

**THE EXPERIENCE OF PAEDIATRIC CARE CLOSER TO HOME:
A PLACE AND SPACE PERSPECTIVE**

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ABSTRACT

NHS reforms have sought to ensure that children and young people who are ill receive timely, high quality and effective care as close to home as possible (DH, 2004). This study examined the experience and impact of introducing new, 'closer to home' community-based paediatric outpatient clinics from the perspectives of NHS service-users and providers. Twenty-seven interviews conducted with parents and patients (aged 8-16), were analysed using a descriptive phenomenological approach. Thirty-seven interviews conducted with healthcare professionals, were analysed using a thematic framework method. Findings reveal that paediatric outpatient 'care close to home' is experienced in ways that go beyond concerns about location and proximity. For families it means care that 'fits into their lives' spatially, temporally and emotionally; facilitating a sense of 'at-homeness' within the self and within the place, through the creation of a warm and welcoming environment, and by providing timely consultations which attend to aspects of the families' lifeworld. For service-providers, place and professional identity were closely related, with implicit assumptions made about where high quality of care and clinical expertise were located. Place, time and human relations were thus shown to be meaningful constituents of the experience of paediatric outpatient care. These previously 'taken-for-granted' nuances of healthcare delivery have implications for the design and implementation of effective 'closer to home' services.

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TABLE OF CONTENTS

1	BACKGROUND.....	1
1.0	Introduction to policy and practice	1
1.1	Policy context.....	1
1.1.1	Implementing Care Closer To Home	3
1.1.2	Liberating the NHS	5
1.1.3	The Nicholson Challenge	6
1.1.4	Services for children.....	6
1.1.5	Where are we now?	7
1.2	Birmingham Children’s Hospital	10
1.2.1	Quality and Innovation.....	10
1.2.2	Capacity	12
1.2.3	Attendance	13
1.2.4	Birmingham Children’s Hospital as a health place.....	14
1.2.5	Outpatient Care.....	14
1.2.6	General Paediatric Service	15
1.3	Satellite clinics	16
1.3.1	Sparkbrook locality.....	18
1.3.2	Greet community health centre.....	18
1.3.3	Northfield / Kings Norton locality	19
1.3.4	Wychall family and children’s centre	19
1.3.5	Evaluation.....	20
1.4	Summary.....	21
2	LITERATURE REVIEW.....	23
2.0	Introduction	23
2.1	Search Strategy	24
2.2	Evaluations of Care Closer to Home	25
2.2.1	Care Closer to Home demonstration sites	26
2.2.2	Evaluations of Specialist Outreach clinics	27
2.2.3	Factors affecting implementation	31
2.2.4	Patients’ experiences of Care Closer to Home.....	33
2.2.5	Paediatric Care Closer to Home	34
2.2.6	Paediatric Outpatient Care.....	36
2.2.7	Summary of Care Closer To Home Evaluations.....	37
2.3	Patient experience.....	38
2.3.1	What is patient satisfaction?.....	39
2.3.2	What is patient experience?	41
2.3.3	Patient experience as a driver for quality	43
2.3.4	Approaches to measuring patient experience	44
2.3.5	Linking patient experience to service improvement.....	47
2.3.6	Lifeworld-led healthcare	51
2.3.7	Involving children and young people in healthcare	53
2.3.8	Summary of patient experience literature.....	56
2.4	Place and Space	56
2.4.1	Phenomenological perspective	57
2.4.2	Social Constructionist perspective	61
2.4.3	Place-related concepts.....	63

2.4.4	Summary of Place as a theoretical concept	64
2.5	'Place-based' health research.....	64
2.5.1	The Hospital.....	65
2.5.2	The Community	68
2.5.3	Summary of 'place-based' health research.....	72
2.6	Conclusion.....	73
3	FAMILIES' EXPERIENCES OF RECEIVING SPECIALIST PAEDIATRIC CARE OUTSIDE OF A HOSPITAL SETTING: META- SYNTHESIS OF QUALITATIVE LITERATURE	74
3.0	Background	74
3.1	New models of service delivery	74
3.2	New places, new experiences.....	75
3.3	Introduction to Meta-synthesis	76
3.4	Aim.....	77
3.5	Methods.....	78
3.5.1	Systematic search and screening	78
3.5.2	Inclusion criteria	78
3.5.3	Critical appraisal	79
3.5.4	Data synthesis	79
3.6	Findings.....	83
3.6.1	Included Studies	83
3.6.2	Quality	84
3.6.3	Synthesis of findings.....	89
3.6.4	Transformation of the meaning of 'parent'	89
3.6.5	Transformation of the meaning of 'home'	92
3.6.6	Maintaining a sense of normality.....	94
3.6.7	Support and Coping.....	96
3.6.8	Working in Partnership	100
3.7	Discussion	102
3.7.1	Families' experiences of CCTH	102
3.7.2	Implications for policy, practice and research	105
3.7.3	Trustworthiness.....	106
3.7.4	Limitations.....	106
3.8	Conclusion.....	107
4	METHODOLOGICAL APPROACH.....	108
4.0	Introduction	108
4.1	The research paradigm	108
4.1.1	A pluralistic approach.....	110
4.2	Philosophical underpinning of phenomenological inquiry	112
4.2.1	What is Phenomenology?	112
4.2.2	Natural attitude.....	113
4.2.3	Intentionality	114
4.2.4	Lifeworld.....	115
4.2.5	Essence	115
4.2.6	Phenomenological reduction	116
4.2.7	Epoché.....	116
4.3	Phenomenology as a research methodology	117
4.3.1	Description versus interpretation	118
4.3.2	Giorgi's Descriptive Phenomenological method	119

