professional input, they both recalled some challenging interactions. This included an incident where Ellie self-harmed, as she felt *"nobody was listening:"*

> Mark: *I, err, got a phone call off her early one morning. I'd, err, just got to work and she was really upset, and she said, 'I've tried self-harming.' So err, that upset me. I got panicky, so I rang the centre, the unit myself and talked to her personal nurse. And I said 'you're gonna have to sort of spend some extra time with her today. I said I wish I could be there today but she, she needs, she's really bad again at this time, she's took a dip.' And she said, 'well there's more than her in here and we're really busy, so I, umm, can't spend too much more time with her today.' … so, umm, that*

> *really, that upset me quite a bit that they weren't going to spend that little bit of extra time with her when she was feeling at that low … I got in touch with Katie and had a talk with her. She actually called Ellie, calmed her down and reassured her – she did more over the phone for Ellie that day than the nurses in the unit did.*

> Ellie: *there were a couple of nurses on there that kind of, you would almost wonder why they went into that profession … I'd had a particularly bad night, umm, I'd gone into the nursing room a couple of times and sort of said to the staff in there 'I'm really struggling tonight, I can't get to sleep.' Umm Diazepam had been taken off my meds by that time so they couldn't give me anything else, so I was kind of just told to get on with it … honestly, like the tutting and eye rolling was just horrendous at times.*

This highlights the importance of caring and compassionate relationships, with Katie again appearing as a stabilising influence. This contrasts with care lacking in compassion, which negatively affected Ellie and Mark.

### b. *MBU as "the right place"*

For Mark and Ellie, the MBU was *"the right place"* and provided them with reassurance:

> Ellie: *oh, as soon as I stepped foot in that building, I just had a wave of real like, a massive wave of, umm, I just felt safe. I just wanted to hug everybody … It was a place full of professionals, umm, I finally knew I was going to get the help I needed.*

> Mark: *[the head nurse] said 'oh, she's in the right place, we'll look after her' … she had a nurse, a personal nurse with her all the time, sat outside her room, walked*

> *with her wherever she went, which reassured me that she was going to be well looked after.*

This indicates how accessing specialist support gave the couple confidence Ellie would be safely looked after. This was powerfully captured in Ellie's belief the MBU *"saved my life."*

When recalling their experiences of the MBU, the couple suggested PP requires specialist care. They appreciated the MBU in enabling Ellie and Harry to stay together:

> Mark: *I don't like to say what she would have done had she not had Harry … I think [being in the MBU together] kept the bond really. Erm, if they'd have been separated and not, she couldn't have spent that time getting better with him there. I think it could have took longer, I think maybe, erm, the bond could have gone.*

> Ellie: *I had Harry with me that was like kind of all I needed. I kind of felt like I didn't need anybody else and I just needed time to myself to work on me and Harry … I definitely don't think I would have been able to not have him with me.*

Mark describes here the essential role of the MBU in supporting the mother-baby bond while Ellie highlights how crucial her connection with Harry was for recovery.

*Differences:*

A central aspect in Ellie's experience of the MBU, not discussed by Mark, was being with other mums with shared experiences:

> Interviewer: *was there anything particularly helpful that maybe the staff or other patients on the ward did that sort of helped you make those steps?*

> Ellie: *it was the girls on the ward, it was nice to feel like you weren't the only person feeling so down and, yeh, so it was almost like a comfort that I wasn't the only person who was feeling this.*

These interactions reduced Ellie's feelings of isolation. She also described experiencing a sense of community in the MBU, which facilitated her recovery:

> Ellie: *I've still got contact with two [of the other mums] … if you're willing to take on those friendships and kind of not be embarrassed or ashamed of why you're in there, once you start talking everybody around you starts talking as well, and I kind of, I kind of feel like that was my therapy.*

This divergence potentially reflects Ellie being on the MBU with other mothers, whereas Mark's experience was more indirect and focused on Ellie.

Reflecting literature where PMI are viewed as unexpected within pregnancy (Heron et al., 2012), Ellie presented her experience as a hidden story:

> Ellie: *I just also don't think that postpartum psychosis is talked about either. I just think the whole having a child thing is seen to be this memorable occasion: happy families, new baby, everything is going to be great; and it's not always like that.*

This was partly captured by Mark in finding visiting the MBU *"strange,"* and *"not normal for you."* It appeared less explicit than for Ellie, who also highlighted the unknown nature of MBUs:

> Ellie: *if [an MBU bed] is offered to you, kind of accept it, cos I feel I was like, in my head I was like 'oh my god, they're going to strap me to the bed. I'm going to be locked in my room, it's going to be a padded cell.' I didn't know really.*

This depicts Ellie's lack of awareness about MBUs and supports Mark's sense they are *"something different."* Ellie also expressed a need for *"more of them."* Together, presenting PMI as not openly discussed and there being limited resources for managing PMI.

In summary, this theme emphasises how important specialist care was for the couple. It indicates the value of the MBU in providing reassurance, keeping Ellie and Harry together, and Ellie connecting with others who understood.

### 3. *'Different challenges: it was hard for us both:'*

Theme three represents Ellie and Mark experiencing the episode of PP as a couple and how it impacted their relationship. It highlights individual challenges, alongside their perception and management of input from their support network.

#### <u>Shared Elements:</u>

#### a. *Responsibilities and needs*

The couple described on-going demands and responsibilities during Ellie's illness. Their experiences highlighted how PP affected Ellie and *"the whole family."* They both recalled the sense of managing everyone's needs and the pressures this posed. Ellie spoke about this in relation to her admission:

> Ellie: *I almost feel like, possibly a weight had lifted off Mark's shoulders as well, because obviously he was having to look after me … I was obviously quite demanding, and it was quite stressful for him, but also, he was also having to look*

> *after Lily and Harry as well. And I just think sometimes he probably thought, 'oh thank god for that, somebody else is looking after her and she's safe.'*

This captures Ellie's awareness of the additional pressures on Mark, and he described how his work's understanding enabled him to juggle these extra responsibilities:

> Mark: *my work, they were really good as well, also they understood it as I talked to my boss. He was really good. They let me start later so I could take Lily to school, they let me finish early so I could go pick her up.*

Here, we see managing the PP and MBU admission required careful consideration of different needs and required Mark to take on different and additional responsibilities.

### b. *Impact on their relationship*

Ellie and Mark spoke about the impact on their relationship. This related to Ellie's symptomatic experiences and the associated challenges, alongside the separation during Ellie's admission. The difficulties they experienced in managing Ellie's initial presentation, was captured by Ellie recalling a conversation they had:

> Ellie: *[Mark] has quite openly said to me, 'there was, at times I was just thinking I can't do this. I can't cope. I just can't do it.' He said, 'I literally thought one day I can't do it, somebody else can deal with her.*

Mark describes this further when sharing his experience of being separated:

> Mark: *it put strain on the relationship whilst she was in the unit, yep, but again I understood she needed to be there, and I had a job to do with Lily … we've actually talked about it since she's come out and I said to her, when she was in there, I said 'that it'll either make us or break us.'*

Together, Ellie and Mark indicated how challenging a time it was for them both. Their experiences reflect, as a couple, they were affected before and during the MBU admission. For them, it appeared helpful to consider the impact and how to manage together. Mark recalled how *“it wasn’t sort of going to be forever,”* and that they *“talked about that when she was in there.”* This suggests PP is something they experienced together that could significantly impact their relationship, as captured in Mark’s view: *“it’ll either make us or break us.”*

c. *Needing to manage the system’s input*

Another convergence was feeling they needed to manage input from their support system. This related to them considering their needs when help was offered. Ellie needed time to herself, despite others wanting to be there for her:

> Ellie: *I just didn’t want to be bombarded all the time, like kind of people saying like ‘are you okay?’ well clearly no, I’m not okay…not, I’m so not okay and you don’t need to keep asking me cos I’m clearly not okay cos I’m in here [i.e. the MBU].*

This illustrates how others could be an additional stressor for Ellie, which was also acknowledged by Mark, reflecting their mutual understanding and shared experience:

> Mark: *she didn’t want visitors in the first few days anyway, cos her mum and dad offered to go and see her but she wasn’t well enough or in the right mental state to want to be with people all the time.*

Following Ellie’s admission, Mark experienced his own need to manage input from others, prioritising his and his daughter’s needs:

> Mark: *I had a lot of personal, personal support, erm, come from all sort of people when they realised what was happening. But I, umm, I said I need, cos they said 'I'll have Lily. We'll have Lily.' But I wanted to keep as much of a normal routine for Lily and to do it all myself if I could, because then she'd be going 'why am I going here? Why am I going there?*

This continued post-discharge where Ellie recalled having *"to kind of say to family, look we don't want to be bombarded, we'll come to you."* Despite needing to manage the input, it was well-received support with Mark recalling *"I told everybody that I appreciated their offers of help."* This indicates how important it was for the couple to feel supported.

*Differences:*

The emotional impact of Ellie and Harry being together was addressed by them both, albeit differently, reflecting unique challenges experienced. Ellie recalled strong feelings of guilt:

> Ellie: *I really missed them all. I felt really guilty that other people were doing my job as a mum to Lily. Really guilty that his mum was having to take time off work, sometimes, to take Lily to school and to pick her up from school when [Mark] couldn't.*

Ellie's guilt related to awareness of additional tasks required of others because of her illness and admission, including parenting Lily. Her admission also affected her fulfilling different roles, recalling *"I hadn't been a partner to [Mark], I haven't been a proper mum to Lily."* This reveals how life continues despite the PP and the difficulties this poses, with additional challenges for mothers with other children.

Mark powerfully described his experience of being separated from Ellie and Harry, with a sense that he lost part of himself:

> Mark: *it felt horrendous for me. It felt like someone had ripped my arm off but there was nothing I could do about it, she needed to be there … I was very upset and I, I felt abandoned you could say, but, but she needed to be there, and I understood that.*

Here, Mark describes the pain of abandonment and reiterates the feelings of powerlessness discussed in theme one in feeling there was *"nothing [he] could do*."

Given the emotional impact, Mark acknowledged requiring support, viewing family and work colleagues invaluable:

> Mark: *I've had a lot of good work colleagues in both my jobs and, and my family to talk to, and just, just being able to talk it out was a big relief for me…if I'd have had no-one to talk to I think I would have gone insane too.*

Mark valued others being there for him, stating *"I didn't expect them to know answers but just to listen."* His approach to managing his emotional needs related to past experiences and access to support. He described knowing he *"needed"* to talk based on previous personal struggles and relying upon *"external support"* whereby he *"didn't really need help from"* the MBU, despite support being offered. This suggests partners' needs differ according to their situation, further highlighted by Mark viewing Lily as both *"a responsibility and a crutch for [him]."* It, therefore, seems important for professionals to take an individual approach and consider the partner's response to their situation.

In summary, this theme indicates the widespread impact of PP on the couple and the family. It highlights needs and responsibilities to manage alongside PP's emotional impact on them. Ellie and Mark's experiences suggest PP can be understood as dyadic in nature, reflecting the importance of a systemic approach, considered further in theme four.

### 4. *'Mum's getting better and we're getting closer:'*

Theme four describes how the couple experienced the recovery process. Reflected is the idea of a gradual process beginning in the MBU and an active involvement in returning home. Moving forward is also discussed, with Mark and Ellie taking different approaches.

#### *Shared Elements:*

#### a. *Starting to get better*

There was a strong sense for Ellie and Mark that once Ellie was in the MBU, she could start getting better. This was captured by Ellie's sense she was *"in the recovery process,"* and Mark acknowledging needing to *"take it one day at a time,"* presenting their view of recovery as a gradual process.

A key part of Ellie's recovery was a shared sense of her regaining abilities and doing things she had stopped or been unable to do:

> Mark: *she was more relaxed, more, she could interact in a conversation a lot better, cos at times you could see it going in one ear and out the other…as you went on you could have a better conversation with her and then she got more confident.*

> Ellie: *in that [first week on the MBU], I felt like I did things that I'd not done for the whole eight weeks that I'd had Harry, like I asked to go out to the shopping centre with a nurse. I wouldn't have ever done that whilst I was at home. I just wouldn't have felt like I could.*

This describes how they noticed Ellie recovering through contrasting her presentation with previously. Mark recalled *"I could see her improving all the time"* and Ellie described knowing she *"was making progress because [she] was getting back to [herself]."* This demonstrates how recovery was experienced by Ellie and observed by Mark, sharing a sense she was *"improving."*

b. *Returning home: life after the MBU*

The couple described leaving the MBU as a *"steady release."* This related to viewing Ellie's recovery as gradual, recalling *"little steps"* and *"little goals,"* which felt important. For Mark this linked to Ellie *"still showing signs of being very anxious"* and feeling they needed to *"make sure if she was right"* and ready to be home.

The gradual, collaborative process appeared helpful for them given challenges they felt Ellie had to overcome:

> Ellie: *my first home leave was only for an hour and a half cos that's all I could feel like I could manage…they were kind of saying 'oh well I think you need to go home for a bit longer.' And I was kind of saying 'no, please don't push me…I can't manage more than an hour and a half because the last memories that I'd had at home were so horrendous.'*

> Mark: *she handled [leave process] well. Umm, the first afternoon she was very anxious about being back home cos it brought back memories for her from when she left, but, umm yeh, I think it was a good way of doing it, just giving her a little bit of time and then increasing it each time before saying 'right, that's it, now go on and have a good go.'*

They also reflected on the adjustment to returning home, which related to feeling Ellie was not fully recovered. Mark considered Ellie *"80% better"* and did not *"want her to relapse,"* fearing re-admission. Ellie recalled recurrent symptoms and needing support:

> Ellie: *[I] had to call the perinatal team, and kind of say 'I need help. I have no idea what is going on, but I can't, I can't sit still. I've got suicidal thoughts again, umm, I feel like I'm going to harm Harry' … but then within half an hour I was fine again. I think sometimes it was just talking to someone and being reassured that there is someone there to talk 24/7.*

Together, these excerpts present Ellie's recovery as on-going and active. They illustrate staff and post-discharge support played important roles given the couple needed to see *"how she'd cope coming back home."*

They described moving forwards as a couple, explaining they were *"rekindling"* and *"closer"* than before. This relates to overcoming the *"strain"* they felt PP placed on their relationship:

> Ellie: *it was just like everything rekindled and like as I've been getting more well everything has just fit back into place again, and it's almost like we've met each*

> *other again for the first time … we are just so much closer, like, just with everything, we just do everything together now.*

> Mark: *I think we both agree that it's made us stronger, umm, emotionally stronger. I think she's realised as well that a lot of people could have quite easily walked away from that situation and I haven't, I've stayed there and supported her. We've, we've helped each other through it as well, I guess, as she's got stronger, she's helped me.*

Overall, this highlights the couple's recovery occurring in conjunction with Ellie's recovery, with Mark describing how *"we got closer again as she got better."*

*Differences:*

Differences were present in their understanding of the recovery process, indicating variation in what was important. They spoke about moving on but differed in their approach, which can be considered in relation to recovery styles. Mark adopted a 'sealing over' approach whereas Ellie demonstrated an 'integrative' approach (McGlashan, Levy & Carpenter, 1975), also evidencing post-traumatic growth (Tedeschi & Calhoun, 2004). Mark recalled not trying to *"look into things too deeply and analyse it all,"* contrasting with Ellie's approach:

> Ellie: *after Katie said she had the onset of postpartum psychosis, I was like 'oh my god!' It was like a couple of days after I said to Mark like 'what don't I know? what the hell!' So, it was like starting all over again, I was having to piece together eight weeks.*

This reflects Mark's desire to move on, perhaps without a full understanding, acknowledging *"still I don't really fully understand it [i.e. her diagnosis],"* whereas Ellie expressed an intense desire to comprehend her experiences, describing a *"want to know*." This can be related to Mark accepting the situation that *"it was what it was"* and the fragmentating nature of Ellie's symptomatic experience, discussed in theme one.

Ellie also spoke about personal growth, including seeking to learn more about herself and her experience:

> Ellie: *I started reading some self-help books. I did a bit of studying on CBT and I've done a postnatal depression awareness course online, so I've kind of kept myself busy and if anything out of a horrendous situation, I've learnt so much about myself…I've learnt so much about other stuff in general, like I've got the want to study and to better myself.*

Ellie's desire to learn reflects her attempts to reconnect to her self, enabling her to take something positive from this experience. She described *"feeling like I'm me again,"* suggesting recovery involved moving away from the fragmented self triggered by PP. This reflects McGlashan et al's (1975) view that 'integrators' are curious about psychosis, driving them to seek understanding.

In summary, this theme illustrates multiple aspects to recovering from PP when hospitalisation is necessary. It presents recovery as occurring individually for Ellie and for them as a couple. It suggests recovery is an on-going process with Mark and Ellie experiencing a process of adjustment, reiterating PP is a dyadic experience.

# DISCUSSION

## Summary of Findings

This study aimed to explore how an episode of PP is experienced by mothers and partners when a MBU admission is required. A purposive sample of two dyads were interviewed, with multi-perspectival IPA identifying four superordinate themes for each couple. Couples were analysed individually due to between-dyad differences, including variation in the mother's symptomatic experience, age difference within the couple and whether they had previously experienced childbirth. Analysis provided an insight into the process for the couples whilst acknowledging the individual aspects to their experiences. Overall, PP and admission to an MBU were an unexpected, unknown, and confusing aspect of childbirth. For these couples, admission to the MBU was experienced as essential in supporting recovery through a multi-stage process that occurred individually and dyadically. This study has highlighted the needs of mothers, partners, and couples, and reveals what was helpful in managing this experience.

## Research Findings in Context

### *PMI as unknown*

This study found several features highlighted by previous research. Neither couple knew about PP or that psychosis could occur after childbirth, as Heron et al (2012) found. This lack of knowledge was associated with confusion and concern, replicating Boddy et al's (2016) findings. Their confusion led couples to question the situation and contextualise it within childbirth, including how their experiences were not meeting expectations. These ideas parallel existing findings with mothers (Glover et al., 2014; Heron et al., 2012) and extend them to partners.

This study partly replicates Boddy et al's (2016) 'what the f*** is going on?' theme, with partners in both studies recalling little understanding during the onset of symptoms. Boddy et al's (2016) sense of partners not feeling heard was not found as couples recalled fathers being offered support and spoken to by MBU staff. This suggests perinatal services can operate in a way that does not unintentionally marginalise partners (by focusing on mothers and new-borns), contrasting with findings outlined by Fletcher, Matthey and Marley (2006).

The couples' sense of PP being unknown and a complex illness can be considered in relation to models of PMI, in which such disorders are presented as an interplay of biological, social and psychological factors. As outlined within the *Introduction,* there is greater understanding within the literature of the biological and hormonal factors that appear to contribute to the onset of PP than other factors (e.g. Balaraman & Schmetzer, 2011; Bergink et al., 2015). With regards to the assessment process captured within Dhanesh's interview *(see Analysis - Differences within 'finding out it's psychosis and we're not on our own'),* this can be related to the psychological vulnerabilities of the biopsychosocial model of perinatal distress (Wenzel & Kleiman, 2015). For example, Dhanesh reflected on the Doctors asking about Priya's childhood and how this may contribute to understanding her presentation at the time. In this way, the models of both Wenzel and Kleiman (2015) and Davies (2017) can be considered to guide clinicians' in how they assess for PP, with both emphasising a role for psychological vulnerabilities.

### ***Loss***

Analysis revealed a sense of loss for mothers, partners, and couples. Loss occurred in relation to identity, roles, and relationships.

Mothers experienced their PP symptoms as disconnecting them from themselves. This related to noticing a mismatch from their usual self, which women with PP have previously described (Wyatt et al., 2015). Partners also felt mothers were not their usual self, which develops understanding of PP by indicating couples jointly view mothers’ sense of self as affected.

Couples recalled the mother’s symptomatic experience and her MBU admission affecting their relationship. This corresponds with previous findings of mothers (Wyatt et al., 2015) and partners (Boddy et al., 2016) experiencing loss of their relationship during the illness. This study furthers understanding by finding partners play a significant role for the mother throughout her illness, indicating the importance of services involving partners and considering their needs to ensure they can fulfil this role.

Women experienced loss and feelings of guilt due to not fulfilling their role as mothers, as found previously (Robertson & Lyons, 2003). For Ellie, her guilt also related to being unable to care for Lily alongside the impact it placed on others to fulfil this role. This illustrates the complexity of PP, including additional challenges faced when this is not a first pregnancy, and the importance of considering individual circumstances.

### ***System-wide impact***

An episode of PP was found to affect mothers, partners, and their families. Couples recalled the emotional impact on fathers, additional pressures they faced and the challenges of separation. The system-wide effect the couples shared can be related to the interplay of factors seen within the biopsychosocial model of perinatal distress (Wenzel & Kleiman, 2015). This model suggests a bidirectional relationship between life stressors and perinatal distress, whereby perinatal distress can exacerbate life stressors and increase sensitivity to different vulnerabilities (e.g. biological, neurochemical, and psychological). Both couples spoke about the additional challenges faced as a result of the perinatal distress alongside continuing life stress (i.e. work, other childcare responsibilities) but also the value of having support from others (i.e. protective factors that reduce sensitivity to vulnerabilities). This can also be understood using the Stress-Vulnerability Model (Zubin & Spring, 1977). According to this model, each individual has a level of vulnerability with respect to experiencing a psychotic presentation if the circumstances present, with the exact circumstances required dependent on the individual's vulnerability. This model also suggests a feedback loop whereby high levels of stress increase the severity of the illness, and illness functions as a source of stress. Within this study, the understanding the couples gained from receiving a diagnosis of PP and finding out more helped reduce the concern (i.e. level of stress), with this also being considered the start of the mother's recovery (i.e. illness improving).

The impact on partners relates to fathers feeling they were *"holding the fort"* in Boddy et al's (2016, pp. 404) study. Previous research also found mothers felt their partners were not adequately supported (Robertson & Lyons, 2003). The current study identified the pressures partners experience but did not find fathers to be inadequately supported with fathers expressing how support prevented their own mental breakdown. This highlights the importance of an individualised approach to recognising partners' support requirements.

Previous research found some women experienced limited support from family and friends, due to limited understanding or feeling unable to cope with the illness (Glover et al., 2014). Despite couples acknowledging limited understanding within their system, they recalled how much support their friends and family provided. This contrast suggests the support couples require may differ based on their existing support network's ability to meet their needs. This advocates for a family system approach (Rolland, 1990), whereby the illness is considered in context, not isolation.

### ***Valuing the MBU***

A central finding was the essential role the MBU played for couples. This was captured by them viewing it as *"the right place"* and perceiving the setting and range of professionals as reassuring. Partners expressed relief about the MBU admission and receiving the diagnosis, corresponding with fathers finding the diagnosis reduced confusion and the MBU instilled hopefulness about recovery (Boddy et al., 2016). This relates to their limited understanding and research where mothers and partners wanted information about PP (Doucet, Letourneau & Blackmore, 2012). These findings support understanding of PP, contextualise these experiences within MBUs and highlight what couples value about MBUs.

Mothers echoed feelings shared by women previously. This included how hearing from others with experience of PP (i.e. Experts by Experience, EbE) was more *"tangible evidence"* of the potential to recover than *"abstract reassurances"* from professionals (Heron et al., 2012; pp. 161). The specificity of the current findings to MBUs develops understanding of these settings by highlighting the facilitative role of EbE for the women's recovery.

Plunkett et al. (2015) found mothers felt their baby was important when recovering from PP, a view shared by mothers and partners in this study. Women in Plunkett et al's (2015) study perceived caring for their baby as a hindrance to recovery but this was not experienced by couples in the current study. This difference may reflect that not all women in Plunkett et al's (2015) study were treated in MBUs, meaning caring for their baby was an additional demand post-discharge. They perceived this as negatively impacting their recovery, illustrating the value of MBUs in keeping mother and baby together.

***Recovery***

McGrath et al (2013) identified five stages to recovery for women treated for PP in MBUs (

Table *16*). These were reflected in the current study, indicating the stages are also experienced by couples. This included mutual understanding and appreciation of recovery as a gradual process, and each partner acknowledging positive change in mother's presentation following professional input at the MBU. Mothers regaining a sense of self was jointly recognised by couples as a key indicator of improvement.

Table 16.

*Overview of the stages of recovering from PP as proposed by McGrath et al. (2013).*

| Stage of Recovery | Overview of Stage |
|---|---|
| Immobilisation | Considered a pre-requisite for women in beginning the recovery process. It reflected a reliance on others due to the severity of symptoms being experienced, which enabled them to progress to actively engaging in their recovery. |
| Recognising recovery | Attending to and noticing changes in their presentation, which reflected improvement and were considered indicators of getting better. This also involved others noticing and pointing out such changes. |
| Accepting loss | Needing to accept aspects of their experience, including the loss of being a mother and the guilt at being unable to care for their child. For some women, this also included a loss of their self with a perception of having experienced permanent changes despite regaining a sense of self. |
| Using experience positively | The desire to take something positive from a difficult experience, which facilitated them in moving forwards in their recovery. This related to them individually and interpersonally. |
| Maintaining recovery versus recurrence | Recovery was viewed as on-going, which was reflected in women's concern about their symptoms recurring and actively seeking to maintain their recovery. |

These stages were also present within the couples' recovery. This included the shared sense their experience brought them closer and valuing a gradual discharge process, due to feeling recovery continued post-discharge. This indicates the importance of not rushing the discharge and families being supported post-discharge.

Another aspect of recovery, particularly for the mothers, was the idea of personal growth. This relates to the 'using experience positively' stage of recovery within McGrath et al's (2013) model. It can also be considered with regards to Tedeschi and Calhoun's (2004) concept of post-traumatic growth, which is where individuals experience a positive change in response to an extremely difficult life event. Both Priya and Ellie spoke about several domains captured within posttraumatic growth, including a change in outlook with more appreciation for life, sensing new opportunities and more intimate relationships with others (Ramos & Leal, 2013). The idea of individual growth was particularly apparent for Ellie, potentially reflecting differences between the mothers. For Lucy, her understanding was more strongly associated with changes linked to becoming a first-time mother. Ellie had another child which contextualised her experiences and the associated understanding differently. Given Ellie also described more severe psychotic experiences and infanticidal ideation, it can be hypothesised that her experience may have been more traumatic. This relates to existing research highlighting the emotional impact of infanticidal ideation on both women and their next-of-kin (Engqvist & Nilsson, 2013) and literature indicating psychotic symptoms are distressing and can trigger post-traumatic stress symptoms (Berry, Ford, Jellicoe-Jones & Haddock, 2013). It is, however, important to acknowledge that trauma is a very subjective experience (Boals, 2018).

Partners did not appear to discuss the experience of personal growth, reflecting post-traumatic growth following vicarious trauma being less well evidenced (e.g. Abel, Walker, Samios & Morozow, 2014). It may also reflect differences between directly and indirectly experiencing psychotic symptoms, in line with the fragmentation of self that direct experiences can elicit (Lysaker et al., 2020). By evidencing posttraumatic growth in mothers experiencing PP, these findings add to existing literature which has focused on physical health difficulties posing a threat to life (e.g. Bellizzi & Blank, 2006).

## Methodological Considerations

### *Strengths and Limitations*

There are several strengths related to how the considerations of involving dyads were addressed. The first included identifying the most appropriate interview method (Warin, Solomon & Lewis, 2007). Conducting individual interviews enabled participants to share their experiences openly, acknowledging the topic's sensitive nature (Loaring, Larkin, Shaw & Flowers, 2015) and capturing idiographic aspects of experiences required for IPA (Smith et al., 2009). In addition, the interview schedule helped ensure that the questions asked were not guided by content from previous interviews. This was important given some interviews were conducted after analysis had been started, and in the researcher's reflective process similarities in aspects being discussed were noted, with the researcher ensuring leading questions were not asked based on previously identified themes.

Another strength was using multiperspectival IPA, in line with Larkin et al’s (2019) recommendations. This focused on individual narratives ensuring a comprehensive understanding at the idiographic level before considering the dyad. The sample size enabled a thorough analysis, helping ensure the participants’ voices were heard (Smith et al., 2009). The small sample means the experiences and themes captured may not represent all couples experiencing an episode of PP in MBUs. This is partially reflected in presenting separate analyses to acknowledge between-dyad differences. It is important, however, to acknowledge IPA focuses on homogeneity and depth of analysis rather than generalising findings (Pietkiewicz & Smith, 2014).

As mentioned, the sample size was smaller than desired due to various difficulties impacting upon recruitment. A limitation resulting from the restricted sample size is the heterogeneity that occurred, despite the commonality that it was a first experience of a psychotic illness for both couples with both mothers receiving treatment on a MBU. The heterogeneity presented in terms of the couples differing in ethnicity, varying in the time between the birth and the diagnosis of PP being received, the exact nature of the symptomatic presentation and for one couple it being their second child. It is of note, however, that some of these differences were considered within analysis and the final analysis (i.e. presenting the couples individually) reflects acknowledgement of these differences.

Regarding the heterogeneity between the couples arising from differences in their ethnicities, it is unclear from the information gathered whether this impacted on their experience and understanding of PP. This is due to such information not being specifically explored within the interviews. Existing literature indicates cross-cultural variation in postpartum practices and rituals, which may influence how symptoms of PP are viewed and how the transition to motherhood is experienced (Dennis et al., 2007). This includes different practices around support for the mother and the extent to which they are expected to care for their new-born and to be ‘mothered’ themselves following the birth. These differences have the potential to impact upon symptoms of PP being noticed and/or identified as reflective of PMI as opposed to cultural practices. Further research in this area would be beneficial in understanding potential differences in the needs of couples experiencing PP related to culture and ethnicity.

With regards to the analysis, it is important to consider that this was taking place whilst subsequent interviews were being conducted. As a result, in the reflective process through use of the reflective diary, it was noted that themes from previous interviews were perceived in more recent interviews. To balance this, care was taken to hold these views gently and to seek evidence in the data rather than assuming they must be present.

### ***Quality***

The quality and credibility of qualitative research can be explored using four principles (Yardley, 2000). Regarding ‘sensitivity to context,’ the study’s rationale and findings were grounded in existing literature. The selected methodology ensured the focus remained idiographic and particular to the research question. Using verbatim extracts to illustrate themes ensured the participants remained the focus of attention.

The second principle, ‘commitment and rigour,’ is reflected in the interviewing and in-depth level of analysis undertaken. The semi-structured interview schedule enabled matters of importance to participants to be explored further. COVID-19 restrictions did, however, mean interviews were conducted via different means. The researcher acknowledged feeling more connected with participants when interviewing face-to-face, related to greater awareness of non-verbal behaviour (e.g. body posture) which supported emotional attunement. Analysis ensured the themes captured aspects important to individuals and shared within couples, overcoming potential limitations of traditional IPA which may not fully acknowledge relational elements (Larkin et al., 2019).

Yardley’s (2000) third principle is ‘transparency and coherence.’ Transparency is reflected in the detail provided regarding recruitment, interviewing and analysis. Regarding coherence, each theme was explained by considering how individual experiences interact and overlap with that of their partner. Including interview excerpts enables the reader to consider the coherence of the interpretation.

The final principle concerns the research's 'impact and importance.' Limited research existed on couples' experiences of PP and no studies specifically focused on treatment setting. The findings provide a novel insight into couples' experiences of PP when treated in MBUs, which is important given recent service developments (NHS, 2017).

## Clinical Implications

This research identifies areas of consideration for perinatal services to ensure couples experiencing PP are appropriately supported. Findings suggested partners face significant emotional and practical challenges, with input from others considered crucial in enabling them to support their partner whilst protecting their own mental wellbeing. It is, therefore, important for services to consider the personal support available and additional input partners may require.

The findings offer insight into what couples value about MBUs, supporting ideas from women who felt their needs were not met on general psychiatric wards (Robertson & Lyons, 2003). Despite MBUs being considered the right place, limited availability made getting a bed difficult, presenting a case for more MBU beds. Location was also important given mothers valued support from their partner, but limited availability meant they could be geographically distant. It may, therefore, be beneficial to enable partners to stay overnight, on occasion.

The impact on the mothers' sense of self, suggests a role for services in helping them reconnect, perhaps involving fathers given their knowledge of their partner. Engqvist and Nilsson (2013) also identified the disconnect Ellie experienced towards her baby. It, therefore, seems useful for staff to consider how psychosis may impact the mother's engagement with her baby when supporting the mother-baby bond to develop, given potential long-term consequences of early difficulties in this relationship (Hogg, 2013) .

The findings suggest a role for EbE within MBUs and perinatal community teams. This relates to couples' limited knowledge and finding it beneficial to be with others experiencing similar situations. In the antenatal period EbE could have a role in increasing awareness of PMI, and in supporting couples through their experience postnatally. Antenatal care can be considered further regarding inability to sleep as the first symptom, which previous studies have reported (Engqvist & Nilsson, 2013). It may be helpful to discuss early indicators of or risk factors for PP with couples during pregnancy.

Lastly, couples perceived recovery as continuing post-discharge, with mothers finding the return home difficult. This related to having less support, feeling alone in caring for their baby and symptoms returning, which have been discussed by mothers experiencing various PMI in MBUs (Connerty, Roberts & Williams, 2016). Together illustrating the importance of post-discharge support, with this study informing services about support needs for mothers and couples experiencing PP.

## Future Research

Future research would benefit from replicating this study to overcome limitations resulting from COVID-19. A larger sample would enable across-dyad analysis, providing greater understanding of the shared experiential aspects to inform services of couples' needs. Provision of antenatal care could also be developed by considering what it would be helpful to hear about during pregnancy, given PP and MBUs were viewed as unexpected.

This study revealed an episode of PP impacts the whole system and that the system's input can need managing to ensure all needs are met. Future research could explore views and needs of the wider system, helping inform the care approach offered by services.

Lastly, this study suggests posttraumatic growth can occur in women experiencing PP. This was more apparent for Ellie, potentially reflecting individual differences. Further research could explore the presence of posttraumatic growth after PP, helping inform treatment provision and post-discharge support. It would also develop understanding of posttraumatic growth following vicarious trauma, by identifying whether partners experience personal growth.

## Conclusion

This study explored how couples experience PP when treated in MBUs. Existing research was supported and understanding developed by contextualising PP within MBUs.

It highlighted the dyadic nature of this experiencing, including the widespread effects of PP, and MBUs being perceived as essential by mothers and partners, despite additional challenges the admission posed the couple and their system.

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# CHAPTER THREE: PUBLIC DISSEMINATION DOCUMENTS

# PRESS RELEASE 1: LITERATURE REVIEW

## CLINICIANS AND SERVICE USERS REST ASSURED - THE CALGARY DEPRESSION SCALE FOR SCHIZOPHRENIA IS FIT FOR PURPOSE!

A clinical tool commonly used to measure symptoms of depression in people suffering from schizophrenia is reliable and fit for purpose. This is according to a recent literature review carried out by psychology researchers at the University of Birmingham.

The Calgary Depression Scale for Schizophrenia (CDSS) is widely used in clinical settings and in research. It was developed because other methods of assessment were found to be unsuitable for people with psychotic disorders, such as schizophrenia. It is seen as an important resource by clinicians responsible for making key treatment decisions as it measures depressive symptoms separately from those of schizophrenia.

The Birmingham University researchers carried out a thorough review of existing literature on the CDSS. They concluded that the CDSS has ‘good internal reliability,’ meaning the individual items within the CDSS are all measuring symptoms of depression. It also revealed it has ‘excellent inter-rater reliability,’ indicating there is a high level of agreement between different raters when using the measure on the same individual.

Previous research on the CDSS largely features single studies reporting on its reliability. This limits understanding of the overall pattern of results across studies, which is important in establishing a measures' suitability for clinical and research purposes. The current research helps ensure conclusions from single study outcomes are not misleading.

This review involved systematically searching the available literature for research which both used the CDSS and reported its reliability. The search identified 39 articles suitable for the review, with 26 used for the internal consistency analysis and 28 involved in the inter-rater reliability analysis. Advanced statistical means were used in a novel approach for analysing these data.

Overall, the analysis revealed that the CDSS has 'good internal consistency' and 'excellent inter-rater reliability.' The review also explored versions of the CDSS that have been developed in different languages. The analysis suggested these translated versions are also reliable. Together, the findings present the CDSS as a robust tool. This means both service users and clinicians can be confident in its use for assessing individuals with schizophrenia for depressive symptoms. The research also identified what change in score constitutes a clinically meaningful difference – this is particularly useful for clinicians to monitor a client's progress.

Clinicians working in this field have highlighted how valuable this review will be for their practice. Supervisor of the research project, Dr Andrew Fox, commented: “It just sounds really useful. Brilliant – we can start using this in our services immediately.”

So, what next? The dataset for the test-retest reliability data was lacking, with only seven studies identified which limited the analysis that could be conducted. The lead researcher, therefore, recommends further research on the measure’s test-retest reliability. This would help to increase understanding of the CDSS’ ability to measure depressive symptoms in individuals consistently over time.

# PRESS RELEASE 2: EMPIRICAL RESEARCH PAPER

## POSTPARTUM PSYCHOSIS: IT AFFECTS PARTNERS TOO

Mother and Baby Units (MBUs) play a vital role for families in understanding and coping with Postpartum Psychosis (PP), finds a new study by the University of Birmingham.

PP is a rare but serious mental illness, affecting around two women per 1,000 who give birth in the UK each year (NICE, 2014). It occurs in women regardless of previous mental health difficulties, although those with bipolar disorder are at higher risk (NICE, 2014). PP poses a threat to the life of the mother and baby, whilst affecting their family. Individuals experiencing PP often require hospitalisation and existing guidelines recommend treatment in MBUs (Kohl, 2004; Lewis, 2007).

The experience of PP has not been extensively explored and no study has focused on the treatment setting. Previous research found that not all mothers had access to professionals with specialist perinatal knowledge and only some remained with their baby (McGrath, Peters, Wieck & Wittkowski, 2013; Robertson & Lyons, 2003). There is a lack of research on how couples experience PP and how it affects their relationship. This creates difficulties in understanding what these families require, meaning services may not be adequately meeting their needs.

This study was supported by a NHS Trust within England. The lead researcher spoke to new mothers and their partners who had experienced PP and were treated in MBUs. The aim was to explore their experiences and the care they received, including how they managed following discharge. Two couples took part in separate interviews providing four interviews. The sample was smaller than planned due to restrictions arising from the COVID-19 pandemic.

The findings revealed a shared sense that *"psychosis and how it's linked to giving birth [is] not really heard of."* This contributed to couples describing their experience as *"confusing"* and leading them to question whether it was normal and a part of adapting to motherhood. The couples perceived the MBU as the right place for mothers to receive care. Couples experienced relief upon their arrival at the MBU, with one mother recalling *"I wasn't as such worried because I knew I was in the right place."* For mothers and partners, this relief was experienced jointly and related to realising *"it's not just us, there are others as well"* who experience this. The MBU was also seen as essential because it allowed the mothers to stay with their baby, maintaining and developing the mother-baby bond.

The study found PP has a widespread impact, affecting mothers, partners, and their families. This impact linked to the mother requiring hospitalisation and being admitted with her new-born, with one partner describing the admission as feeling *"like someone had ripped my arm off."* It also found couples feel it is an illness experienced together but with each having individual needs and facing unique challenges. Findings suggested recovery has several components, occurring for the mother but also for the couple as they become a family after discharge.

These findings have important implications for professionals in perinatal services. The results provide insight into the needs of these couples and can inform service development. They reveal PP and MBUs need to be more widely spoken about during the perinatal period. This may reduce some of the confusion and concern that couples experience due to not understanding the situation. It is also important that MBUs and community teams consider the impact of the illness and the separation on partners, including what support they may require. For mothers, the importance of connecting with others having a similar experience is something for services to consider when establishing their teams, with a possible role for individuals who have experienced PP.