4.3.3	Rationale for use	120
4.4	Thematic Framework method	122
4.4.1	Rationale for use	122
4.4.2	Summary of methodological approach.....	123
5	METHODS OF DATA COLLECTION AND ANALYSIS.....	124
5.0	Introduction	124
5.1	Identifying and accessing the research sites	124
5.2	Selection of participants	126
5.2.1	Selecting parents and young people	127
5.2.2	Selecting NHS staff and stakeholders.....	128
5.3	Materials.....	129
5.4	Gaining access to participants	130
5.5	Recruiting interview participants	132
5.5.1	Recruiting families.....	132
5.5.2	Recruiting NHS Staff and Stakeholders	133
5.6	The interview process.....	134
5.6.1	Phenomenological interviews	134
5.6.2	Semi-structured interviews	136
5.6.3	Interview setting	137
5.6.4	Informed consent.....	138
5.6.5	Interview techniques.....	139
5.6.6	Closing the interview.....	140
5.7	Recording.....	141
5.8	Transcription.....	141
5.9	Ethical considerations.....	141
5.10	Reflexivity	143
5.11	Methods of data analysis: family study	146
5.11.1	Obtain a sense of the whole	147
5.11.2	Determination of meaning units	147
5.11.3	Transformation of data	148
5.11.4	Formulation of essential general structures	150
5.11.5	Trustworthiness.....	151
5.12	Methods of data analysis: Staff and stakeholder study	153
5.12.1	Familiarisation	153
5.12.2	Identification of a thematic framework	153
5.12.3	Indexing	155
5.12.4	Charting	156
5.12.5	Mapping and interpretation.....	158
5.12.6	Trustworthiness.....	158
5.13	Summary of methods	159
6	FAMILY STUDY FINDINGS.....	160
6.0	Introduction	160
6.1	Research question	160
6.2	Description of participants	161
6.3	General structure.....	163
6.3.1	Receiving General Paediatric outpatient care at the Children’s Hospital.....	164
6.4	Constituents of the general structure	165
6.4.1	Preparation.....	166

6.4.2	Journey	168
6.4.3	Arrival	170
6.4.4	Waiting...	173
6.4.5	Height and weight	182
6.4.6	More Waiting...	183
6.4.7	Consultation and care	184
6.4.8	Post appointment.....	187
6.5	General structure: Receiving General Paediatric outpatient care in a community-based clinic	188
6.6	Constituents of the general structure	189
6.6.1	Preceding the appointment	189
6.6.2	Journey	192
6.6.3	Arrival	194
6.6.4	Waiting...	197
6.6.5	Consultation and care	201
6.6.6	After the appointment	206
6.7	The experience of receiving paediatric outpatient care in hospital and community settings: Similarities and differences.....	206
6.7.1	Time wasted, time saved.....	207
6.7.2	Space and place.....	208
6.7.3	Consultation and care	209
6.7.4	Adolescent needs - all is forgotten.....	209
6.7.5	My community, not the community	210
6.8	Summary of findings.....	210
7	NHS STAFF AND STAKEHOLDER STUDY FINDINGS	212
7.0	Introduction	212
7.1	Research question	212
7.2	Description of participants	212
7.3	Organisational factors.....	215
7.3.1	Space and place.....	215
7.3.2	The Ivory Tower.....	222
7.3.3	Impact on healthcare professionals	230
7.4	Policy implementation.....	233
7.4.1	Bringing about change	237
7.5	Service design	237
7.5.1	'Drag and Drop' model	237
7.5.2	'Drop-in' clinics.....	238
7.5.3	'One-stop-shop' model	239
7.5.4	Telemedicine	241
7.5.5	GPs with Special Interests	242
7.5.6	'Out-of-hours' clinics	242
7.6	Summary of findings.....	243
8	DISCUSSION	245
8.0	Introduction	245
8.1	Revisiting the aims.....	245
8.2	Discussion of main findings	248
8.2.1	Temporality	249
8.2.2	Spatiality.....	256

8.2.3	Professional Identity	262
8.2.4	Inter-subjectivity	265
8.3	Contributions to knowledge	272
8.3.1	Understanding Paediatric Care Closer to Home	272
8.4	Implications for policy, practice and research.....	275
8.4.1	Recommendations for policy and practice	276
8.4.2	Recommendations for future research.....	277
8.5	Methodological considerations	278
8.6	Limitations	280
8.6.1	Reflections on the research process	282
8.7	Concluding remarks	283
APPENDIX 1 Meta-synthesis documents		284
1.1	Electronic Search Strategy	284
1.2	Data Extraction Form	285
APPENDIX 2 Study materials		290
2.1	Recruitment Leaflet: Families	290
2.2	Recruitment Poster: Families.....	292
2.3	Invitation letter: Families.....	293
2.4	Invitation letter: Staff	294
2.5	Information Sheet: Parents	295
2.6	Information Sheet: Parents of young people participants	297
2.7	Information Sheet: Young People.....	299
2.8	Information Sheet: Staff	301
2.9	Consent Form: Parents	304
2.10	Consent form: Parents of Young people.....	305
2.11	Assent Form: Young People.....	306
2.12	Consent Forms: Staff	307
APPENDIX 3 MCRN young person group correspondence.....		308
3.1	Letter inviting review of study documents.....	308
3.2	Summary of feedback on study documents	309
APPENDIX 4 Study approval letters		311
4.1	Approval from West Midlands REC	311
4.2	Approval from West Midlands REC (Amendment).....	314
APPENDIX 5 Interview schedules.....		316
5.1	Interview Schedule: Families	316
5.2	Interview Schedule: Staff.....	317
APPENDIX 6 Thematic framework		319
APPENDIX 7 Analytic Memo 'Philosophy of Care'		324
APPENDIX 8 BCH Outpatient Report		326
APPENDIX 9 Published Paper		337

LIST OF TABLES

Table 1: Key documents outlining Care Closer to Home	9
Table 2: Example taken from Matrix of 1st and 2nd order constructs	81
Table 3: Coding Framework	82
Table 4: Study Characteristics	86
Table 5: Prompts for appraising qualitative research	88
Table 6: Matrix of third order constructs.....	89
Table 7: Example of data transformation	150
Table 8: Example of a category from the final thematic framework	155
Table 9: Extract from the 'Philosophy of Care' matrix.....	157
Table 10: Characteristics of parent participants	162
Table 11: Characteristics of young people participants.....	163
Table 12: Characteristics of staff and stakeholder participants.....	214
Table 13: Synthesis of concepts from each study	249

LIST OF FIGURES

Figure 1: Map showing BCH and two satellite clinics.....	21
Figure 2: Advantages of using patient stories for improving health services.....	47
Figure 3: Steps of a Meta-Ethnography	77
Figure 4: Flow chart outlining number of articles retrieved, and included or excluded at each stage of review process.....	85
Figure 5: Topics covered in staff interviews.....	137
Figure 6: Example of a transcript split into meaning units	148
Figure 7: Example of open coding.....	154
Figure 8: Example of application of the thematic framework to part of a transcript.....	156
Figure 9: Seamon’s notion of ‘At homeness’	258
Figure 10: Recommendations for policy and practice	277
Figure 11: Recommendations for future research.....	278

LIST OF ABBREVIATIONS

BCH: Birmingham Children's Hospital NHS Foundation Trust

CCG: Clinical Commissioning Group

CCTH: Care Closer to Home

CLAHRC: Collaborations for Leadership in Applied Health Research and Care

CQUIN: Commissioning for Quality and Innovation

DH: Department of Health

EBD: Experience-based Design

GCP: Good Clinical Practice

GP: General Practitioner

HOB tPCT: Heart of Birmingham teaching Primary Care Trust

HSR: Health Services Research

MCRN: Medicines for Children Research Network

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health Research

NSF: National Service Framework

PCT: Primary Care Trust

PFCC: Patient and Family Centred Care

PLACES: Paediatric Location And Care EvaluationS

QIPP: Quality Innovation Productivity and Prevention

REC: Research Ethics Committee

R&D: Research and Development

SBPCT: South Birmingham Primary Care Trust

SHA: Strategic Health Authority

UK: United Kingdom

YP: Young Person

AN INTRODUCTION TO THE STUDY

In line with the philosophy that families' lives should continue as normally as possible when children require medical treatment, NHS reforms have sought to ensure that children and young people who are ill receive timely, high quality and effective care as close to home as possible (DH, 2004). Health policy in the United Kingdom (UK) is thus directing the delivery of specialist paediatric health services away from traditional hospital settings and into new, community-based, closer to home and in home settings (DH, 2004, 2009). The rationale for such changes to the location of care delivery include potential benefits of keeping young people out of hospital, better access to services, higher levels of patient satisfaction and improved health outcomes (DH, 2007). There is also an inherent assumption within policy documents that new, closer to home models of care are preferred by families. However, shifting services away from their traditional setting has implications for healthcare experience and perceptions of quality as the 'place' of healthcare activity could hold complex meanings for service-users and their families (Poland et al., 2005, Andrews, 2006).

This study is part of the wider Paediatric Location and Care Evaluations (PLACES) project funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) programme. The PLACES Project comprises a collaborative partnership between researchers at the University of Birmingham and clinicians and managers at Birmingham Children's Hospital NHS Foundation Trust (BCH). The aim is to carry out research in response to the priorities of the Trust which will produce findings of direct benefit to patients. Of particular interest

are evaluations of existing and innovative models of paediatric health service provision, with the purpose of identifying areas for improved care and patient outcomes. This includes for example, exploring the uptake of paediatric health services by families, the acceptability of new models of care delivery and the effect of system re-design on reducing inequalities in access to healthcare.