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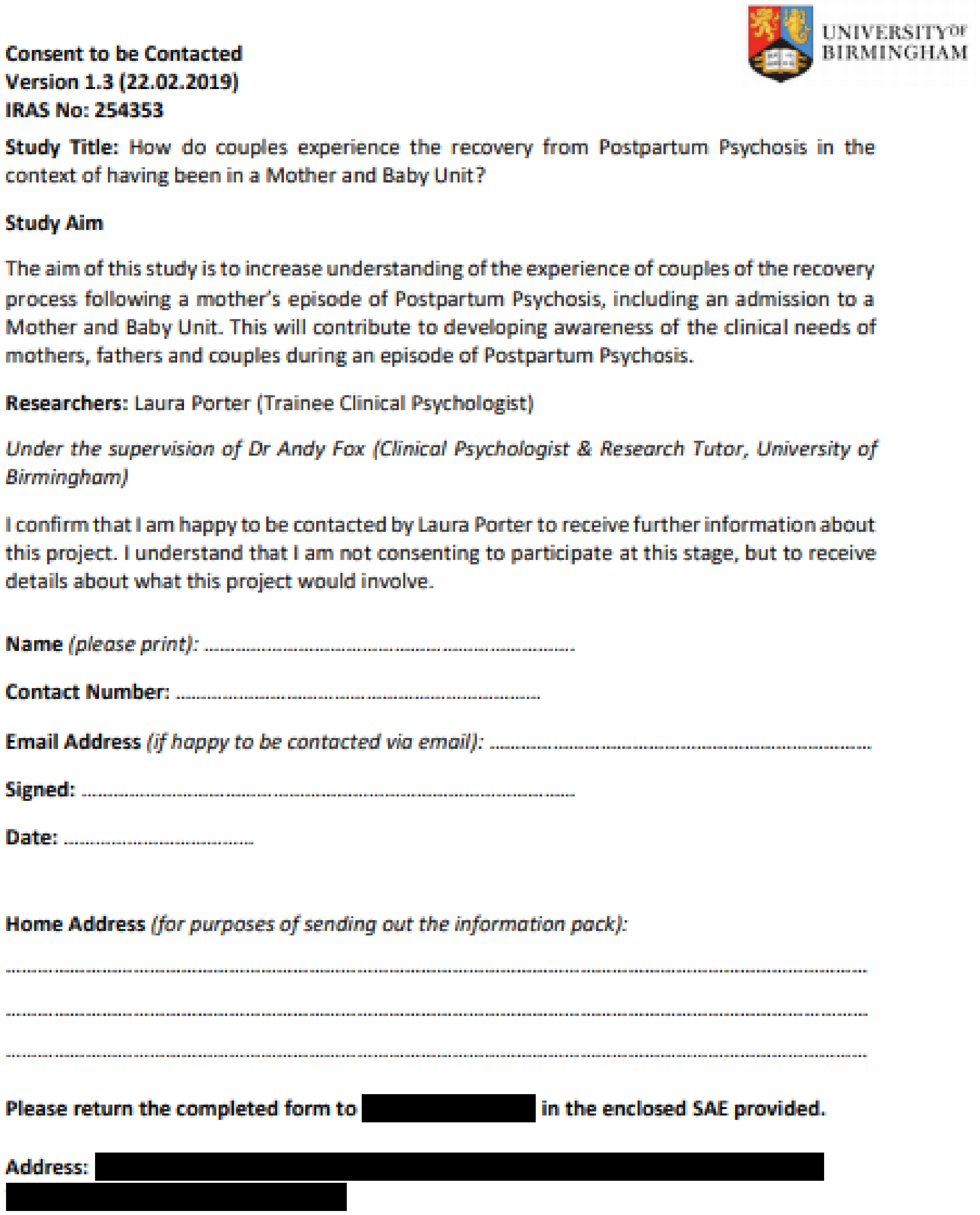
# APPENDICES: CHAPTER ONE

## Appendix A: Calgary Depression Scale for Schizophrenia

*Copyrighted material removed.*

# APPENDICES: CHAPTER TWO

## Appendix B: Consent to be Contacted Form



UNIVERSITY OF BIRMINGHAM

**Consent to be Contacted**
**Version 1.3 (22.02.2019)**
**IRAS No: 254353**

**Study Title:** How do couples experience the recovery from Postpartum Psychosis in the context of having been in a Mother and Baby Unit?

**Study Aim**

The aim of this study is to increase understanding of the experience of couples of the recovery process following a mother's episode of Postpartum Psychosis, including an admission to a Mother and Baby Unit. This will contribute to developing awareness of the clinical needs of mothers, fathers and couples during an episode of Postpartum Psychosis.

**Researchers:** Laura Porter (Trainee Clinical Psychologist)

*Under the supervision of Dr Andy Fox (Clinical Psychologist & Research Tutor, University of Birmingham)*

I confirm that I am happy to be contacted by Laura Porter to receive further information about this project. I understand that I am not consenting to participate at this stage, but to receive details about what this project would involve.

**Name** *(please print)*: ……………………………………………………………

**Contact Number:** ……………………………………………………………

**Email Address** *(if happy to be contacted via email)*: ……………………………………………………………

**Signed:** ……………………………………………………………

**Date:** ……………………………

**Home Address** *(for purposes of sending out the information pack)*:

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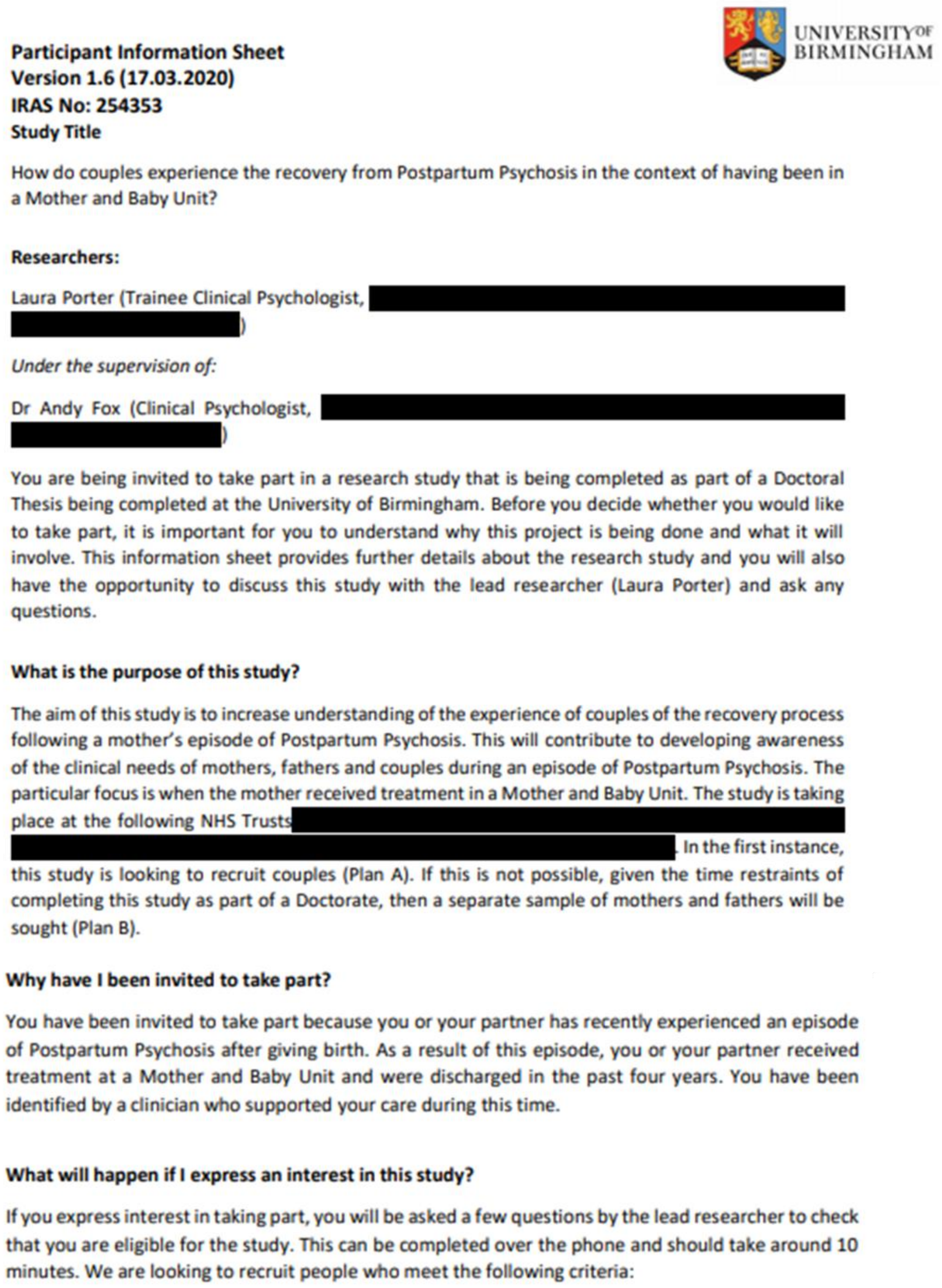
**Please return the completed form to** [redacted] **in the enclosed SAE provided.**

**Address:** [redacted]

# Appendix C: Participant Information Sheet



**Participant Information Sheet**
**Version 1.6 (17.03.2020)**
**IRAS No: 254353**
**Study Title**

How do couples experience the recovery from Postpartum Psychosis in the context of having been in a Mother and Baby Unit?

**Researchers:**

Laura Porter (Trainee Clinical Psychologist, [redacted])

*Under the supervision of:*

Dr Andy Fox (Clinical Psychologist, [redacted])

You are being invited to take part in a research study that is being completed as part of a Doctoral Thesis being completed at the University of Birmingham. Before you decide whether you would like to take part, it is important for you to understand why this project is being done and what it will involve. This information sheet provides further details about the research study and you will also have the opportunity to discuss this study with the lead researcher (Laura Porter) and ask any questions.

**What is the purpose of this study?**

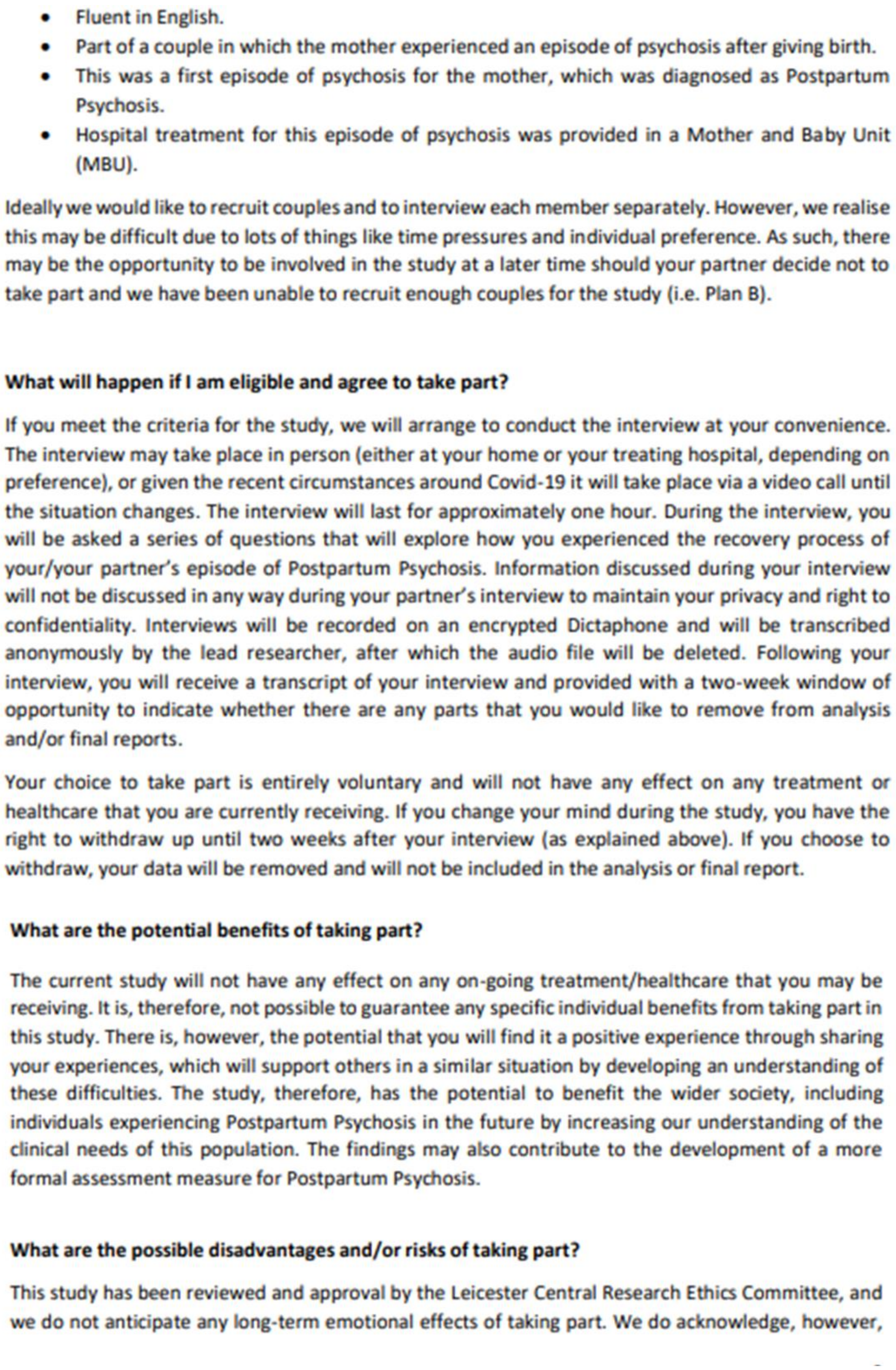
The aim of this study is to increase understanding of the experience of couples of the recovery process following a mother's episode of Postpartum Psychosis. This will contribute to developing awareness of the clinical needs of mothers, fathers and couples during an episode of Postpartum Psychosis. The particular focus is when the mother received treatment in a Mother and Baby Unit. The study is taking place at the following NHS Trusts [redacted]. In the first instance, this study is looking to recruit couples (Plan A). If this is not possible, given the time restraints of completing this study as part of a Doctorate, then a separate sample of mothers and fathers will be sought (Plan B).

**Why have I been invited to take part?**

You have been invited to take part because you or your partner has recently experienced an episode of Postpartum Psychosis after giving birth. As a result of this episode, you or your partner received treatment at a Mother and Baby Unit and were discharged in the past four years. You have been identified by a clinician who supported your care during this time.

**What will happen if I express an interest in this study?**

If you express interest in taking part, you will be asked a few questions by the lead researcher to check that you are eligible for the study. This can be completed over the phone and should take around 10 minutes. We are looking to recruit people who meet the following criteria:



- Fluent in English.
- Part of a couple in which the mother experienced an episode of psychosis after giving birth.
- This was a first episode of psychosis for the mother, which was diagnosed as Postpartum Psychosis.
- Hospital treatment for this episode of psychosis was provided in a Mother and Baby Unit (MBU).

Ideally we would like to recruit couples and to interview each member separately. However, we realise this may be difficult due to lots of things like time pressures and individual preference. As such, there may be the opportunity to be involved in the study at a later time should your partner decide not to take part and we have been unable to recruit enough couples for the study (i.e. Plan B).

**What will happen if I am eligible and agree to take part?**

If you meet the criteria for the study, we will arrange to conduct the interview at your convenience. The interview may take place in person (either at your home or your treating hospital, depending on preference), or given the recent circumstances around Covid-19 it will take place via a video call until the situation changes. The interview will last for approximately one hour. During the interview, you will be asked a series of questions that will explore how you experienced the recovery process of your/your partner's episode of Postpartum Psychosis. Information discussed during your interview will not be discussed in any way during your partner's interview to maintain your privacy and right to confidentiality. Interviews will be recorded on an encrypted Dictaphone and will be transcribed anonymously by the lead researcher, after which the audio file will be deleted. Following your interview, you will receive a transcript of your interview and provided with a two-week window of opportunity to indicate whether there are any parts that you would like to remove from analysis and/or final reports.

Your choice to take part is entirely voluntary and will not have any effect on any treatment or healthcare that you are currently receiving. If you change your mind during the study, you have the right to withdraw up until two weeks after your interview (as explained above). If you choose to withdraw, your data will be removed and will not be included in the analysis or final report.

**What are the potential benefits of taking part?**

The current study will not have any effect on any on-going treatment/healthcare that you may be receiving. It is, therefore, not possible to guarantee any specific individual benefits from taking part in this study. There is, however, the potential that you will find it a positive experience through sharing your experiences, which will support others in a similar situation by developing an understanding of these difficulties. The study, therefore, has the potential to benefit the wider society, including individuals experiencing Postpartum Psychosis in the future by increasing our understanding of the clinical needs of this population. The findings may also contribute to the development of a more formal assessment measure for Postpartum Psychosis.

**What are the possible disadvantages and/or risks of taking part?**

This study has been reviewed and approval by the Leicester Central Research Ethics Committee, and we do not anticipate any long-term emotional effects of taking part. We do acknowledge, however, that there is the potential for you to experience some short-term distress because of the nature of the topic, which we understand may be highly emotive. If you are feeling emotionally distressed during the interview, you can ask to stop at any time. The lead researcher will also monitor for any signs of emotional distress, and if concerned they will ask whether you wish to continue with the interview. After the interview, you will be provided with details of third-party organisations if you would like additional support.

We appreciate that taking part in the study will take up some of your time, which may be an inconvenience to you. To minimise this inconvenience, if you are interviewed in person, you can choose whether to be interviewed at home or the hospital where you received treatment. If you choose to be interviewed at the hospital, you will be reimbursed at face-value for any public transport (i.e. bus and/or train tickets) travel expenses up to a maximum value of £15.

**What will happen to the results of the study?**

The research study is due to be completed by September 2020. It is expected that the results will be published in a peer-reviewed journal, of which you will receive a copy if you wish. This will include data extracts from interviews, but extracts will be carefully selected to ensure you cannot be identified, nor you or your partner as a couple. You will also receive a summary paper, outlining the findings of the study. No personal information about you will be published in any of the reports, to ensure your confidentiality and right to privacy.

**What will happen if any concerns or risk issues arise?**

If any concerns arise during the interviews about risk (e.g. abuse, neglect or potential harm) either to yourself or your child, the researcher has a duty of care to act to ensure the safety of all individuals. This may include contacting either your NHS trust's safeguarding department or your local council's safeguarding body. Where possible, the researcher will inform you of the need to discuss the information raised in the interview with others and will outline any action(s) they may have to consider making in respect to the information shared with them in confidence.

**Who will have access to my information and data?**

The University of Birmingham is the sponsor for this study based in England. We will be using information from you to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. After the study has finished, the University of Birmingham will only keep identifiable information about you until you have been provided with a summary of the findings.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. As mentioned above, if you choose to withdraw from the study within the permitted timeframe, your data will be removed from the study. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at: https://www.birmingham.ac.uk/privacy/index.aspx.

[redacted] will keep your name and contact details (i.e. home address, telephone number) confidential and will not pass this information to the University of Birmingham. [redacted] will use the information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from the University of Birmingham and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The University of Birmingham will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not find out your name or contact details.

[redacted] will keep identifiable information about you from this study until the lead researcher (Laura Porter) has completed her Doctor of Clinical Psychology award (expected end date 30.09.2020).

All personal information, including name and address about you will be kept confidential. This information will not be passed onto individuals outside the supervisory team and will be used as needed (e.g. to contact you about the research study or to inform members of the research team of the location of the interview if it is to be conducted at your home address). Your data, including the audio interview file and personal details, will be stored with the use of passwords and encryption to ensure it is stored securely. Data, including hard copies of forms and audio files, will not be stored for longer than is required. All individuals involved in conducting this research study will fully comply and adhere to the Data Protection Act (2018) and General Data Protection Regulations (GDPR), alongside the data protection policies of the involved NHS Trusts [redacted] and the University of Birmingham.

***I would like to thank you for taking the time to read this sheet and I hope that you consider taking part in this research study.***

If you have any questions about this study or would like to discuss this information before deciding whether to take part, please contact the research team on the following details:

**Email:** lsp759@student.bham.ac.uk or laura.porter5@nhs.net

**Post:** Miss Laura Porter, Department of Psychology, 52 Pritchatts Road, University of Birmingham, Edgbaston, B15 2TT.

The lead research (Laura Porter) will aim to contact you using the details you provided in the 'consent to be contacted' form to discuss this project and answer any questions. This will happen after a minimum of 48 hours of receiving this information pack to allow you time to consider the information.

If you would like to make a complaint in relation to this project, please use the following contact details to do so:

- Dr Andrew Fox (Academic Supervisor of this project, University of Birmingham):
  - Email: a.p.fox@bham.ac.uk
  - Tel: 0121 414 2752
- Dr Theresa Powell (Clinical Psychology Programme Director, University of Birmingham):
  - Email: t.powell@bham.ac.uk
  - Tel: 0121 414 7124
- Patient Advise and Liaison Service (PALS):
  - [redacted]

# Appendix D: Screening Questionnaire

**Participant *(Identification Code)*:**

1. What is your age?

   ____________________________________________________________________

2. What is your ethnicity?

   ____________________________________________________________________

3. What is your relationship to this child?

   Mother Father Other *(please specify)*

   ____________________________________________________________________

4. What type of delivery did you/your partner have prior to experiencing Postpartum Psychosis? (e.g. emergency, planned Caesarean, vaginal) And were there any complications during this birth?