This particular project was developed because of the requirement to shift acute care away from hospitals and into community settings, both regionally and nationally. In response to Care Closer To Home (CCTH) policy objectives (DH, 2007, 2008a) and concerns regarding hospital demand and capacity, a new 'satellite' clinic model for providing General Paediatric outpatient care closer to families' homes, in community settings, has been established at BCH. Evidence regarding the benefits of this model however is limited. Existing evaluations of CCTH initiatives have failed to explore the experiential dimensions of service change from the perspectives of service-users and providers; making it unclear whether this approach is appropriate and acceptable to parents, young people and staff. Moreover, despite health policy placing increasing emphasis on delivering CCTH, implementation has been slow and inconsistent (The Audit Commission, 2009). Paediatric outpatient CCTH was therefore identified by NHS stakeholders at BCH as an area in need of further investigation.

This is the first qualitative evaluation of paediatric outpatient CCTH in the UK. It sought to examine the experience and impact of introducing new, community-based paediatric outpatient clinics, from the perspectives of (i) children and young people, (ii) parents and carers, (iii) healthcare professionals and other NHS stakeholders. Findings contribute

to the evidence-base for delivering specialist care in alternative settings, thus building on existing quantitative evaluations of CCTH and studies exploring the provision of care within the home for children with complex needs. Findings further enable children's and parent's perspectives to inform service design and development, which in turn may improve their experiences of outpatient services as well as improve the practitioner-patient-parent relationship. In addition to implications for policy and practice, findings are of methodological and theoretical interest. An empirical focus on the lived experience of parents and patients supports the concept of 'humanisation' within health services research (HSR); a theoretical focus on the concepts of 'place and space', defined here as settings which provide experiences, attachments, symbolism and identity for their users (Andrews, 2006) allows for new and deeper understandings of the geographical aspects of healthcare experience.

Set within the context of paediatric CCTH, the aims of this applied study are:

- To describe the experiences of families receiving specialist paediatric healthcare in traditional and alternative settings;
- To explore the views and experiences of healthcare professionals and other NHS stakeholders on providing paediatric outpatient care in different settings;
- To better understand the role of place and space in the experience of providing and receiving CCTH.

Research design

To achieve these aims, a programme of research was devised, using a qualitative methodological approach. This included a meta-synthesis of qualitative literature; an

interview study with parents, children and young people who have attended General Paediatric outpatient appointments; and a second interview study with NHS staff and stakeholders to explore their views on satellite clinic service provision.

Qualitative evidence review

The first study in this thesis answers the question: What does the qualitative literature tell us about parents' and patients' experiences of receiving specialist paediatric care outside of a traditional hospital setting? New insights from a synthesis of qualitative literature in this area will contribute to the development of an evidence-base for designing innovative and acceptable models of specialist paediatric healthcare outside of the hospital.

Service-user perspective

The second study in this thesis answers the question: What are the experiences of families receiving specialist paediatric outpatient care in different settings? This phenomenological study focuses on an exploration of the meanings of healthcare experience within diverse settings, using interviews with parents and young people.

Service-provider perspective

As providers of healthcare, professionals and other NHS stakeholders are instrumental to the implementation of policy initiatives and success of new models of service delivery.

The third study in this thesis therefore answers the question: What are the views and experiences of healthcare professionals and other NHS stakeholders on providing paediatric outpatient care in different settings? This is a qualitative study, using semi-

structured interviews with staff and stakeholders and a thematic Framework method of analysis (Ritchie and Spencer, 1994).

Synthesis of findings

Finally, the findings of these studies are synthesised to think about the third question from both service-user and service-provider perspectives: What is the role of place and space in providing and receiving care closer to home?

Key objectives of this research therefore are (i) to enhance understanding of satellite clinics as a model of service provision for paediatric outpatient care and (ii) to develop understanding of the theoretical constructs of place and space in healthcare experience.

Outline of Thesis

The chapters of this thesis tell the story of the research project; starting with the national policy and local hospital context that informed the study, moving through to a review of existing literature, a description of the philosophical foundations of the study and methods of data collection and analysis, and finally to the findings and their implications for policy, practice and future research.

Chapter one provides an introduction to the historical, political and economic background that has contributed to the development and shaping of Care Closer to Home (CCTH) policy initiatives. It also details the research setting (Birmingham Children's Hospital NHS Foundation Trust and local Primary Care Trusts) so that the reader may understand the context of the research in terms of the Trust's organisational

structure, hospital location and physical environment, patient population and service demands.

Chapter two presents a more detailed account of the literature relating to paediatric CCTH, including an overview of existing evaluations, with particular focus on the 'specialist outreach clinic' model (Gruen et al., 2009) utilised by BCH for delivering community-based, General Paediatric outpatient services. The use of patient satisfaction and experience measures to indicate healthcare quality and inform service improvement are then examined, before consideration is given to the involvement of children and young people in healthcare. Finally an exploration of the theoretical and empirical literature relating to the concept of 'Place and Space' is provided; proposing that the creation and therapeutic function of 'place' holds a central role in healthcare reforms, making it a valuable area for research inquiry.