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

5. Did you/your partner receive a formal diagnosis of Postpartum Psychosis?

   Yes No Don't Know

6. How soon after giving birth did you/your partner receive this diagnosis?

   ___________________________________________________________
   ____________________________________________________________________

7. Where were you/your partner cared for during this episode of Postpartum Psychosis?

   ___________________________________________________________
   ____________________________________________________________________

8. When were you/your partner discharged from here?

   __________________________________________________________

9. How many children do you have? _____________

10. When you/your partner experienced Postpartum psychosis, which number child was this? _______________________

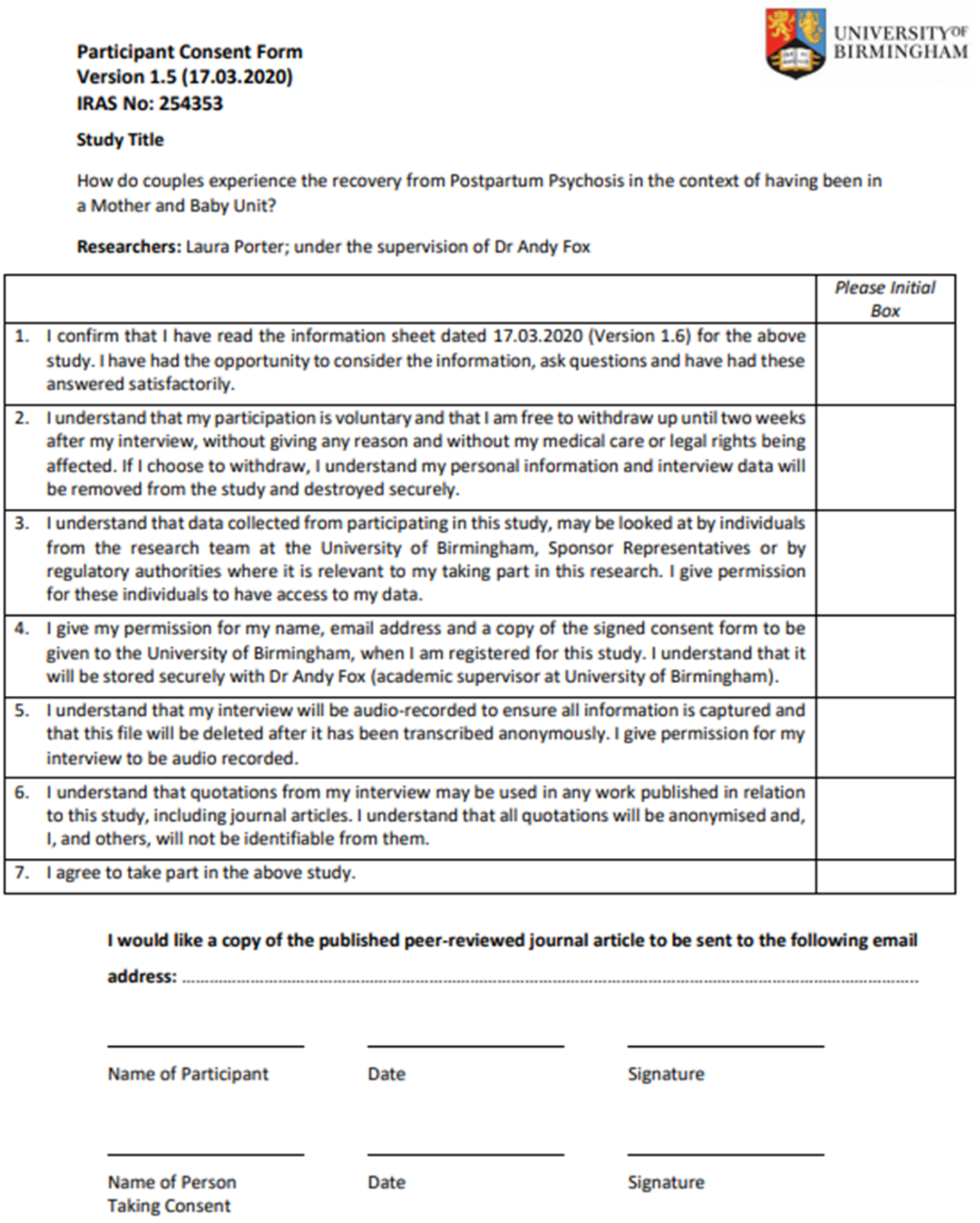
11. Did you/your partner experience an episode of Postpartum Psychosis following any previous births? If so which ones?

    ________________________________________________________
    _________________________________________________________________

12. Prior to this episode of Postpartum Psychosis, had you previously received a diagnosis of any mental health illness? (e.g. depression, anxiety, schizophrenia)

    _________________________________________________________
    _________________________________________________________

# Appendix E: Consent Form



UNIVERSITY OF BIRMINGHAM

**Participant Consent Form**
**Version 1.5 (17.03.2020)**
**IRAS No: 254353**

**Study Title**

How do couples experience the recovery from Postpartum Psychosis in the context of having been in a Mother and Baby Unit?

**Researchers:** Laura Porter; under the supervision of Dr Andy Fox

| | *Please Initial Box* |
|---|---|
| 1. I confirm that I have read the information sheet dated 17.03.2020 (Version 1.6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2. I understand that my participation is voluntary and that I am free to withdraw up until two weeks after my interview, without giving any reason and without my medical care or legal rights being affected. If I choose to withdraw, I understand my personal information and interview data will be removed from the study and destroyed securely. | |
| 3. I understand that data collected from participating in this study, may be looked at by individuals from the research team at the University of Birmingham, Sponsor Representatives or by regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. | |
| 4. I give my permission for my name, email address and a copy of the signed consent form to be given to the University of Birmingham, when I am registered for this study. I understand that it will be stored securely with Dr Andy Fox (academic supervisor at University of Birmingham). | |
| 5. I understand that my interview will be audio-recorded to ensure all information is captured and that this file will be deleted after it has been transcribed anonymously. I give permission for my interview to be audio recorded. | |
| 6. I understand that quotations from my interview may be used in any work published in relation to this study, including journal articles. I understand that all quotations will be anonymised and, I, and others, will not be identifiable from them. | |
| 7. I agree to take part in the above study. | |

**I would like a copy of the published peer-reviewed journal article to be sent to the following email address:** ..............................................................................................

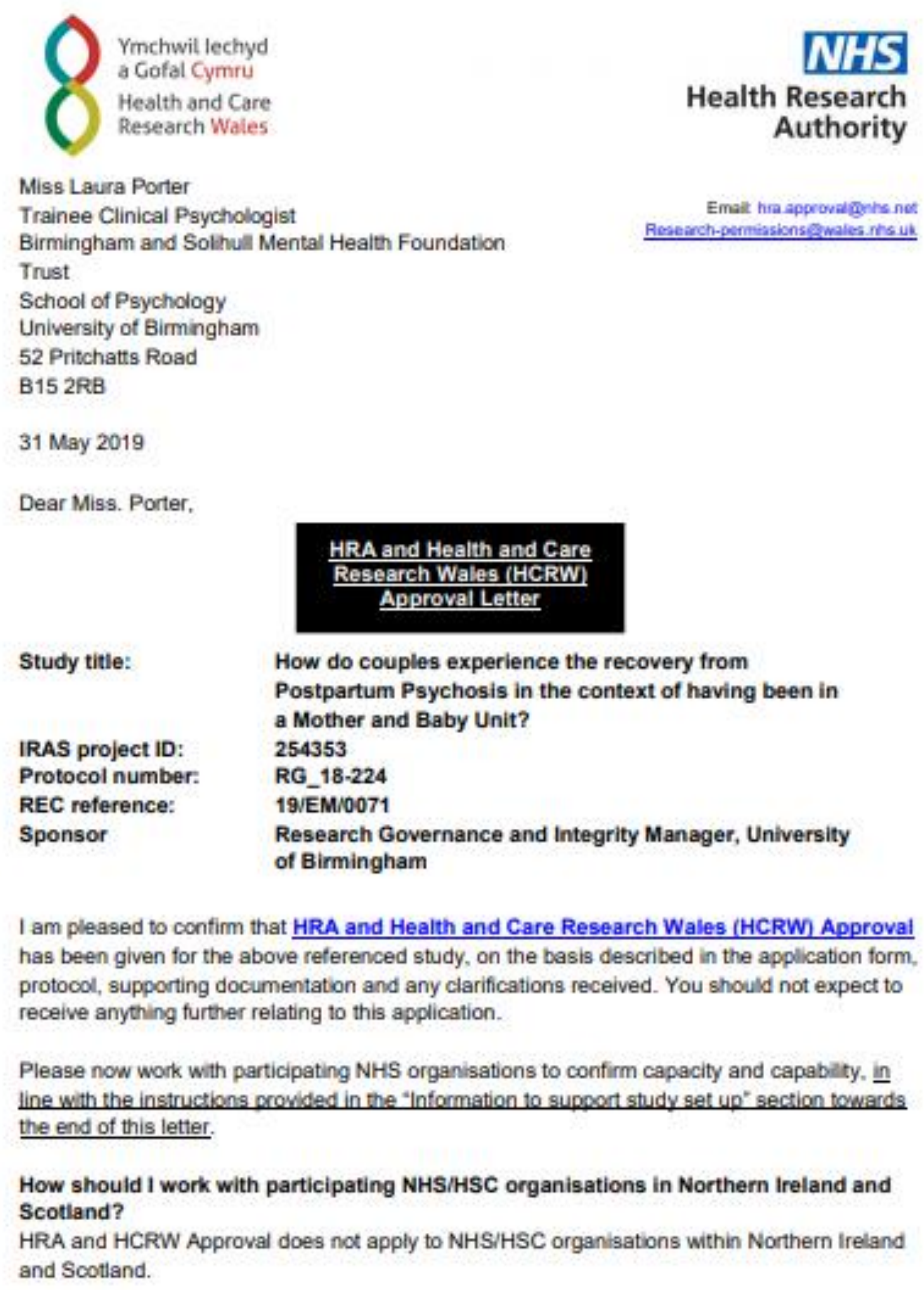
| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person Taking Consent | Date | Signature |

# Appendix F: Interview Schedule

| Mothers | Partners |
|---|---|
| **Q: Please can you tell me how you came to stay in a MBU?**<br>*[to elicit a narrative of the experience]*<br>*[ask about the different steps in the journey, and the experiences associated with this:*<br>- *Prodrome*<br>- *Early signs*<br>- *Admission* | **Q: Please can you tell me how X came to be staying in a MBU?**<br>*[to elicit a narrative of the experience]*<br>*[ask about the different steps in the journey, and the experiences associated with this:*<br>- *Prodrome*<br>- *Early signs*<br>- *Admission* |
| **Q: What was it like to be on the MBU?**<br>- *What types of things happen on a regular basis?*<br>- *Any events that stand out?*<br>- *How were you feeling?*<br>- *What was the ward like?* | **Q: What was it like for you while X was in the MBU?**<br>- *Did things change at all? In what way?*<br>- *How did you feel when X went into the MBU?*<br>- *How did you find visiting X on the MBU?* |
| **Q: Was there anything that you found particularly helpful in arriving / staying / leaving at the MBU?**<br>*[to elicit a narrative of the help and support received at the various stages]*<br>*Is there anything that you would want to know at the point of admission, having been through your experience now?* | **Q: Was there anything that you found particularly helpful while X was arriving / staying / leaving the MBU?**<br>*[to elicit a narrative of the help and support received at the various stages]*<br>*Is there anything that you would want to know at the point of admission, having been through your experience now?* |
| **Q: Was there anything that you found particularly unhelpful in arriving / staying / leaving at the MBU?**<br>*[to elicit a narrative of difficulties or limited support experienced]* | **Q: Was there anything that you found particularly unhelpful in arriving / staying / leaving at the MBU?**<br>*[to elicit a narrative of difficulties or limited support experienced]* |
| **Q: What was it like being away from X during this time?**<br>*If it seems appropriate, this may begin a dialogue around their relationship:*<br>- *How it impacted on the relationship*<br>- *Any positives?*<br>- *Any difficulties/strains?* | **Q: What was it like being away from X during this time?**<br>*If it seems appropriate, this may begin a dialogue around their relationship:*<br>- *How it impacted on the relationship*<br>- *Any positives?*<br>- *Any difficulties/strains?* |

| | |
|---|---|
| **Q: How did you know you were getting better?**<br>- *What did you notice?*<br>- *What was different?* | **Q: How did you know that X was getting better?**<br>- *What did you notice?*<br>- *What was different?* |
| **Q: How did you come to leave the MBU?** | **Q: How did X come to leave the MBU?** |
| **Q: What was it like going home?**<br>*[to elicit a narrative of adjusting to returning home and to the end of the period of separation]* | **Q: What was X coming home like?**<br>*[to elicit a narrative of adjusting to returning home and to the end of the period of separation]* |
| **Q: Is anything different now, compared to how things were before you went into X? In what way?** | **Q: Is anything different now, compared to how things were before X went into X? In what way?** |

# Appendix G: Letter of Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Laura Porter
Trainee Clinical Psychologist
Birmingham and Solihull Mental Health Foundation
Trust
School of Psychology
University of Birmingham
52 Pritchatts Road
B15 2RB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

31 May 2019

Dear Miss. Porter,

**HRA and Health and Care Research Wales (HCRW) Approval Letter**

| | |
|---|---|
| **Study title:** | **How do couples experience the recovery from Postpartum Psychosis in the context of having been in a Mother and Baby Unit?** |
| **IRAS project ID:** | **254353** |
| **Protocol number:** | **RG_18-224** |
| **REC reference:** | **19/EM/0071** |
| **Sponsor** | **Research Governance and Integrity Manager, University of Birmingham** |

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

**What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

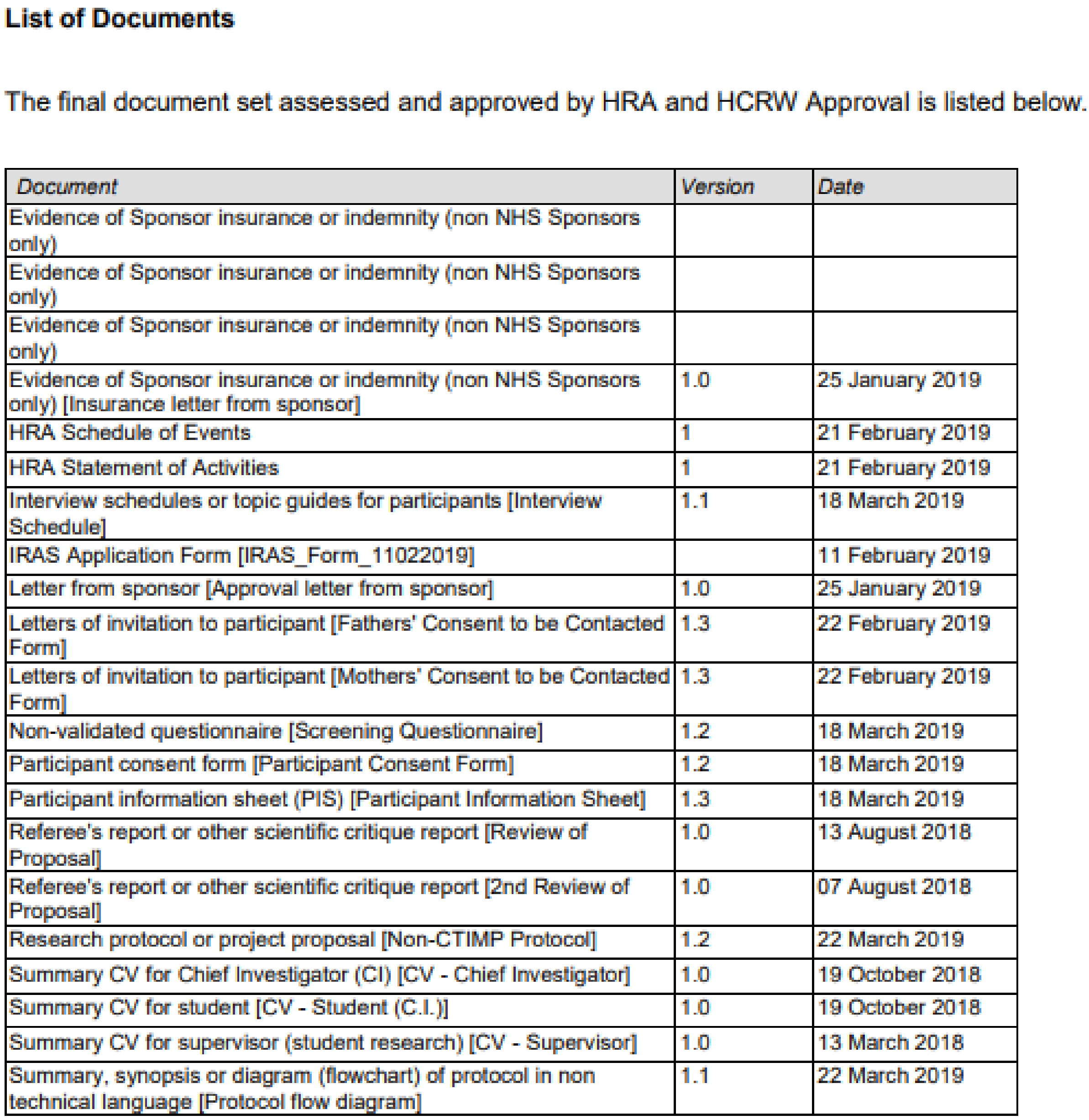
Your IRAS project ID is **254353**. Please quote this on all correspondence.

Yours sincerely,
Laura Greenfield

Approvals Specialist

Email: hra.approval@nhs.net

*Copy to:* *Dr Birgit Whitman [Sponsor Contact]*

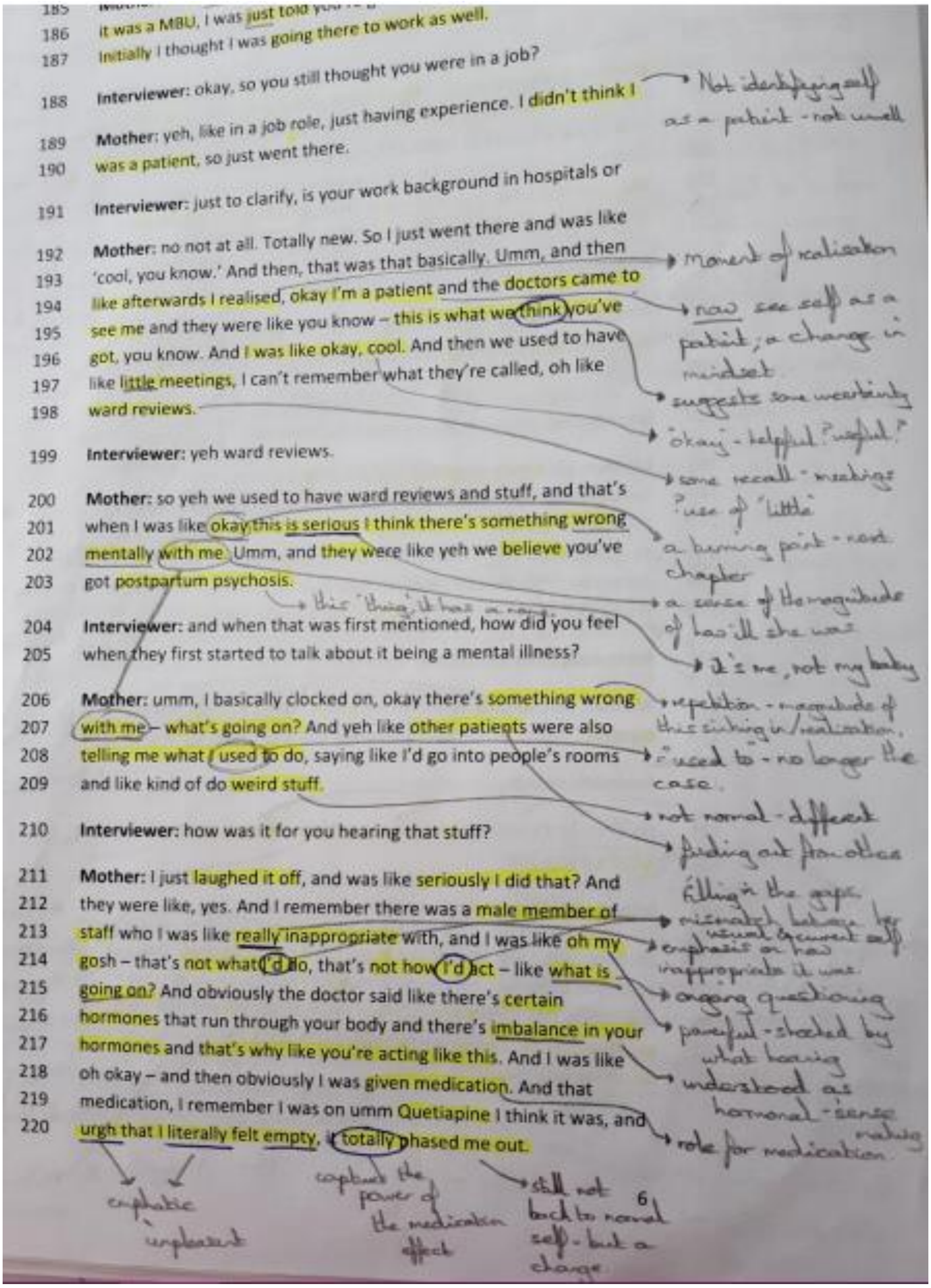


**List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

| *Document* | *Version* | *Date* |
|---|---|---|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | | |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | | |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | | |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter from sponsor] | 1.0 | 25 January 2019 |
| HRA Schedule of Events | 1 | 21 February 2019 |
| HRA Statement of Activities | 1 | 21 February 2019 |
| Interview schedules or topic guides for participants [Interview Schedule] | 1.1 | 18 March 2019 |
| IRAS Application Form [IRAS_Form_11022019] | | 11 February 2019 |
| Letter from sponsor [Approval letter from sponsor] | 1.0 | 25 January 2019 |
| Letters of invitation to participant [Fathers' Consent to be Contacted Form] | 1.3 | 22 February 2019 |
| Letters of invitation to participant [Mothers' Consent to be Contacted Form] | 1.3 | 22 February 2019 |
| Non-validated questionnaire [Screening Questionnaire] | 1.2 | 18 March 2019 |
| Participant consent form [Participant Consent Form] | 1.2 | 18 March 2019 |
| Participant information sheet (PIS) [Participant Information Sheet] | 1.3 | 18 March 2019 |
| Referee's report or other scientific critique report [Review of Proposal] | 1.0 | 13 August 2018 |
| Referee's report or other scientific critique report [2nd Review of Proposal] | 1.0 | 07 August 2018 |
| Research protocol or project proposal [Non-CTIMP Protocol] | 1.2 | 22 March 2019 |
| Summary CV for Chief Investigator (CI) [CV - Chief Investigator] | 1.0 | 19 October 2018 |
| Summary CV for student [CV - Student (C.I.)] | 1.0 | 19 October 2018 |
| Summary CV for supervisor (student research) [CV - Supervisor] | 1.0 | 13 March 2018 |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol flow diagram] | 1.1 | 22 March 2019 |

# Appendix H: Example of initial coding (analysis stage 2)



it was a MBU, I was just told you Initially I thought I was going there to work as well.