Chapter three is a meta-synthesis of qualitative literature on families' experiences of receiving specialist paediatric healthcare outside of a hospital setting. The aim of this review is to examine the qualitative evidence for providing paediatric CCTH and to derive new, conceptual understandings of families' experiences of receiving specialist paediatric care in the community and at home. The aim is reflected in the choice of synthesis method, meta-ethnography, which is purposefully designed to be "interpretative rather than aggregative" (Noblit and Hare, 1988, p.11). In addition to developing new conceptual insights, this meta-synthesis will contribute to the evidence-base of paediatric CCTH, enabling service-providers to make more informed decisions.

Chapter four describes the qualitative methodological approach taken in the two empirical studies, providing a rationale for the use of different qualitative methods in response to the distinct research questions, asked of two distinct groups of participants; service-users and service-providers (a descriptive phenomenological approach for families (Giorgi, 2009) and thematic Framework method (Ritchie and Spencer, 1994) for NHS healthcare professionals and stakeholders). Further details on the philosophical foundations of descriptive phenomenology and Giorgi's (2009) method are then presented, before the thematic Framework approach (Ritchie and Spencer, 1994) is described.

Chapter five describes the methods of data collection and analysis used in the phenomenological study of families' experiences of receiving paediatric CCTH and the qualitative study of healthcare professionals and NHS stakeholders' views and experiences of delivering paediatric CCTH. This includes a description of the research processes, including sampling, interviewing and data analysis; the application of Giorgi's (2009) descriptive phenomenological method for family data and thematic Framework method (Ritchie and Spencer, 1994) for staff data. Access to the research sites and research ethics are further examined, before detailing the processes employed to maintain rigour and reflexivity.

Chapter six presents the findings of the family study, describing families' experiences of receiving paediatric outpatient care at the Children's Hospital and then at the two community-based clinics. The chapter begins with a description of the participants, before presenting the essential, general structure of the phenomenon, followed by more

detailed descriptions of the constituents of the general structure, supported by verbatim quotations. Commonalities and variations between participants' accounts are also illuminated. In line with the phenomenological tradition, findings are written in a way that attempts to retain the 'texture' of human experience as well as maintaining structural accuracy. Thus the style of writing within this chapter is deliberately used to provoke a sense of recognition and empathy within the reader (Todres, 1998). The chapter concludes by comparing participants' experiences of different settings in order to initiate discussion about the impact of place on paediatric outpatient experience.

Chapter seven presents the findings from staff and stakeholder interviews. After describing the range of primary and secondary care participants purposefully recruited for the study, three main themes generated from data analysis are discussed: organisational factors, policy implementation and service design. Each theme is supplemented with verbatim quotations, highlighting interesting and important points within the analysis. Findings also illuminate potential barriers to implementation of CCTH policy initiatives.

The final chapter draws together findings from the meta-synthesis, phenomenological family study and qualitative staff and stakeholder study, discussing them in relation to the research questions and current literature. Contributions made by this thesis to paediatric health service policy and practice and theoretical conceptions of place and space are then provided, along with a discussion of strengths and limitations of the research, highlighting areas for future study.

CHAPTER ONE

1 BACKGROUND

1.0 Introduction to policy and practice

In this chapter, the current and historical context of Care Closer to Home (CCTH) policy and implementation is reviewed, with additional focus on paediatric health services. This is followed by a description of the research setting (Birmingham Children's Hospital NHS Foundation Trust) including the Trust's organisational structure, hospital location and physical environment, patient population and service demands. Finally, the two community-based clinics are described in terms of their geographical location and demographic characteristics.

1.1 Policy context

In recent years, health policy has pushed for at least some aspects of secondary care to be shifted out of hospitals and into community settings. Anticipated benefits of this initiative include: improved health and wellbeing for patients, more cost-effective provision of healthcare and greater patient satisfaction. A key policy driver for this shift of care in England was the publication of the White Paper, 'Our Health, Our Care, Our Say' (DH, 2006) which, following public consultation set a new strategic direction for services to be provided closer to patients' homes. This white paper built on previous policy initiatives seeking to deliver NHS improvements through 'Creating a patient-led NHS' (DH, 2005) which urged healthcare teams to "move from a service that does things to and for its patients to one which is patient-led where the service works with patients to support them

with their health needs” (p.3). Shifting care out of hospitals and into more local settings thus gave life to the National Health Service (NHS) vision of more personalised and convenient healthcare that was responsive to patient need:

“When people access community services, they should do so in places and at times that fit in with the way they lead their lives. Organisational boundaries should not be barriers. Furthermore, services that would serve people better if they were placed in local communities should be located there and not in general hospitals.” (DH, 2006, p.13)

Policy suggests that many health services, including outpatient appointments, are provided in hospitals due to tradition rather than necessity. Hence there may be no clinical reason why some services could not potentially be provided in health centres, General Practitioner (GP) practices, or other community locations:

“Currently there are nearly 45 million outpatient appointments every year in England. Estimates vary by specialty, but for some specialties up to half of these could eventually be provided in a community setting.” (DH, 2006, p.135)

Benefits of providing outpatient care in the community are suggested to include more efficient and sustainable services that relieve demand on the acute sector, provide better quality care with shorter waits for treatment and shorter journey times, improved patient choice and consistent care regardless of demographic, socio-economic or geographical status (DH, 2007). This transformation of care was assumed to be preferred by patients and their families, as well as facilitate more joined-up working across traditional primary-secondary care boundaries (Patterson, 2010). As such, CCTH was considered more than simply changing the place in which services were provided. Rather, the initiative was intended to instigate changes in the entire way that care was conceptualised and organised

(Singh, 2006). Thus, alongside a shift in the geographical location of services, there was also a drive to shift the culture of the NHS towards a more integrated approach, whereby multi-professional teams would work in partnership to deliver truly patient-centred care (Royal College of Physicians et al., 2008):

“Shifting care closer to home is one of the pillars that supports our vision of improved community health and social care. What we are seeking is nothing less than a fundamental change in the way health and social care operates, a change that will inspire staff to deliver better quality care and that will put people in control. The next chapter sets out how we will ensure that this vision becomes a reality.” (DH, 2006, p.154)

1.1.1 Implementing Care Closer To Home

Implementation documents (DH, 2007, 2008a) subsequently set out the need to take a ‘whole system’ approach, with critical elements of the challenge emerging as:

1. Bringing care closer to home in a way that both involves people as partners in designing services and delivering their care, and which reaches all of the population, addressing inequalities;
2. Ensuring that services closer to home form part of integrated care pathways for users, making effective links between health, social care and other services;
3. Building commissioning capacity and capability, working with communities to establish the outcomes that matter to them and the most appropriate ways of meeting them;
4. The development of leadership, both clinical and managerial, to grasp the strategic opportunities, work with local communities to co-design change, and to see change through;
5. Developing community premises and estates that are fit for the future as well as the present;

6. Workforce - putting in place the roles, skills and planning to facilitate services that support people at home and in the community;
7. Making greater use of technology to provide more care in community settings and at home. (DH, 2008a, p.2-3)

In his 'next stage review' of the NHS (DH, 2008b), Lord Darzi also set about making recommendations to implement policy changes. He suggested moving 'routine healthcare' such as outpatient appointments, away from acute hospitals and into new, community-based polyclinics to provide a 'one-stop-shop' for healthcare (DH, 2008b). A key part of this plan was to extend the opening times of such clinics, so as to make services more accessible for working people. In proposing a polyclinic model as the way forward, Darzi's recommendations echoed his preceding review of healthcare in London (Darzi, 2007).

Labour's open-all-hours 'Darzi centres' thus became the centrepiece of their health reforms, resulting in many Primary Care Trusts (PCTs) in England attempting to break down traditional boundaries by bringing primary and secondary care services together. An example of this was demonstrated in Hartlepool, where two hospitals were closed and replaced with one new hospital and two new, purpose built integrated health centres, located in the north and south of the town. These community health centres provided GP services as well as specialist chronic disease services, urgent care services, physio and speech and language therapies, outpatient care, minor surgery and x-ray. There was also a pharmacy and a large breakout space for community meetings and classes (University Hospital of Hartlepool Study Day, 2010).

1.1.2 Liberating the NHS

In May 2010 (six months after the start of this study) a General Election was held in England and Wales, resulting in the Labour government being replaced by a Conservative and Liberal Democrat coalition. Under this new Government, Labour's Darzi centres found themselves "stranded in a very different political and economic climate" (Davies, 2010, p.1023) and following a major review, London's polyclinic programme was axed. In this politically symbolic act (Gainsbury and West, 2010), the new Health Secretary, Andrew Lansley declared that a top down, 'one size fits all' programme would be replaced with a new initiative whereby more responsibility would be handed to clinicians and to the public (Gainsbury, 2010).

With a new Government came the introduction of a new White Paper. In July 2010 'Equity and Excellence: Liberating the NHS' (DH, 2010a) was released, coining the catchphrase "no decision about me without me" (p.3). Retaining Darzi's focus on quality, the main objective of this reform was to put patients at the centre of healthcare by giving them more choice over care providers and encouraging shared-decision making with regards to treatment. Through this and the subsequent Health and Social Care Act (DH, 2012), the Government confirmed its new direction for the NHS by outlining fundamental changes to its functioning. In a move not too dissimilar from the previous Conservative GP fund-holding initiative, Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) were replaced with Clinical Commissioning Groups (CCGs), in which GPs became responsible for commissioning all health services on behalf of their patients. Despite this major reorganisation, there remained a push to deliver more services in the community, partly in

an effort to “reduce costs, and partly to make care more patient-centred” (Munton et al., 2011, p.2). Such restructuring of the health service together with the development of CCGs is therefore likely to lead to further development of community-based secondary care services (Abdelhamid et al., 2012).

1.1.3 The Nicholson Challenge

Changes to the provision of healthcare also need to be located within the context of recent economic decline and austerity measures, resulting in the NHS Chief Executive David Nicholson, ‘challenging’ the entire NHS to make between £15bn and £20bn in efficiency savings over four years from 2011 to 2014 (Hawkes, 2012). This challenge calls for new, more productive ways of working to be found so that similar outcomes can be achieved at little extra cost. Part of this ‘doing more for less’ has been the Quality Innovation Productivity Prevention (QIPP) initiative. This is supported by the new white paper and demonstrates the government’s commitment to ensuring that the NHS makes efficiency savings, which can be reinvested into services to improve care quality (DH, 2010a). The challenge of improving productivity and quality, while also saving money is likely to prompt further changes within the NHS, particularly with the demands of commissioners who want to see more services moved closer to home (DH, 2011c).