**Interviewer:** okay, so you still thought you were in a job?

**Mother:** yeh, like in a job role, just having experience. I didn't think I was a patient, so just went there.

**Interviewer:** just to clarify, is your work background in hospitals or

**Mother:** no not at all. Totally new. So I just went there and was like 'cool, you know.' And then, that was that basically. Umm, and then like afterwards I realised, okay I'm a patient and the doctors came to see me and they were like you know – this is what we think you've got, you know. And I was like okay, cool. And then we used to have like little meetings, I can't remember what they're called, oh like ward reviews.

**Interviewer:** yeh ward reviews.

**Mother:** so yeh we used to have ward reviews and stuff, and that's when I was like okay this is serious I think there's something wrong mentally with me. Umm, and they were like yeh we believe you've got postpartum psychosis.

**Interviewer:** and when that was first mentioned, how did you feel when they first started to talk about it being a mental illness?

**Mother:** umm, I basically clocked on, okay there's something wrong with me – what's going on? And yeh like other patients were also telling me what I used to do, saying like I'd go into people's rooms and like kind of do weird stuff.

**Interviewer:** how was it for you hearing that stuff?

**Mother:** I just laughed it off, and was like seriously I did that? And they were like, yes. And I remember there was a male member of staff who I was like really inappropriate with, and I was like oh my gosh – that's not what I'd do, that's not how I'd act – like what is going on? And obviously the doctor said like there's certain hormones that run through your body and there's imbalance in your hormones and that's why like you're acting like this. And I was like oh okay – and then obviously I was given medication. And that medication, I remember I was on umm Quetiapine I think it was, and urgh that I literally felt empty, it totally phased me out.

Not identifying self as a patient - not unwell

moment of realisation

now see self as a patient; a change in mindset

suggests some uncertainty

'okay' - helpful? useful?

some recall - meetings ? use of 'little'

a turning point - next chapter

a sense of the magnitude of how ill she was

this 'thing', it has a name

it's me, not my baby

repetition - magnitude of this sinking in/realisation.

'used to' - no longer the case.

not normal - different

finding out from others

filling in the gaps

mismatch between her usual & current self

emphasis on how inappropriate it was

ongoing questioning

powerful - shocked by what hearing

understood as hormonal - sense making

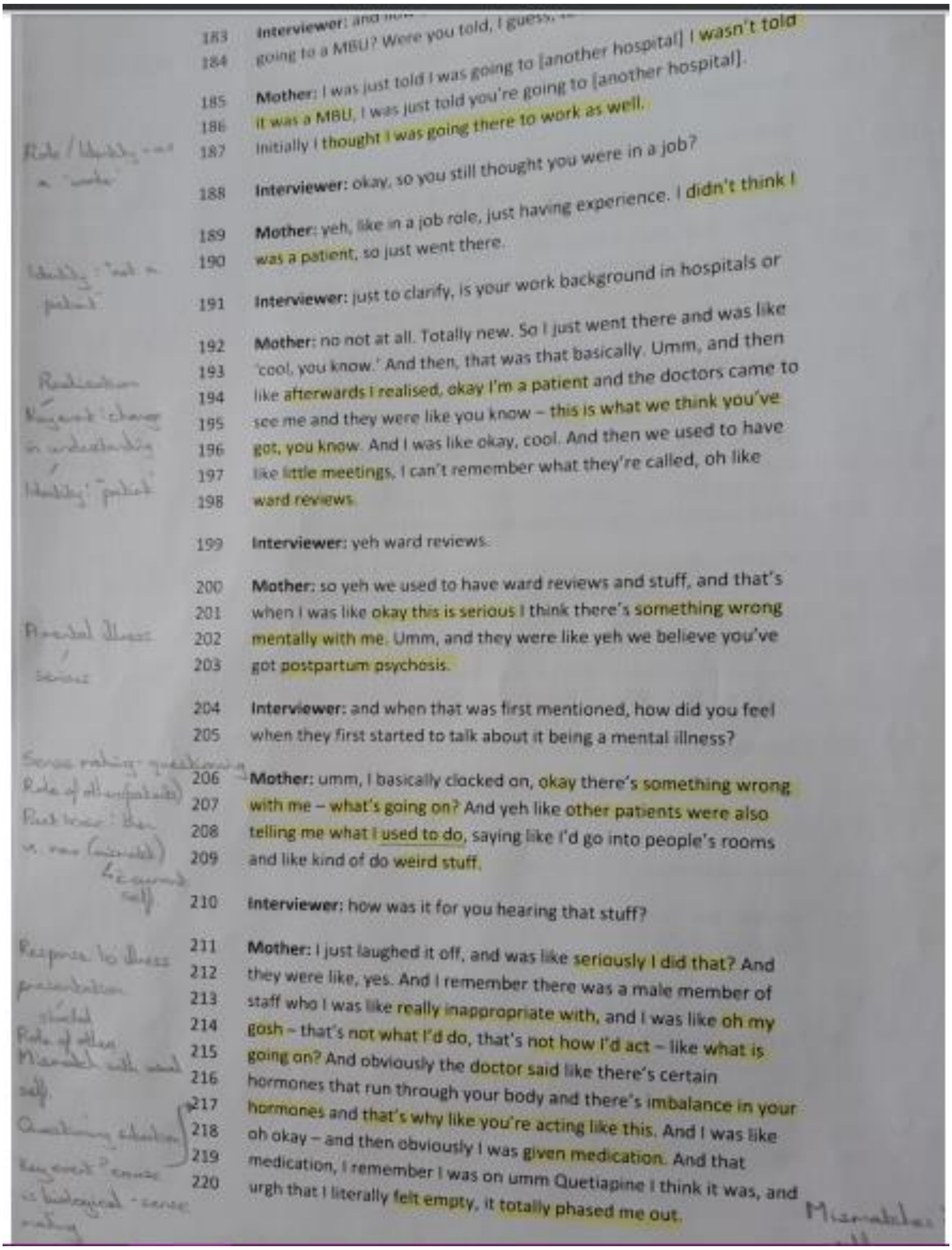
role for medication

emphatic unpleasant

captures the power of the medication effect

still not back to normal self - but a change

## Appendix I: Example of developing prototype themes (analysis stage 3)



**Interviewer:** and [illegible] going to a MBU? Were you told, I guess,

**Mother:** I was just told I was going to [another hospital] I wasn't told it was a MBU, I was just told you're going to [another hospital]. Initially I thought I was going there to work as well.

Role / Identity – not a 'worker'

**Interviewer:** okay, so you still thought you were in a job?

**Mother:** yeh, like in a job role, just having experience. I didn't think I was a patient, so just went there.

Identity: 'not a patient'

**Interviewer:** just to clarify, is your work background in hospitals or

**Mother:** no not at all. Totally new. So I just went there and was like 'cool, you know.' And then, that was that basically. Umm, and then like afterwards I realised, okay I'm a patient and the doctors came to see me and they were like you know – this is what we think you've got, you know. And I was like okay, cool. And then we used to have like little meetings, I can't remember what they're called, oh like ward reviews.

Realisation / Key event: change in understanding / Identity: 'patient'

**Interviewer:** yeh ward reviews.

**Mother:** so yeh we used to have ward reviews and stuff, and that's when I was like okay this is serious I think there's something wrong mentally with me. Umm, and they were like yeh we believe you've got postpartum psychosis.

Mental Illness / serious

**Interviewer:** and when that was first mentioned, how did you feel when they first started to talk about it being a mental illness?

**Mother:** umm, I basically clocked on, okay there's something wrong with me – what's going on? And yeh like other patients were also telling me what I used to do, saying like I'd go into people's rooms and like kind of do weird stuff.

Sense making: questioning
Role of others (patients)
Past [illegible]: then vs. now (mismatch) ← [illegible] self

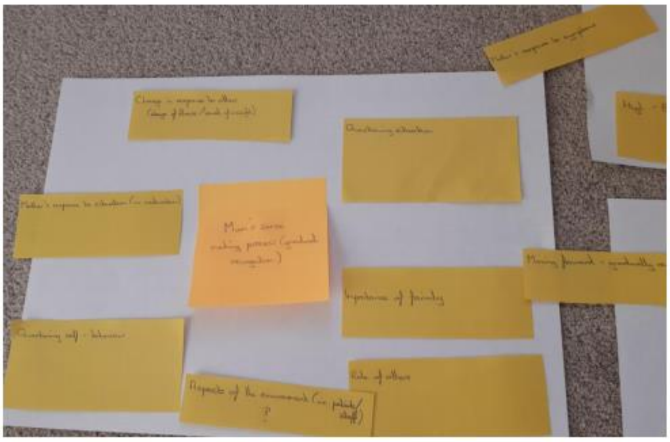
**Interviewer:** how was it for you hearing that stuff?

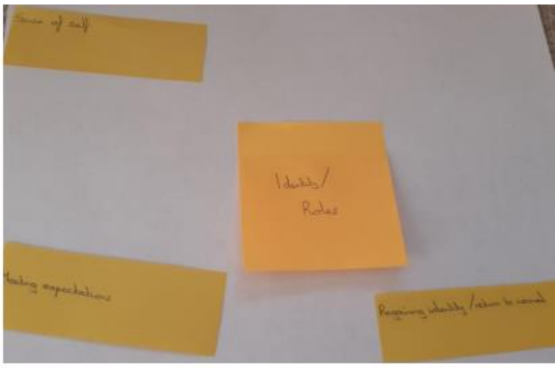
**Mother:** I just laughed it off, and was like seriously I did that? And they were like, yes. And I remember there was a male member of staff who I was like really inappropriate with, and I was like oh my gosh – that's not what I'd do, that's not how I'd act – like what is going on? And obviously the doctor said like there's certain hormones that run through your body and there's imbalance in your hormones and that's why like you're acting like this. And I was like oh okay – and then obviously I was given medication. And that medication, I remember I was on umm Quetiapine I think it was, and urgh that I literally felt empty, it totally phased me out.

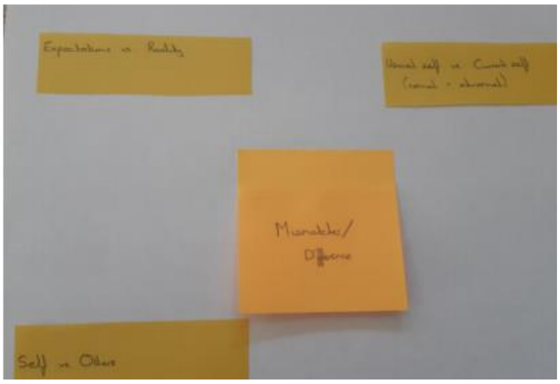
Response to illness presentation / shocked
Role of others
Mismatch with usual self.
Questioning situation
Key event? cause is biological - sense making

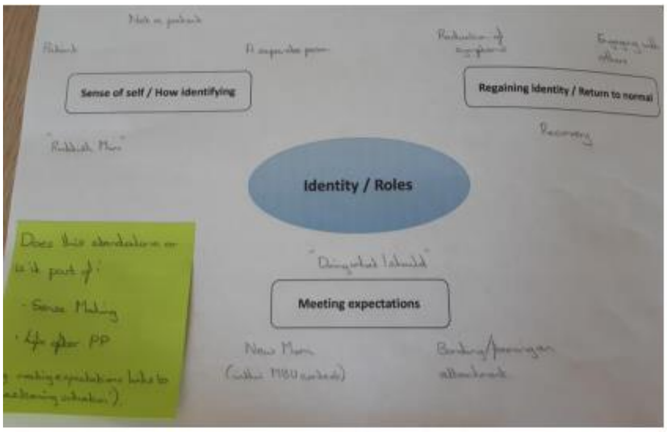
Mismatches?

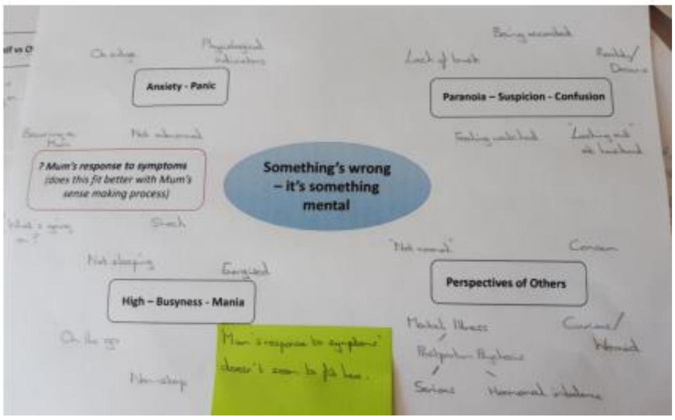
# Appendix J: Example of process of developing superordinate theme (analysis stage 4)

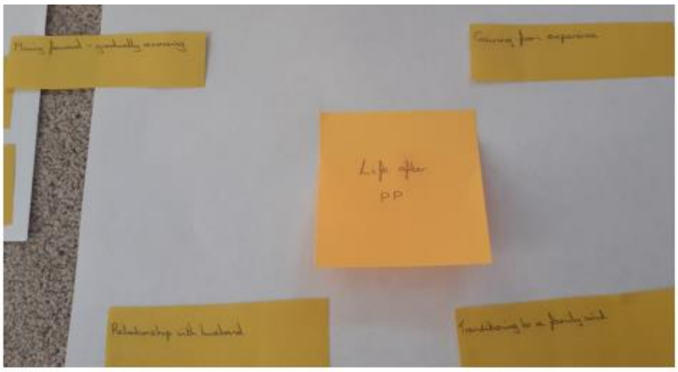


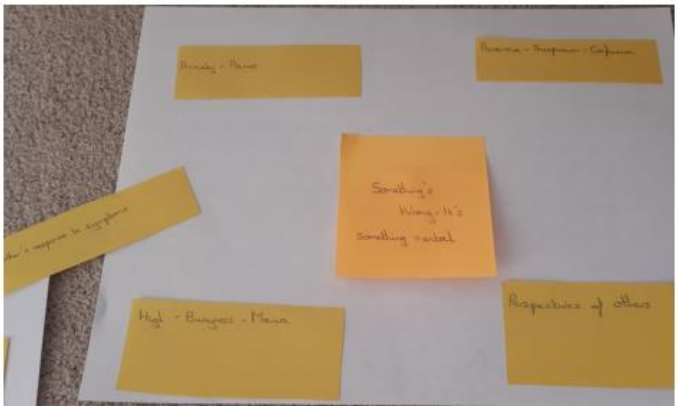




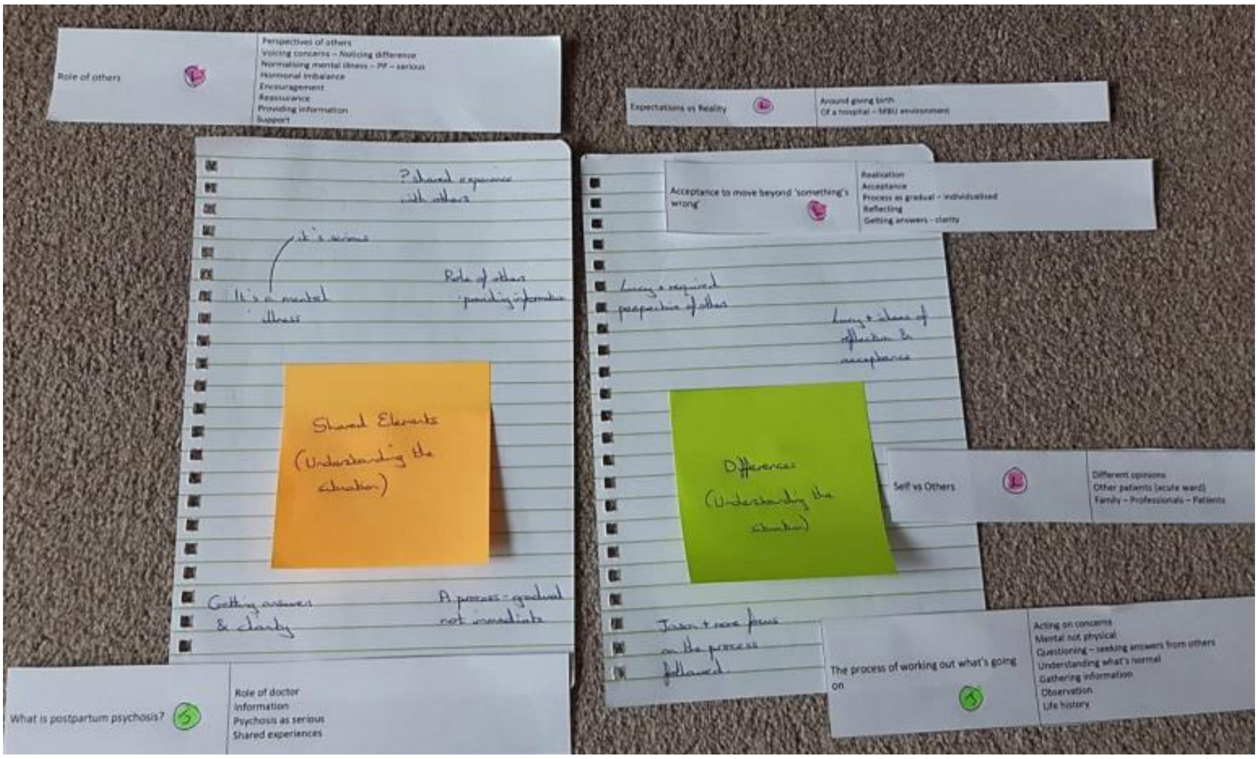

Identity / Roles
Sense of self / How identifying
Regaining identity / Return to normal
Meeting expectations
"Rubbish Mum"
Reduction of symptoms
Engaging with others
Recovery
"Doing what I should"
New Mum
(within MBU context)
Bonding/forming an attachment
Does this standalone or is it part of:
- Sense Making
- Life after PP
meeting expectations links to sense making situation)


Something's wrong – it's something mental
Anxiety - Panic
Paranoia – Suspicion - Confusion
? Mum's response to symptoms (does this fit better with Mum's sense making process)
High – Busyness - Mania
Perspectives of Others
On edge
Physiological indicators
Lack of trust
Feeling watched
Shock
What's going on?
Not sleeping
Energised
On the go
Non-stop
"Not normal"
Concern
Mental Illness
Postpartum Psychosis
Serious
Hormonal imbalance
Concerned/Worried
'Mum's response to symptoms' doesn't seem to fit here.