1.1.4 Services for children

Although the shift of healthcare from hospitals into community settings is relatively new in adult healthcare, the theme has been running through policy for paediatric health services since the Platt Report in 1959. Based on the philosophy that families’ lives should continue

as normally as possible when children require medical treatment, NHS reforms have sought to ensure that children and young people who are ill receive timely, high quality and effective care as close to home as possible (DH, 2004). In recommending that families receive services which are coordinated around their individual needs and take account of their views (DH, 2004), the National Service Framework (NSF) for children and young people further draws on the United Nations Convention on the Rights of the Child (1989). This outlines the basic human rights of all children, including the right to good quality healthcare and to respect of their views. The NSF also formed a crucial part of the Every Child Matters programme (Department for Education and Skills, 2004) which encouraged organisations to work together to provide coordinated services around the needs of the child. The NSF and Every Child Matters programme were later reinforced by the publication of the child health strategy, Healthy Lives, Brighter Futures (DH, 2009) and the Kennedy report (2010) which was commissioned to review barriers to the improvement of children's healthcare. In his report, Kennedy (2010) reiterates that services for children and young people should be planned in a joined-up and holistic way, with greater engagement from children themselves. It is clear then, that policy has directed paediatric healthcare towards a more 'family-centred' approach (Shields et al., 2006) which aims to keep children and young people out of hospital and encourages them to work in partnership with healthcare providers to ensure that services are built around their needs.

1.1.5 Where are we now?

Political and economic changes have redefined health services by focusing on the active participation of patients in decisions about their service provider, treatment and in the

design of new models of service provision (see table 1). Through shared responsibility and patient involvement, these changes are intended to transform healthcare by improving quality and minimising demand, and therefore costs. Reforms in health policy have also focused on rethinking the location of care (Ham et al., 2012), directing services away from hospitals and into new, 'closer to home' community settings. Thus, despite recent changes to the commissioning landscape, the concepts of quality, patient experience and 'place' remain central to government policy initiatives, including those considering health services for children and young people.

Table 1: Key documents outlining Care Closer to Home

Author & Year	Title	Contribution
Platt, 1959	The Welfare of Children in Hospital	Children shall be admitted to hospital only if the care they require cannot be equally provided at home or on a daily basis as an outpatient; Parents should be allowed to visit children in hospital whenever they can and to help as much as possible with the care of the child.
DH, 2004	National Service Framework for Children, Young people and Maternity Services	Standard 3: Children, young people and families should receive high quality services which are co-ordinated around their individual and family needs and take account of their views; Standard 6: Children and young people who are ill should receive timely, high quality and effective care as close to home as possible, within a local system that co-ordinates health, social care and education in a way that meets individual needs.
DH, 2005	Creating a Patient-led NHS	Outlines action for local and national leaders to transform the NHS into a patient-led organisation which responds to the needs and wishes of patients, offering them more choice and joined-up care.
DH, 2006	Our Health, Our Care, Our Say	Recommends shifting services away from acute hospitals and into the community, citing benefits of better quality care with shorter waits for treatment and shorter journey times, thus improving both the patient experience and health outcomes.
DH, 2007	Implementing Care Closer to Home	Provides case study examples of best practice for delivering care closer to home, including practitioners with special interests.
DH, 2008	High Quality Care for All: NHS Next Stage Review	Highlights the need to bring care closer to home to deliver better care for patients.
DH, 2008	Delivering Care Closer to Home: Meeting the Challenge	Outlines the challenges involved in shifting care closer to home and tools to support delivery.
DH, 2009	Healthy lives, brighter futures – The strategy for children and young people's health	Long-term strategy to improve health outcomes for all children and young people; highlights a need for partnerships between health, social and education authorities to provide high quality support for families at key stages in their children's lives.
Kennedy, 2010	Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs	Review carried out amid concern about services provided by the NHS to children and young people. Recommended giving children's services a higher priority within the NHS, with more partnership working and more involvement of children and young people.
DH, 2010	Equity and Excellence: Liberating the NHS	Outlines plans to 'liberate' the NHS by reducing bureaucracy, focusing on clinical outcomes and devolving power to local clinicians. Advocates taking a 'genuinely patient-centred approach' to care by giving patients more choice, involvement and control.
DH, 2012	Health and Social Care Act	Supports a shift of care from hospitals to community / home settings and from professionals to patients. Clinical Commissioning Groups formed to take control of the NHS budget from PCTs; GPs to be in charge of planning and buying all health services for patients.

1.2 Birmingham Children's Hospital

Birmingham Children's Hospital NHS Foundation Trust (BCH) is a major children's teaching hospital situated in Birmingham (UK) city centre. The city has a youthful age profile with 227,800 children (aged 0-15) representing 22% of the population (Office for National Statistics, 2011). The population is ethnically diverse with one third belonging to an ethnic group other than White (Office for National Statistics, 2011) and has considerable demographic variation, with several areas of significant health and social need.