Moving forward - gradually recovering
Growing from experience
Life after PP
Relationship with husband
Transitioning to a family unit


Anxiety - Panic
Paranoia - Suspicion - Confusion
Something's Wrong - It's something mental
um's response to symptoms
High - Busyness - Mania
Perspectives of others

# Appendix K: Example of multi-perspective level of analysis, moving from the individual to the dyad level (analysis stage 6)


Role of others
Perspectives of others
Voicing concerns – Noticing difference
Normalising mental illness – PP – serious
Hormonal imbalance
Encouragement
Reassurance
Providing information
Support

?shared experience with others

it's serious

It's a mental illness

Role of others: providing information

Shared Elements (Understanding the situation)

Getting answers & clarity

A process: gradual not immediate

What is postpartum psychosis?
Role of doctor
Information
Psychosis as serious
Shared experiences

Expectations vs Reality
Around giving birth
Of a hospital – MBU environment

Acceptance to move beyond 'something's wrong'
Realisation
Acceptance
Process as gradual – individualised
Reflecting
Getting answers - clarity

Lucy + required perspective of others

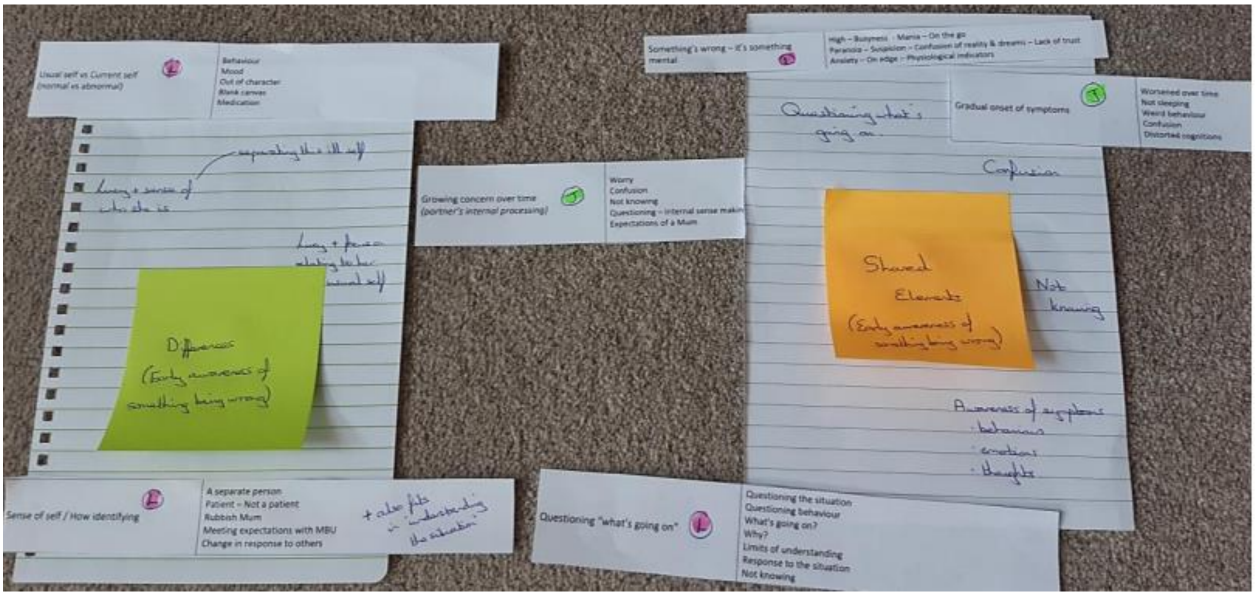
Lucy + chance of reflection & acceptance

Differences (Understanding the situation)

Self vs Others
Different opinions
Other patients (acute ward)
Family – Professionals – Patients

Jason + more focus on the process followed.

The process of working out what's going on
Acting on concerns
Mental not physical
Questioning – seeking answers from others
Understanding what's normal
Gathering information
Observation
Life history


*Usual self vs Current self (normal vs abnormal)*
Behaviour
Mood
Out of character
Blank canvas
Medication

Lucy + sense of who she is

separating the ill self

Lucy + focus on relating to her usual self

Differences (Early awareness of something being wrong)

*Growing concern over time (partner's internal processing)*
Worry
Confusion
Not knowing
Questioning – internal sense makin
Expectations of a Mum

Something's wrong – it's something mental
High – Busyness – Mania – On the go
Paranoia – Suspicion – Confusion of reality & dreams – Lack of trust
Anxiety – On edge – Physiological indicators

Questioning what's going on.

Gradual onset of symptoms
Worsened over time
Not sleeping
Weird behaviour
Confusion
Distorted cognitions

Confusion

Shared Elements (Early awareness of something being wrong)

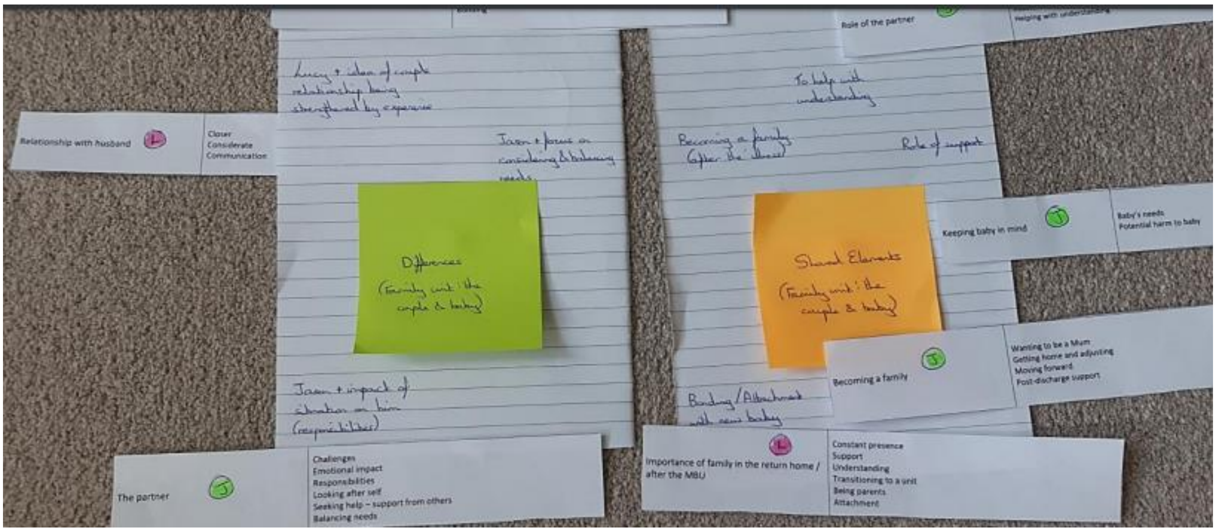
Not knowing

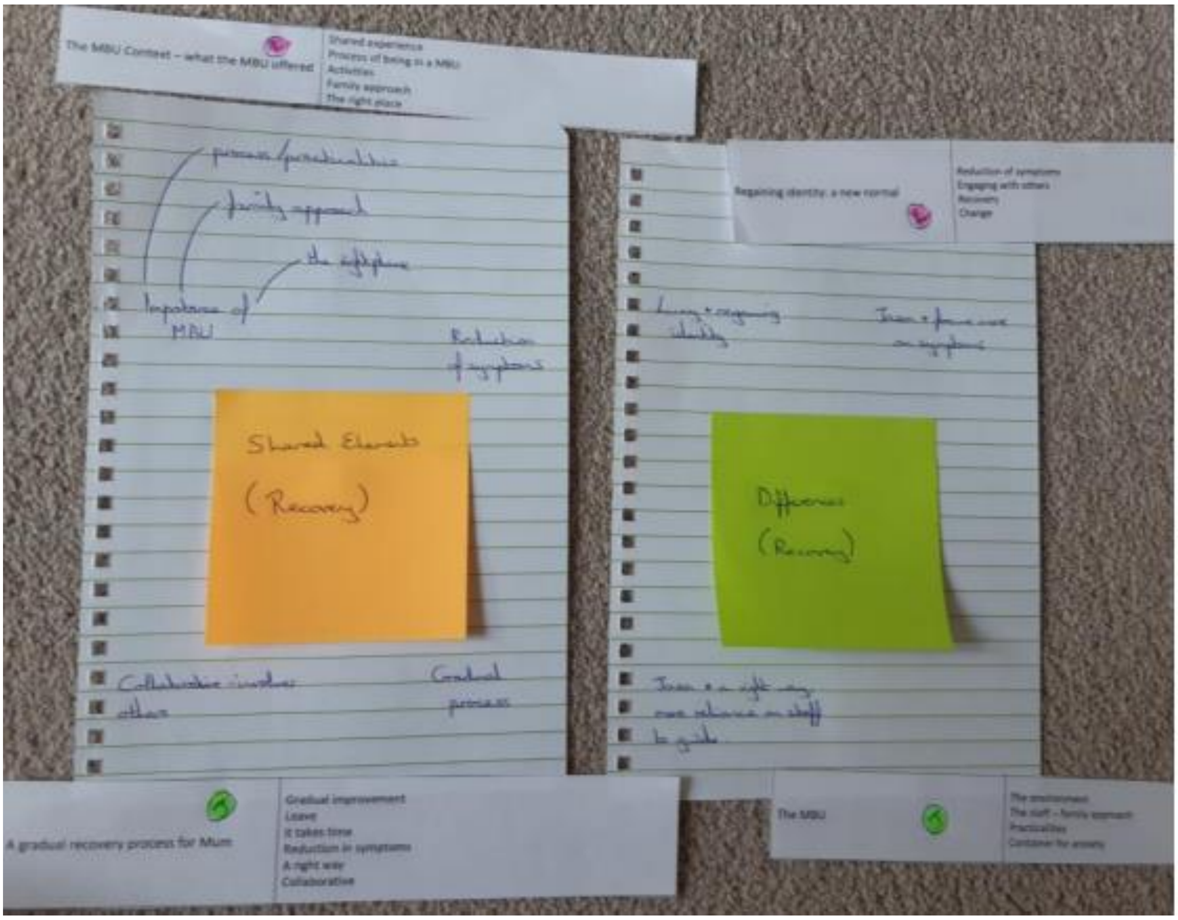
Awareness of symptoms
: behaviours
: emotions
: thoughts

Sense of self / How identifying
A separate person
Patient – Not a patient
Rubbish Mum
Meeting expectations with MBU
Change in response to others

+ also fits in 'understanding the situation'

Questioning "what's going on"
Questioning the situation
Questioning behaviour
What's going on?
Why?
Limits of understanding
Response to the situation
Not knowing


Role of the partner
Helping with understanding
Lucy + idea of couple relationship being strengthened by experience
Relationship with husband
L
Closer
Considerate
Communication
Jason + focus on considering & balancing needs
Differences
(Family unit: the couple & baby)
Jason + impact of situation on him (responsibilities)
The partner
J
Challenges
Emotional impact
Responsibilities
Looking after self
Seeking help – support from others
Balancing needs
To help with understanding
Becoming a family (after the illness)
Role of support
Keeping baby in mind
J
Baby's needs
Potential harm to baby
Shared Elements
(Family unit: the couple & baby)
Becoming a family
J
Wanting to be a Mum
Getting home and adjusting
Moving forward
Post-discharge support
Bonding / Attachment with new baby
Importance of family in the return home / after the MBU
L
Constant presence
Support
Understanding
Transitioning to a unit
Being parents
Attachment


The MBU Context – what the MBU offered
L
Shared experience
Process of being in a MBU
Activities
Family approach
The right place
process/practicalities
family approach
the right place
Importance of MBU
Reduction of symptoms
Shared Elements
(Recovery)
Collaboration involves others
Gradual process
A gradual recovery process for Mum
J
Gradual improvement
Leave
It takes time
Reduction in symptoms
A right way
Collaborative
Regaining identity: a new normal
L
Reduction of symptoms
Engaging with others
Recovery
Change
Lucy + regaining identity
Jason + focus more on symptoms
Differences
(Recovery)
Jason + a right way more reliance on staff to guide
The MBU
J
The environment
The staff – family approach
Practicalities
Container for anxiety

# Appendix L: Illustrative quotations for Priya and Dhanesh's Themes

## 1. Something's not right: Is this normal?

| Key Ideas | Shared Elements Quotations |
|---|---|
| Psychosis as unheard of<br>Concern<br>Confusion<br>Expectations and mismatches<br>Gradual onset<br>Not sleeping<br>Anxious<br>Feeling watched<br>Odd behaviour | **It's not what we expected**<br>"I was like is this normal? Is this what people go through?" [Priya]<br>"I was just on the go. Initially, I didn't think anything was wrong, I just thought you know, maybe, because I've just had a baby girl I'm excited about it…it was all new to me, so thought nothing of it…like it's getting used to being a mother, it's all new." [Priya]<br>"after five days Priya couldn't sleep for, err, a couple of days and we thought it's just normal, like me, my mum and mother-in-law; because at that time my mother and mother-in-law they come to help us and to support because it's our first baby…I didn't know about the psychosis stuff, and thought this was just normal because my mother-in-law says [having a baby] takes time for it to become a routine life. [Dhanesh]<br>"after giving birth I mean you'd expect me to be exhausted, but I wasn't." [Priya]<br>"before we went to the MBU I don't know about the psychosis." [Dhanesh]<br>"I'd never heard of psychosis and how it's linked to giving birth." [Priya]<br>"I'm surprised, I don't know anything, I was just blind." [Dhanesh]<br>"her daughter, err, needed breastfeeding so I went to the hospital with Aditi and Priya tried to ignore Aditi because she doesn't care about Aditi at that time because she doesn't know what's, err, going on. And then I'm shocked as well and confused, 'why's she not giving the breastfeeding?'…because mothers love their babies, so Priya was just ignoring [her]. [Dhanesh] |
| | **Noticing symptoms and questioning "what's going on"**<br>"I thought what's wrong with her and then we went to the hospital." [Dhanesh]<br>"I just worry about inside her and just think something isn't right." [Dhanesh]<br>"the A&E transferred Priya to [another hospital] and we went to visit Priya there at 11 o'clock, no 9 o'clock in the morning, and we wanted to see Priya and what was going on…the next day when we went to the hospital and Priya wasn't there. So, I asked, 'where's Priya gone?' and they saw we transfer her to the MBU." [Dhanesh]<br>"I remember there was like a urine specimen bottle near where I brushed my teeth, and I was like did I do that or, yeh, unsure/ And then my bed it wasn't straight it was slanted, and I Was like why's it not straight? Why's it slanted? Like what's going on? I was kind of like in my head, did I do that? Did someone come into my room?" [Priya]<br>"and [when in A&E] Priya was a problem; she was kind of dancing and stuff and whenever any doctor care Priya took a picture like a picture of all staff." [Dhanesh]<br>"2am I woke up and Priya wasn't there. I look around upstairs and she wasn't there, and then the light was on downstairs and I come downstairs. And Priya was like drawing on the paper, she put a candle everywhere, outside as well, outside were lit candles but inside were real ones. And I was shocked, and wondered what was going on?" [Dhanesh] |

| | |
|---|---|
| | **Noticing symptoms and questioning "what's going on" (continued):**<br>"I was like doing weird stuff in the middle of the night, like sorting out paperwork, folding clothes, coming downstairs and you know tidying up…I kept repeating words over and over again, like a sentence or a word…and my husband was like 'okay, what's going on here?'" [Priya]<br>"me and Aditi were sleeping down there about 11 o'clock and she was asleep, but after half an hour she just shout 'can you take Aditi?' because she thought Aditi was on the sofa and that she'd tried to fall off, but it was a weird dream." [Dhanesh]<br>"I was shocked and wondered what was going on…she said 'I'm just praying to God.' I said 'are you okay, what's wrong with you, there's nothing wrong with you' – but something isn't right but I didn't tell her you're ill." [Dhanesh]<br>"I was just on 100 miles an hour, just all the time. I mean even when I was speaking, I was really, really fast in my speech." [Priya]<br>"I just thought what's going on, and felt really on edge and panicky, like 'who's watching me, what's going on?' You know, like the Big Brother house as if there's cameras constantly watching me and that kind of thing." [Priya]<br>"I felt like I was being recorded, whether or not that was true I don't know." [Priya] |
| | **Differences Quotations** |
| | **Mismatch with others in level of awareness [Priya]**<br>"I didn't really realise it at first, because I was totally out of it, I was just like not, I didn't know what was going on around me." [Priya]<br>"everyone was saying 'this isn't normal' and 'what's going on,' and I thought let's just go and like check it out." [Priya] "were you worried about anything?" [interviewer] "no, not at all. Not initially." [Priya]<br>"I didn't think I needed to be [in hospital]. I was like what's going on, why am I here?' Umm, I kind of thought that I was there cos, just for work for like experience. I just didn't think I was there as a patient." [Priya]<br>"I didn't even know what I was doing at the time, like patients were telling me you'd just randomly go into patients' rooms and sort of scream your head off…and I didn't even know that, like know I was doing that at the time." [Priya]<br><br>**Focus on difference from her usual self [Priya]**<br>"I wasn't sleeping at all, I had tremendous amounts of energy, just totally on the go." [Priya] "is that quite out of character?" [interviewer] "yeh, totally out of character." [Priya]<br>"my heartbeat is irregular anyway but the heart palpitations I was having when I felt like my heart was beating like really, really fast, umm, that was, umm, when I was really, really anxious." [Priya]<br>"totally out of character…I was just up and, on the go, constantly doing stuff…my heart was like beating fast, I've never been so anxious. I've never been repeating my words. I've never been confused about anything…my behaviour just wasn't right." [Priya] |

## 2. Finding out it's psychosis and we're not on our own

| **Key Ideas** | **Shared Elements Quotations** |
|---|---|
| Working out what's going on<br>Observation<br>Gathering information<br>Role of others<br>Getting a diagnosis<br>Finding out about postpartum psychosis<br>It's not something physical<br>Shared experiences | **Discovering it's a mental illness**<br>"one of my family members, they're not a doctor but he works in the pharmacy, so we just call him and take some advice from him. He said, he just gave a few advice and said leave her alone and just follow the doctor and what they are saying." [Dhanesh]<br>"when they transferred Priya to the MBU, I had spoken to the doctor and she had explained everything and not to worry as there is support and 24-hour monitoring." [Dhanesh]<br>"it's been like six or seven days continuously where she hasn't like slept, so it's mentally health problem" [Dhanesh]<br>"the doctor said like there's certain hormones that run through your body and there's imbalance in your hormones and that's why like you're acting like this. And I was like 'ah okay' and then obviously I was given medication." [Priya]<br>"when I saw the doctor he explained to me about the psychosis and that psychosis does not just come like flu but that you can build up in your mind and that if you don't share or are hiding something that it's very bad." [Dhanesh]<br>"the doctors came to see me, and they were like you know this is what we think you've got, you know … we believe you've got postpartum psychosis … there's imbalance in your hormones and that's why you're acting like this." [Priya]<br>"I was obviously confused and wanting to know answers…like I said I've never heard of psychosis and how it's linked to giving birth…yeh, like not really heard of, like obviously postnatal depression and antenatal depression and all that has been heard of, but psychosis is quite you know never heard of, first time I heard of it, first time I came across it. So, initially I was like, okay, so what is psychosis? That was my first question I asked, like what is it? Umm, what are the symptoms of it and what does someone experience when they do have psychosis? Umm so these were all my questions and then I was like okay yeh this is me, yeh what you're saying is making sense." [Priya]<br>"they'd given me a leaflet and I'd read through it and was like yeh, yeh lack of sleep, yeh, having tremendous amounts of energy YES! Able to see myself and reflect, and was like yeh I've got it, I've got psychosis." [Priya]<br>"when I felt like my heart was beating like really, really fast, umm, that was, umm, when I was really, really anxious. And they were basically like that might have been like a dream you were having or maybe it's the voices you were hearing in your head, maybe it was kind of like a confusion part when you're not sure what reality is and what your dreams are, cos that's another part of psychosis as well." [Priya]<br>"yeh, some answers and some clarity about what was going on. So yeh, it was a huge relief, like a huge burden off my shoulders." [Priya]<br>"there was nothing there but mentally…yeh mind, so very bad…it was very bad. The mental health is very dangerous, so very bad and I was shocked at the time." [Dhanesh]<br>"it was very negative thoughts. there was nothing there but mentally." [Dhanesh]<br>"they didn't think there was anything physically wrong with me, but something mental, but they obviously didn't tell me this at the time." [Priya] |

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| | **There are others like us**<br>“yes, same situation [as us], so I can worry less.” [Dhanesh]<br>“it was quite nice to engage with other people and other patients and umm kind of have that environment where you don’t feel so isolated or all by yourself, kind of thing, like that there’s other people there, you know.” [Priya]<br>“before I was like is this normal? Is this what people go through? Umm, you know, umm that type of thing. Whereas like when I was speaking to other people, I felt like I Was normal and, you know, it didn’t feel so, my symptoms didn’t feel so abnormal as such.” [Priya]<br>“I didn’t feel like I was on my own. I felt like that there were other people who were experiencing similar things…my symptoms didn’t seem so abnormal as such, like I didn’t feel I was on my own, and that there were other people with me in this, kind of that are experiencing the same thing.” [Priya]<br>“I less worry about her because when we came to the MBU I thought we were only one case but then I saw a few women, a few, so I feel ah it’s not just us, there are others as well, so it’s not only a problem for Priya.” [Dhanesh] |
| | **Differences Quotations** |
| | **Focus on the process followed [Dhanesh]**<br>“the doctor just came and asked about how she feels.” [Dhanesh]<br>“the doctor suggest, because doctor don’t want to sleep Priya because they want to know what’s going on, so what about the previous life as well, so doctor asked Priya everything about her previous life, like when she was a child and growing up…and doctor said because it’s not only one point and that Priya builds up everything from her childhood and her life to here, it’s not just happened quick.” [Dhanesh]<br>“[the MBU staff] say we want to observe Priya 24-hours and we can’t give medication straight away, we have to observe what Priya is doing all night and during the day … they want to observe everything to decide what’s best.” [Dhanesh]<br>“doctor said about negative thoughts and that once they come up, it’s not just one but they stay.” [Dhanesh]<br><br>**Greater input from others for realisation and acceptance [Priya]**<br>“*[idea of a time before this happened]* I wasn’t in denial, I was just totally open and like there’s something wrong, even I admitted there’s something wrong.” [Priya]<br>“*[talking about being transferred to the MBU]* I just went there and was like ‘cool, you know.’ And then that was that basically, umm, and then like afterwards I realised okay I’m a patient and the doctors came to see me and they were like you know, this is what we think you’ve got, and I was like okay.” [Priya]<br>“other patients were also telling me what I used to do, saying like I’d go into people’s rooms and like kind of do weird stuff.” [Priya]<br>“one day I totally lost it, I was like ‘you don’t need to be here, I’m totally fine’ but [observing nurse] didn’t argue back…but was like ‘look you’re a patient here and it’s my duty to take care of you, that’s why I’m here, I’m not here to judge you.’” [Priya] |

## 3. We're facing it together

| **Key Ideas** | **Shared Elements Quotations** |
|---|---|
| Multiple needs to consider and balance<br>Keeping baby in mind<br>Emotionally challenging<br>Support and reassurance from others<br>Wider impact of postpartum psychosis | **Impact of separation**<br>"even now I ask my husband like 'am I a good Mum? Do I look after Aditi well?' and he's like 'of course you are, she's thriving, like you know.' Yeh, 'it wasn't your fault that you'd fallen ill, you know, but you did the best that you could and that's all you could do,' you know … that encouragement was really, really good. It reassured me. That reassurance was really, really good because I needed to hear that." [Priya]<br>"we tried to divert her mind, we tried to get out from the hospital – we'd go for a walk." [Dhanesh]<br>"my sister-in-law and brother also visited, and Priya was saying 'why are they coming' and 'don't want to see her anymore.' And I tried to explain that she can look after you and she wants to see you, and that she misses you…I explained that over a few days and then she was understanding." [Dhanesh]<br>"I stayed in there for quite a long period of time. I was, umm, sort of getting a bit, umm homesick and I wanted to be around my family quite a lot. I was feeling really, really homesick and it was a shame I couldn't spend a lot of time with my family." [Priya]<br>"I tried to bring her back as soon as possible, after 28 days, but they said that she wasn't ready to be released…I just tried to, I want to see Priya and see her stay at home, but after a couple of weeks I became patient and I want to see her better." [Dhanesh]<br>"I remember calling my husband and asking 'why am I here? What's going on?'" [Priya]<br>"she say 'I feel very bad because I'm not looking after my baby,' and then after a few weeks she can recognise that she was not looking after her baby because I saw 'you have to look after yourself first and then worry about your baby.'" [Dhanesh]<br>"'look, trust me, you're in the right place, there are professionals there to help you.'" [Priya]<br>"I tried to explain that Priya was dreaming, and it'll stop. Then next day I took the picture of me at home to show her and try and explain that I was at home [not at the hospital as she thought]…next couple of days I just tried to explain…but it was difficult to explain to her…it was difficult but I was trying to explain to her every day, and think about six or seven days she asked me and I explained to her. I explained that over a few days and then she was understanding." [Dhanesh] |
| | **Keeping everyone in mind**<br>"but the evening Aditi was [at home], her daughter, and err needed breastfeeding so I went to the hospital with Aditi." [Dhanesh]<br>"at that time my mother and mother-in-law they come to help us and to support because it's our first baby." [Dhanesh]<br>"after a week still Priya didn't, didn't sleep, and I recognised to Priya 'can you take one tablet?' and she said, err, no because of the effect to the baby, and I'm fine with that." [Dhanesh]<br>"I err worry about both of them. Aditi was fine and I worry about her a little but I'm more worried about Priya." [Dhanesh]<br>"Doctor said leave Priya alone because we want to know what's going on so don't come every day … so we try to, not ignore her but to come less." [Dhanesh]<br>"I remember I was sectioned, so there was 24 hours, so 24 hours someone with my daughter and 24 hours someone with me." [Priya] |

**Keeping everyone in mind (continued)**

"[MBU staff] had to look after Priya and Aditi, as after one week we dropped Aditi off with Priya because they want to know mother and baby are bonding…because mother and baby need to bond." [Dhanesh]

"I ask my husband like 'am I a good Mum? Do I look after Aditi well?' and he's like 'of course you do' … that encouragement was really, really good, it reassured me. That reassurance was really, really good." [Priya]

"she doesn't care about Aditi at that time because she doesn't know what's, err, going on" [Dhanesh]

"doctor advised don't take a tablet, you know like a sleeping tablet. They say just don't take a tablet because it's, err, too high a dose and because if Priya is feeding the baby it can have an effect on the baby too." [Dhanesh]

"it was quite soon after my daughter was born that I, err, went to the MBU, so it's kind of like everybody probably wants to see my daughter and that kind of thing…I just want to be home with my family like sort of celebrating her birth." [Priya]

"I want to look after our baby but I want to see if Priya can look after our baby … as after one week we dropped Aditi off with Priya because they want to know mother and baby are bonding." [Dhanesh]

## Differences Quotations

**Focus on impact on him and his needs [Dhanesh]**

"confusing yes, and shocked and worried about her as well because I don't know what's wrong with her…it's very scary." [Dhanesh]

"it just took about 45 minutes to one hour to get there, so I visit about three times a day."

"Whilst travelling there in the ambulance, Priya's blood pressure was 270 and that time I was very upset and very worried." [Dhanesh]

"*[When Priya first arrived at the MBU]* I just tried to rest myself and tell myself that we are in the right place so this is good."

"it was difficult because the little one was here [i.e. with him]." [Dhanesh]

"I ask my Mum 'what's going on?' and then I was crying, so just very sad … one day I lose my confidence because every day it was getting worse and worse, but after I admit this to a few people they gave me the confidence that things will get better." [Dhanesh]

"at that time I had two months paternity leave and one-month holiday so I could ignore the work … [at a later stage in their experience] I have to go to work and then straight after I go to the hospital because my father and mum here too so lots of responsibilities here too…it's Priya, and my mother, and my father, they came over [from where they live] so it felt like it was 24 hours." [Dhanesh]

"if I was on my own, maybe I would have been admitted somewhere." [Dhanesh]

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| | **<u>Considering the impact on the couple’s relationship [Priya]</u>**<br>“initially it impacted a lot, like, but then when I was at the MBU and I was getting the right medication the impact wasn’t as much and it kind of drifted off a little it, but, umm yeh, initially in the first couple of weeks it was intense, really intense.” [Priya]<br>“*[talking about being on medication]* it was making me feel quite like dazed out and stuff, so I remember sleeping quite a lot, like I said not wanting to talk to anyone or to engage with anyone.” [Priya]<br>“in ward reviews like this is when I’d be like open and honest with them and be like ‘rah, rah, rah, rah, raaa, [Dhanesh’s] not doing this properly.” [Priya]<br>“as like I got better and my mood had improved, I wasn’t like lashing out on him and I was thinking before speaking, umm, whereas when I had psychosis I wasn’t thinking about what I was saying.” [Priya]<br>“I remember kind of lashing out on him at times as well, not wanting to see him, and sometimes I was like ‘why are you here?’ you know? Like ‘you’re a rubbish husband, you’re not taking care of me, you’re not engaging in our daughter.’” [Priya] |

## 4. We're getting the right help and becoming a family

| Key Ideas | Shared Elements Quotations |
|---|---|
| MBU as the 'right' place<br>Recovery is a gradual process<br>Family approach<br>Adjusting<br>Transitioning<br>Returning to a 'new normal'<br>Gaining from a difficult experience<br>Support from others | **Importance of the MBU**<br>"and after one night they transferred to MBU – finally!" [Dhanesh]<br>"when we went to the MBU and I see the atmosphere about the building and the staff, I'm very surprised and was very happy at that time because it's very good facility also, like it's a private bathroom, a private bedroom." [Dhanesh]<br>"I wasn't as such worried because I knew I was in the right place." [Priya]<br>"For me to sort of overcome that, well, overcome that like, you know, if it hadn't have been for me going to a MBU and kind of admitted well yeh there is something wrong." [Priya]<br>"everything was fine, very good. The team was very good." [Dhanesh]<br>"I spoke to the doctor every day separately, with a separate meeting…yes, on my own because the doctor asked if I wanted to speak to them on my own." [Dhanesh]<br>"participating in activities, umm, so they had like baby massage. They used to do swimming but my daughter was too young to do that at the time, umm, personal stuff for me like there was Tai Chi, there used to be a girl that would come in and paint nails, there was arts and crafts, cooking as well…yeh, quite a lot going on, yeh, and I was taking part in as much as I wanted to, erm, which was quite nice. I really enjoyed that cos usually you'd think in hospital or on a MBU that they wouldn't have these facilities." [Priya]<br>"the information was there for, umm, my husband as well to read. That was really, really helpful. In leaflets, even with a member of staff talking to my husband like about what was going on with me. That was really good, like the fact he could come to my ward reviews, that was really nice." [Priya]<br>"yeh, involving him in the care as well, yeh, like all my family members, like my mum, my husband, umm, they were all very much involved, which was really nice. Like it wasn't a case of like, no you're not allowed – it's just patient and doctor confidentiality type of thing, it wasn't like that. It was very open and honest. It was like this is what she's going through, this is normal for her to behave like this, and I think that reassurance for my husband was like really good as well." [Priya]<br>"it's not your fault, this is what happens, it's one of those things, but you're doing the best you can." [Priya] |
|  | **Getting better and becoming a family**<br>"she did improve day by day … I see she is getting better and then think she is going to improve … the doctors said this takes time, maybe one week, maybe it takes one month, maybe six months…yeh no set time or pattern, it depends." [Dhanesh]<br>"I worry but then I see she is getting better and then think she is going to improve." [Dhanesh]<br>"after a couple of weeks she improved, and we had meeting with the doctor and Priya is trying to get better because she gotten plenty of negative thoughts, because doctor explained that she was ill and that she hadn't got confidence around that time." [Dhanesh] |

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| | **Getting better and becoming a family (continued)**<br>“first two week as they don’t allow [us to go out from the hospital] as they just want to observe, but after few weeks they allow us to go for a walk or for a coffee or something.” [Dhanesh]<br>“the medication was absolutely well like excellent, like put to bed whatever symptoms I was having…my speech it slowed down quite a bit, erm, I wasn’t repeating umm any sort of words, not having any weird dreams, the confusion had gone like I knew when I was dreaming and knew what reality was. Umm, the emptiness, umm, wasn’t there anymore, like I was engaging with people and was enjoying being back with my family when I did have leave, that was quite nice.” [Priya]<br>“I was starting to take care of my daughter, I’m doing stuff that I should be doing…you know, being the best mother I can be in that environment, providing all that I can provide for her…I was looking after her, sterilising bottles, picking her up when she’s crying and reassuring her, bonding with her as well.” [Priya]<br>“she asked about Aditi and I clicked that she can remember, that she can worry about Aditi…she asked ‘did you change the nappy?’ and now I had confidence that she can look after [Aditi]…after a couple of days Priya started to ask, ‘can I do, can I do it?’ She wanted to do more with Aditi] by herself.” [Dhanesh]<br>“after a few weeks [of leave] it was just [him], Priya and baby; just the three of us” [Dhanesh]<br>“felt like yeh, I’m finally like, I’m finally bonding with my baby.” [Priya]<br>“as like I got better and my mood had improved, I wasn’t like lashing out on him and I was thinking before speaking.” [Priya] |

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| | **Returning home**<br>"it was very difficult at that time…I request to the doctor can we, can I take her with us, if I like, but they don't allow it until she is getting better…so I tried to bring her back as soon as possible, but they said that she wasn't ready to be released." [Dhanesh]<br>"doctor then said that Priya could come for two or three hours with a nurse, so she came about three times a week with a nurse, and after that she came for about one or two nights and then we'd drop her off again." [Dhanesh]<br>"I was worried about [leave] before but doctor explained that they can't release straight away or can't fully discharge, we have to see Priya and what is going on." [Dhanesh]<br>"they want to know that Priya is getting better and they want to release her as soon as possible but need her to be better first. If something happened then, they say that they are responsible, so they don't want to do that." [Dhanesh]<br>"doctor wanted to see that everything was going well and that I wasn't forcing her, and that she was ready to come back…I think it took about one and a half months until she was released." [Dhanesh]<br>"it was quite nice to have that person and have that open and honest sort of conversation," [Priya]<br>"I then came on my own a couple of times before I was discharged, and that went well." [Priya]<br>"so it gradually kind of felt like I was getting back into normal life, whereas it wasn't like okay you're at the MBU and now you're going home – it was like okay you're at the MBU and we are going to take it day-by-day, week-by-week, and for you to have leave for a couple of hours and then to have an overnight stay and then have a couple of days and then have a week or so, let's say, and then we'll think about discharge." [Priya]<br>"I think the doctors realised and were like 'we're going to take it nice and slow. You've just recovered from you know a mental health issue, and you're obviously unsure about what's going on at the minute, umm, so yeh that was kind of really, really nice." [Priya]<br>"when Priya was discharged and came back home, one of the doctors came to the local children's hospital and Priya had an appointment every month. And a few months she went every week for an appointment, and they saw Priya and gave her tablets as well, so it was very good support, and a couple of times they came to the GP practice here too." [Dhanesh]<br>"in the MBU I had kind of a member of staff that I'd rely on if something was to go wrong, umm and [at home] it was just me and my baby…I was like this is overwhelming, like I'm on my own. My husband has gone back to work, my [in-laws] have returned home and I was literally on my own, me and Aditi. I remember ringing my mum, like 'Mum, she's crying, like can you come over? Can you help me out?'" [Priya]<br>"my Mum had come for a couple of days and she was like 'you still need, kind of, someone to just look after you and Aditi for a bit.' So I, umm, stayed at my Mum's house for a couple of months and I'd come home now and again, so that would kind of help as well, so yeh, and having that support from my Mum." [Priya]<br>"I felt fine afterwards, yeh, I think just, like I said the first couple of weeks after I'd come back from hospital, umm, I kind of just needed somebody to not, to not fully look after Aditi but just to be there and just be there as a bit of support." [Priya]<br>"told [him] not to talk about her previous life but to move forward." [Dhanesh] |

# Appendix M: Illustrative quotations for Ellie and Mark's Themes

## 1. Mum's not herself: we don't know why but we need help

| **Key Ideas** | **Shared Elements Quotations** |
|---|---|
| Noticing symptoms<br>Concerns<br>Deterioration<br>Increasing risk<br>Struggle to manage<br>Role of professionals<br>Loss of self<br>Disconnect from self<br>Unravelling<br>Fragmenting<br>Accepting the situation<br>Acknowledging the situation | **Affected thoughts, emotions, and behaviours**<br>"she sort of got more reserved, she was quite upset." [Mark]<br>"the night she got admitted to A&E, the day before she was admitted to the [first MBU], she was broken. You could see she was broken; she couldn't stop shaking, she couldn't stand still, she was as white as a sheet." [Mark]<br>"*[referring to the period before her admission]* the week before, maybe the fortnight before, I saw it creeping up on her just from the way she was acting, erm, the emotion she was showing. She was, she was struggling." [Mark]<br>"I wasn't sleeping, I hadn't slept properly since having him." [Ellie]<br>"my head was just racing all the time of different thoughts, like 'run away,' you know, 'the kids don't need you,' 'you're worthless,' 'nobody will miss you.'" [Ellie]<br>"I just completed paced all day…I just would not sit down." [Ellie]<br>"I was like massively on a high, like, I just felt like I was on top of the world basically. I just felt like, umm, I'm super mum. I can do this, I can do that, I'm capable of this. I'm going to go home and make tea." [Ellie]<br>"I didn't want to be here anymore. Yeh, just basically that. I didn't want him. I resented him … I don't want to be here. I don't want Harry. Umm [Mark] had gone out and I was thinking I'm going to wait till Harry's asleep and then I'm just going to go." [Ellie]<br>"there were thoughts of wanting to harm herself or just walk away from it all. Just leave the house, leave Harry just lying in his cot and just going. They were starting to creep into her head more and more." [Mark] |
| | **Trying to *"battle through"* but needing more help**<br>"she was trying to battle through it herself, but it just got more and more difficult for her." [Mark]<br>"I was still doing the school run and stuff, and like I absolutely hated doing it and I kind of, as soon as I got out the car at school I felt like a wave of someone else's face came over me. So, like I would be so, so down and then as soon as I got out the car this smiley, happy Ellie was back, but it was such a false, and then as soon as I got back in the car I'd just go like [*makes crying sound*]." [Ellie]<br>"they put me on antidepressants" due to "most likely experiencing postnatal depression." [Ellie]<br>"there was no apparent reason why, but obviously she knew, well, well cos she'd had a baby, we knew, well thought that chances were that it was postnatal depression. So, she was trying to battle through it herself, but it just got more and more difficult." [Mark]<br>"when actually I had Harry, [Mark] had a lot of time off, he had about six weeks off, then he went back for a week and then that's when it all sort of took a huge spiral. I think I'd been so used to having him at home, although I wasn't coping at least I knew there was someone with me all the time." [Ellie]<br>"on the Tuesday I definitely thought things were going downhill. I spoke to my health visitor and I said I'm having suicidal thoughts. I just really don't want to be here anymore…by the Wednesday, Mark had now been advised by the health visitor that he needed to be at home with me." [Ellie] |

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| | **<u>Trying to *"battle through"* but needing more help (continued)</u>**<br>"I worried when I went to work each day that she was going to be alright on her own with him [new baby] towards her being admitted … I actually got a phone call from Katie, the health visitor, that was on the Wednesday before the Friday that she got admitted, asking me to come home from work cos she was in a pretty bad way… I came home from work that Wednesday and she was, she was just sat crying on the sofa, umm, she just said, 'I can't, I can't handle it on my own anymore. I need help.' And err, she realised that she needed help." [Mark]<br>"*[after thoughts of suffocating Lily]* so I brought myself out of the bedroom and told Mark that I wanted him to hold me really tight because I thought Harry was going to be next and then I just completely took myself out the situation and took myself downstairs and tried to occupy myself." [Ellie]<br>"my worry was that actually, although I wanted to kill the kids, I probably would have done something to myself first. Cos I always knew that although that was my strong feeling that there was something in my head saying suffocate the kids, kill the kids; I would have always tried to do something to myself first." [Ellie]<br>"the onset had gone too far, as time went on it just got worse and worse … when she got admitted to A&E I could see how bad she was." [Mark]<br>"it didn't pass, umm, it got worse … by the Wednesday and Thursday I said to [Mark]<br>"Thursday I said to [Mark], 'I don't feel like home's my safe space anymore' … by the Thursday night I was actually contemplating killing the children…it was all so quick, umm, I remember getting into bed with Mark cos Harry was in his cot and Mark was in bed. I then got into bed with Lily cos she shouted me, and had fallen asleep and then woke up and there was something just telling me I needed to suffocate Lily." [Ellie]<br>"I was saying I wanted to harm the kids, I actually felt like, I actually felt like that was what I needed." [Ellie]<br>"the crisis team actually came out the Thursday to me, [Katie] must have rung them to come out to me." [Ellie]<br>"when she got admitted, I could see how bad she was" [Mark] |
| | **<u>Changes to Mum's sense of self</u>**<br>"she wasn't herself when she was at her worse and I understood that." [Mark]<br>"Mark said 'I knew I'd lost you and knew that something wasn't right' … I could just remember thinking 'where have I gone?''" [Ellie]<br>"who am I? I don't know who I am anymore.'" [Ellie]<br>"It just felt like I was in my body but somebody else is moving around, somebody else is speaking to me, like basically I've been taken over, like almost like I'm possessed." [Ellie]<br>"I just had no thought for anybody at all and like I'm having therapy for that guilt, because it's just, it's just awful." [Ellie]<br>"I can remember feeling like somebody else was living in my body…whoever it was in my head just saying to me 'just kill yourself and kill everybody else, nobody is going to miss you' … I don't know who she was, oh, but it is just awful. It is literally like somebody is inside of your skin and you're trying so desperately to do what's right but almost like the devil on your shoulder is inside of you and I can't really explain." [Ellie] |

|  | **Differences Quotations** |
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|  | **Focus on her symptomatic experience [Ellie]**<br>"I think with the whole situation, like what the health visitor said with postnatal depression you kind of see that people don't want the children, which I did, but then it's really weird like the other part of me couldn't let him go, like I was constantly battling myself the whole time, it was just completely exhausting." [Ellie]<br>"in the early weeks, Mark said 'you wouldn't let anyone touch him'…he said, 'you were very, very protective over him.' Erm, wouldn't let him do night feeds or anything, wouldn't let my Mum have him. It was almost like nobody else was as good as me. Like you can't meet my baby's needs, the only person that can meet my baby's needs is gonna be me, when obviously that wasn't true, anybody could have help him and comforted him. But I was convinced that it was me and nobody else was having any input at all; but then other, well like half an hour later I was thinking 'well I don't want him.'" [Ellie]<br>"I said to Mark, I almost wanted to feel like I just didn't want him ever, like that would almost have been easier for me, but I was constantly battling between 'I do want him nobody else is touching him' and 'I don't want him.'" [Ellie]<br><br>**A sense of acceptance and feeling powerless [Mark]**<br>"everything just happened so quickly, and I just rolled with it, I had to. Umm, I didn't think about things too much I just got on with it." [Mark]<br>"as I've got older, yeh, I've tried to be open-minded with things and roll with it and do the best I can in the situation." [Mark]<br>"I just had to go along with everything that was happening. I didn't really think about me at the time. Umm, all I was concerned for was her and her mental health … I just had to accept it I guess and get her help; help get her the help that she needed." [Mark] |

## 2. Being in *"the right place"*

| **Key Ideas** | **Shared Elements Quotations** |
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| Importance of the MBU<br>Feeling safe<br>Feeling comfortable<br>Value of shared / lived experiences<br>Importance of the baby<br>Advice from professionals<br>A hidden story<br>Difficult experiences<br>Mismatch with expectations | **Impact of professionals**<br>"Katie was very good with her. She'd always give her some advice about, umm, making lists – to do lists. So if you get up in the morning and you don't feel so clever, like 'oh I'm not going to bother today,' then you've got to force yourself that I'm going to have a shower, and write yourself a little list of what you're going to do to help the day." [Mark]<br>"the Health Visitor was with me near enough every day, erm, and she took me to the doctors…she tried to obviously hold onto me for as long as she could but I can always remember her saying, umm, 'it's gone beyond me now, like you need, you need help' … when Katie had rung the ambulance, she's said that when they arrived, she said to them that we needed somewhere for me to be safe for that night." [Ellie]<br>"she's got the tools to deal with it now, with actually like going into the unit and the coping mechanisms that they've give her." [Mark]<br>"I feel like I've had so much support … [perinatal team] were giving advice all the time, like the occupational therapist was giving me different things to be focusing on. I started a gratitude diary…they were really good at giving me things to do like positive affirmations." [Ellie]<br>"helpful that the perinatal team were involved" [Ellie]<br>"I was told on the Thursday that there was going to be an actual place for me that night, umm, but then obviously the lady that was meant to be discharged wasn't discharged…when I was told I apparently, well like Mark said, I just went, I just lost it, cos you know you've had this promise of this bed and that things are going to be okay. So, like I was going to have to live in this nightmare for another day longer!" [Ellie]<br>"there was about, I don't know, about ten staff and they were all in the office. I said to Ellie 'do they not come out and sit and have a crack and, and just see how you're doing?' and she said 'nah most of the time they just sit in there.' … so, I said 'oh right, well that's a bit strange.'" [Mark]<br>"one morning I rang the health visitor and was like 'you need to get me out of here because I just don't want to be here anymore,' meaning I didn't want to be in the unit anymore, I want to go home. Erm and she said to me 'give one, give the phone to one of the nurses that had been on and that you'd spoken to during the night.' And so the guy had got on the phone and I think Katie had given him a bit of a mouthful and he'd come back into my room and said 'you shouldn't be ringing your health visitor when you've got us.' And I kind of ended up having a bit of a ding dong with him, kinda saying but you weren't helping me, you weren't listening to me…when he'd done that, I took my tweezers to my arms and that's the first time I'd self-harmed ever because nobody was listening to me." [Ellie]<br>"like I said to some of the girls: 'what do you have to do in here for someone to actually listen to you?' I thought 'do I have to throw myself on the floor like a stroppy five year-old to get someone to listen to me?' cos I mean a lot of the staff I have no idea why, why they were in the role they were in because there was absolutely no compassion there whatsoever." [Ellie] |

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| | **MBU as *"the right place"*** <br>"oh, as soon as I stepped foot in that building, I just had a wave of real like, a massive wave of, umm, I just felt safe. I just wanted to hug everybody … It was a place full of professionals, umm, I finally knew I was going to get the help I needed." [Ellie] <br>*"[the head nurse]* said 'oh, she's in the right place, we'll look after her' … she had a nurse, a personal nurse with her all the time, sat outside her room, walked with her wherever she went, which reassured me that she was going to be well looked after." [Mark] <br>"if I hadn't been put in A&E and into a MBU, I dread to think what would have happened." [Ellie] <br>"she was in the right place…I just felt more comfortable her being there rather than at home cos she had nurses and staff around if she needed to speak with them." [Mark] <br>"it definitely helped her having Harry there, yep, umm, I don't think, I don't think she could have been separated from him. Definitely not, no." [Mark] <br>"it was nice that obviously you had your own space, but that everyone, including the staff, were really, really welcoming." [Ellie] <br>"there was somebody watching me like all the time cos I think the first week you're there, my understanding is that you're on watch the whole time, like you and the baby are watched constantly…at night-time when there was always someone sat outside my room, I felt really safe about that." [Ellie] <br>"If I hadn't, if I hadn't got a bed when I did, I wouldn't be here today." [Ellie] <br>"I don't like to say what she would have done had she not had Harry … I think [being in the MBU together] kept the bond really. Erm, if they'd have been separated and not, she couldn't have spent that time getting better with him there. I think it could have took longer, I think maybe, erm, the bond could have gone." [Mark] <br>"I had Harry with me that was like kind of all I needed. I kind of felt like I didn't need anybody else and I just needed time to myself to work on me and Harry … I definitely don't think I would have been able to not have him with me." [Ellie] |
| | **Differences Quotations** |
| | **Importance of being with other mums experiencing the same thing [Ellie]** <br>"there was actually two people who had gone through postpartum psychosis, they used to go [into the MBU] on a Tuesday and they kind of joined in with you and stuff, and they were always there if you wanted to pull them aside for a chat, so that was nice." [Ellie] <br>"I almost wish as well that somebody who was going through the same things as me when I was at home, maybe having like a mentor sort of person." [Ellie] <br>"if the health visitor had said like yeh there is someone who has come through the other side, would you like to speak to her? Cos like although I was constantly being told you will come out the other side, there is light at the end of the tunnel, I was like I don't believe you. I couldn't believe anybody cos I was constantly saying well 'have you been through it?' and maybe they'd say 'no' and I'd be like well 'how do you know then?'" [Ellie] <br>"it was the girls on the ward, it was nice to feel like you weren't the only person feeling so down and, yeh, so it was almost like a comfort that I wasn't the only person who was feeling this." [Ellie] <br>"I've still got contact with two [of the other mums] … if you're willing to take on those friendships and kind of not be embarrassed or ashamed of why you're in there, once you start talking everybody around you starts talking as well, and I kind of, I kind of feel like that was my therapy." [Ellie] |

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| | **Her experience as a hidden story [Ellie]**<br>"I never ever knew there were things like MBUs. Never! And then, I just wish that when you have your midwife appointments, the bad things were told to you as well." [Ellie]<br>"I feel there probably needs to be a better understanding for people about MBUs … I just feel like, like cos I obviously didn't know anything about them."<br>"I just also don't think that postpartum psychosis is talked about either. I just think the whole having a child thing is seen to be this memorable occasion: happy families, new baby, everything is going to be great; and it's not always like that." [Ellie]<br>"if [an MBU bed] is offered to you, kind of accept it, cos I feel I was like, in my head I was like 'oh my god, they're going to strap me to the bed. I'm going to be locked in my room, it's going to be a padded cell.' I didn't know really." [Ellie] |

## 3. Different challenges: It was hard for us both

| Key Ideas | Shared Elements Quotations |
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| Wider impact of the illness<br>Demands<br>Responsibilities<br>Emotionally challenging<br>Being separated<br>Needs within the system<br>Learning from past experiences<br>Role of others<br>Role as parents | **Responsibilities and needs**<br>"I almost feel like, possibly a weight had lifted off Mark's shoulders as well, because obviously he was having to look after me … I was obviously quite demanding, and it was quite stressful for him, but also, he was also having to look after Lily and Harry as well. And I just think sometimes he probably thought, 'oh thank god for that, somebody else is looking after her and she's safe.'" [Ellie]<br>"cos we're just a small team at my work…and I'm a supervisor as well, so it's rare that I get time off at short notice, but Ellie wanted me to go to a couple of meetings with her as well with the staff at the [2nd MBU] further down the line, and work were really good with that." [Mark]<br>"my work, they were really good as well, also they understood it as I talked to my boss. He was really good. They let me start later so I could take Lily to school, they let me finish early so I could go pick her up." [Mark]<br>"we've got a little girl as well, after Ellie had been admitted my sole focus was on keeping Lily as happy as I possibly could, which kept me focused, I suppose." [Mark]<br>"I think things would have been a lot worse for me if I didn't have Lily…she was a responsibility and a crutch for me at the same time." [Mark]<br>"on top of that Lily was starting school, she started reception this year in September, she's four. So, it was just huge pressure for me really, well for us all, for the whole family." [Ellie]<br>"*[talking about going to another MBU]* [first MBU] was like four hours away, Mark was already having to take reduced hours at work to be able to pick Lily up from school and stuff…I would have been quite happy staying [at the first MBU]…but I needed to move closer to be closer to my family." [Ellie] |
| | **Impact on their relationship**<br>"the distance didn't help, yep at all, because if she was closer, I could have, I probably would have gone and seen her all the time." [Mark]<br>"it was, umm, a big change cos you're with someone every day and then for all of a sudden, and then as well cos with Harry it was six or eight weeks in or something from being born, it felt like my arm had been ripped off when they both went away, it was another thing I had to deal with." [Mark]<br>"there probably, kind of, wasn't a relationship at all until I came out." [Ellie]<br>"we had no like sex life at all when I was ill." [Ellie]<br>"[Mark] has quite openly said to me, 'there was, at times I was just thinking I can't do this. I can't cope. I just can't do it.' He said, 'I literally thought one day I can't do it, somebody else can deal with her." [Ellie]<br>"it put strain on the relationship whilst she was in the unit, yep, but again I understood she needed to be there, and I had a job to do with Lily … we've actually talked about it since she's come out and I said to her, when she was in there, I said 'that it'll either make us or break us.'" [Mark] |

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| | **Needing to manage the system's input**<br>"I just didn't want to be bombarded all the time, like kind of people saying like 'are you okay?' well clearly no, I'm not okay…not, I'm so not okay and you don't need to keep asking me cos I'm clearly not okay cos I'm in here [i.e. the MBU]." [Ellie]<br>"she didn't want visitors in the first few days anyway, cos her mum and dad offered to go and see her but she wasn't well enough or in the right mental state to want to be with people all the time." [Mark]<br>"we did have to kind of say to family, look we don't want to be bombarded. Umm, we'll come to you cos obviously I had been out the family home for a long time, and I felt like I didn't want to let anybody else in, and that I needed to concentrate on being a Mum to Lily again and to Harry, and being a partner to Mark. I just felt like I just wanted, I just wanted it to be us and kind of didn't want anybody else involved." [Ellie]<br>"I had a lot of personal, personal support, erm, come from all sort of people when they realised what was happening. But I, umm, I said I need, cos they said 'I'll have Lily. We'll have Lily.' But I wanted to keep as much of a normal routine for Lily and to do it all myself if I could, because then she'd be going 'why am I going here? Why am I going there?" [Mark]<br>"I told everybody I appreciated their offers of help, but I did 95% of it all by myself." [Mark]<br>"Quite a lot of them just didn't know what to say, they just, they were, they felt sorry for me and I told that I didn't want them to feel sorry for me, it's one of them things and not to feel sorry for me. But I, umm, but I just needed their, their support I guess, their understanding of what I was going through." [Mark]<br>"Mum didn't know that I was being admitted until I was literally getting in the ambulance on that Friday night because I knew what would have happened, she would have come down with my Dad, kicked off, tried to make me stay here, 'there's nothing wrong with her,' like and I'd already accepted in my head that I needed the help and I kind of didn't need that negative influence." [Ellie] |
| | **Differences Quotations** |
| | **Impact on him and meeting his own needs [Mark]**<br>"I think being able to talk it out and people listen, umm, quite a lot of them just didn't know what to say – they just, they were, they felt sorry for me and I told them that I didn't want them to feel sorry for me. It's one of them things and not to feel sorry for me." [Mark]<br>"it felt like my arm had been chopped off but I, like I've said to you already, I understood that Ellie needed to be there, and that Harry had to go with her. So, I dealt with that straight away." [Mark]<br>"with suffering from depression before and kept it all bottled up, I knew this time I needed to, I had to talk to people, and I talked to people, really close people that I knew would keep it to themselves. Some offered advice and some just lent an ear but I, err, found that very helpful for myself to be able to talk to people." [Mark]<br>"as long as [MBU staff] were keeping Ellie safe and working with Ellie, that's all my concern was." [Mark]<br>"the nurse said to me if I needed to talk about anything or know anything when she got dropped off [at the first MBU] just to ring the unit if I wanted to ring and speak to them and ask how she was, so they were good about that…I suppose I would have used it if I hadn't had external support." [Mark]<br>"it felt horrendous for me. It felt like someone had ripped my arm off but there was nothing I could do about it, she needed to be there … I was very upset and I, I felt abandoned you could say, but, but she needed to be there, and I understood that." [Mark]<br>*"I've had a lot of good work colleagues in both my jobs and, and my family to talk to, and just, just being able to talk it out was a big relief for me…if I'd have had no-one to talk to I think I would have gone insane too." [Mark]* |

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| | **Strong feelings of guilt [Ellie]**<br>"there was a lot of stuff going on that I missed out on…but I always sort of made sure that someone was always available to go and see Lily doing what she did cos I never wanted her to feel left out but yeh I just really, really missed them." [Ellie]<br>"I just feel like I was a burden to everybody." [Ellie]<br>"I really missed them all. I felt really guilty that other people were doing my job as a mum to Lily. Really guilty that his mum was having to take time off work, sometimes, to take Lily to school and to pick her up from school when [Mark] couldn't." [Ellie]<br>"I hadn't been a partner to [Mark], I haven't been a proper mum to Lily." [Ellie] |

## 4. Mum's getting better and we're becoming closer

| Key Ideas | Shared Elements Quotations |
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| Gradual recovery process<br>Active role in recovery<br>Regaining abilities<br>Ups and downs<br>Prioritising needs<br>Returning to normal | **Starting to get better**<br>"I kept on reassuring her that it wasn't going to be forever and she's, she's got to think right one day at a time, let's take it one day at a time and don't look too far into the future. And I was doing the same, let's take one day at a time and, and not get ahead of ourselves and it's, it's going to take time to get better." [Mark]<br>"she was more relaxed, more, she could interact in a conversation a lot better, cos at times you could see it going in one ear and out the other…as you went on you could have a better conversation with her and then she got more confident." [Mark]<br>"she got more confident, 'oh can we go out today?' and we went out to [nearby town] one afternoon and did a bit of shopping…and that was her choice. We did about an hour and a half's shopping and then she said she was starting to get anxious…but it was another step, and then the next time, I think we went out for a little bit longer and she didn't ask to go back to the unit then we just went back naturally. So, each time she took a little step further and started, I could see her improving all the time." [Mark]<br>"in that [first week on the MBU], I felt like I did things that I'd not done for the whole eight weeks that I'd had Harry, like I asked to go out to the shopping centre with a nurse. I wouldn't have ever done that whilst I was at home. I just wouldn't have felt like I could." [Ellie]<br>"I didn't have any thoughts whilst I was there about harming myself or harming Harry, erm, or running away … I was almost in control of my mind again whereas somebody had been in control of my mind I felt." [Ellie]<br>"I knew I was getting better when I could get up on the morning and could get a shower, cos when I was really ill, I just wasn't doing anything." [Ellie]<br>"I started eating again, my appetite came back, umm, they'd given me some different medication to be able to drop off to sleep…although it wasn't good, I was sleeping so anything was better than what it had been." [Ellie] |

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| Recovering as a couple<br>Ongoing recovery<br>Gaining from a difficult experience | **Returning home: life after the MBU**<br>"they give her day release to start with, erm, she came home for a Sunday afternoon…then it was an overnight stay a week later and then I think it was a few days they let her come home for and then that was it she got discharged." [Mark]<br>"my first home leave was only for an hour and a half cos that's all I could feel like I could manage…they were kind of saying 'oh well I think you need to go home for a bit longer.' And I was kind of saying 'no, please don't push me…I can't manage more than an hour and a half because the last memories that I'd had at home were so horrendous.'" [Ellie]<br>"*[after her first home leave]* I just felt elated, it was like those little goals meant so much to me and that was a way of kind of thinking right I am, I am getting better cos although I don't want to do it, my body and my mind are letting me do it, and I can do it." [Ellie]<br>"she handled [leave process] well. Umm, the first afternoon she was very anxious about being back home cos it brought back memories for her from when she left, but, umm yeh, I think it was a good way of doing it, just giving her a little bit of time and then increasing it each time before saying 'right, that's it, now go on and have a good go.'" [Mark]<br>"I'd done a bit of home leave. They did it gradually…my first visit home was only for an hour and a half… and then my next time was two nights at home … then for my discharge you had to have a full week at home." [Ellie]<br>"[I] had to call the perinatal team, and kind of say 'I need help. I have no idea what is going on, but I can't, I can't sit still. I've got suicidal thoughts again, umm, I feel like I'm going to harm Harry' … but then within half an hour I was fine again. I think sometimes it was just talking to someone and being reassured that there is someone there to talk 24/7." [Ellie]<br>"I had a long time to think about it and what it would be like when they came back, and I was quite nervous them coming home again but so looking forward to it at the same time." [Mark]<br>"over the couple of weeks, we had family round here and she got better and more confident again. And she, she's a different person again now…more her old self again." [Mark]<br>"I don't think she's fully there yet cos she still has some bad days but, and I don't know to be fair if it will ever go away fully, like it's always going to be at the back of your mind." [Mark]<br>"*[referring to ability to leave Harry]* oh, that has only just changed in the last, like the last three or four weeks. Umm up until four weeks ago I hadn't left him…but yeh, umm, that's something I've been working on. I've left him for an hour with my Mum, I've left him for an hour with Mark's Mum and that's just something that we're going to have to gradually build up." [Ellie]<br>"it was just like everything rekindled and like as I've been getting more well everything has just fit back into place again, and it's almost like we've met each other again for the first time … we are just so much closer, like, just with everything, we just do everything together now." [Ellie]<br>"I would not wish that upon my worst enemy, but it has brought us so much closer … we just appreciate each other that little bit more." [Ellie]<br>"I think we both agree that it's made us stronger, umm, emotionally stronger. I think she's realised as well that a lot of people could have quite easily walked away from that situation and I haven't, I've stayed there and supported her. We've, we've helped each other through it as well, I guess, as she's got stronger, she's helped me." [Mark] |

| | **Differences Quotations** |
|---|---|
| | **What's done is done [Mark]**<br>"look into things too deeply and analyse it all." [Mark]<br>"still I don't really fully understand it [i.e. her diagnosis]." [Mark]<br>"it was what it was" [Mark]<br><br>**Wanting to understand [Ellie]**<br>"I kind of said to [Katie and Mark] 'it's time that I want to know now, I feel ready that you need to tell me everything … [in response to being told about her diagnosis] I was like 'oh my god, that must be it, that completely makes sense to me.'" [Ellie]<br>"I kind of felt like [the postpartum psychosis diagnosis] was a relief, then, that I thought 'what I was thinking clearly couldn't have been just like postnatal depression,' like I was clearly severely depressed." [Ellie]<br>"after Katie said she had the onset of postpartum psychosis, I was like 'oh my god!' It was like a couple of days after I said to Mark like 'what don't I know? what the hell!' So, it was like starting all over again, I was having to piece together eight weeks." [Ellie]<br><br>**Personal growth [Ellie]**<br>"I feel like I'll never take anything for granted. I'll never judge anyone, don't every judge anybody … I just feel like I'm never going to judge anybody ever in my life." [Ellie]<br>"I started reading some self-help books. I did a bit of studying on CBT and I've done a postnatal depression awareness course online, so I've kind of kept myself busy and if anything out of a horrendous situation, I've learnt so much about myself…I've learnt so much about other stuff in general, like I've got the want to study and to better myself." [Ellie] |