Providing a wide range of paediatric emergency, secondary and tertiary care locally, regionally, nationally and internationally, Birmingham Children's Hospital has 313 inpatient beds across 15 wards, a 22 bedded paediatric intensive care unit (PICU) and a 24 hour, seven days a week Emergency Department (Care Quality Commission, 2011). It also provides a variety of outpatient services, seeing 154,975 outpatient attendances in 2011/12 (Birmingham Children's Hospital NHS Foundation Trust, 2012/13). The former Heart of Birmingham teaching Primary Care Trust (HOB tPCT) has traditionally been responsible for commissioning secondary healthcare from BCH for the residents of Birmingham, including the provision of General Paediatric services. Following the recent Health and Social Care Act (DH, 2012), this responsibility will be passed to GPs via the introduction of CCGs.

1.2.1 Quality and Innovation

Each year Birmingham Children's Hospital NHS Foundation Trust makes a range of commitments regarding improvements to the quality of services they provide to families. These are decided in consultation with children, young people, families, staff, other NHS

providers, commissioners and stakeholders. In 2009, the first of these consultations entitled 'The Children's InTent: Shaping our Future' identified three key areas for improvement which gave focus for the development of a 5-year strategy (Birmingham Children's Hospital NHS Foundation Trust, 2009/10) and highlighted areas in need of investigation for this research (Cummins et al., 2009):

1. Caring for all of the children and young people who choose and need to use us, so they are admitted to our hospital when they need us, not when we are ready for them;
2. Working in partnership with other hospitals and community providers to ensure children are looked after as close to home as possible;
3. Advocating for children and young people to ensure they get the best possible start in life.

In addition, quality improvement goals have been set in response to national initiatives such as the Quality Innovation Productivity and Prevention (QIPP) and Commissioning for Quality and Innovation (CQUIN) schemes. QIPP schemes agreed and met in 2011 (Birmingham Children's Hospital NHS Foundation Trust, 2012/13) included:

- Reducing outpatient attendances, emergency attendances and admissions;
- Reducing length of stay by treating patients at home;
- Using 'patient journeys' to establish the ideal journey and demonstrate improvements;
- Adopting the Department of Health 'You're Welcome' toolkit;
- Increasing the level of service-user involvement.

The CQUIN framework was introduced in 2009 as a national agenda for locally agreed quality improvement schemes (DH, 2010b). It was devised to enable commissioners to reward excellence by linking a proportion of healthcare providers' funding to the achievement of local quality improvement goals. The aim of the initiative therefore was to create a culture of ongoing quality improvement, with goals agreed on an annual basis (DH, 2010b). Through the CQUIN payment framework, a proportion of BCH's income in 2011/12 was conditional upon achieving quality improvement goals agreed between BCH NHS Foundation Trust and the former HOB tPCT and West Midlands Specialised Commissioning Team (Birmingham Children's Hospital NHS Foundation Trust, 2012/13). These included demonstrating improvements to the family and patient experience.

1.2.2 Capacity

With a city centre site, the implementation of a patient 'Choose and Book' appointment system and 'brand recognition', BCH services operate at near full capacity with a growing demand (Cummins et al., 2009). Ensuring the Trust has enough capacity to manage such an increase however, has been identified by families, staff and commissioners as a key concern (The Healthcare Commission, 2009, Birmingham Children's Hospital NHS Foundation Trust, 2009/10). Consequently, BCH is forced to consider alternative models of service delivery as part of its strategic intentions for the future.

At the Chief Executive's briefing in January 2010, discussions were started with regards to the Trust's capacity issues and exploring potential solutions. Options included re-designing the existing hospital site and co-locating services in community settings (for example using a satellite clinic model) or moving to a new site with more space. A consultation exercise

revealed that staff would prefer to stay at the current site rather than move to a new location. In the medium term then, the Trust is investing in capacity at the existing site with the expansion of PICU, a new theatre block and more services being delivered outside of the hospital (e.g. hospital-at-home and community-based satellite clinics) (Birmingham Children's Hospital NHS Foundation Trust, 2013). Nevertheless, detailed work continues to be carried out by the executive team to explore options for the long term future of the Trust, with the caveat that any move to a new site would take approximately 10 years to complete.

1.2.3 Attendance

Despite problems of capacity, there is a high non-attendance rate (>10 %) at General Paediatric outpatient appointments at BCH, especially from deprived and outlying areas and an apparent lack of access (Birmingham Children's Hospital NHS Foundation Trust, 2009/10). Missed appointments have significant financial, resource and time implications for service providers and can also pose serious consequences for the health of the child. Literature suggests however, that attendance is influenced by a number of complex factors including; experience, beliefs and expectations, perceptions of quality and patient satisfaction (Newsome and Wright, 1999, Strasser et al., 1993, Freed et al., 1998, Spencer, 1993). The General Paediatric service in particular has been identified by BCH as one where investigation and interventions to lower non-attendance rates might be targeted. New models of service provision such as delivering paediatric outpatient care in community settings could help to overcome some of these obstacles (Sibbald et al., 2008).

1.2.4 Birmingham Children's Hospital as a health place

A recent unpublished study (Lam et al., 2012) and anecdotal evidence suggests that families in and around Birmingham bypass more convenient places (e.g. GP surgeries, more local hospitals) in favour of attending BCH Emergency Department with non-emergency conditions. The perceived expertise of practitioners and access to investigations at BCH in comparison to local healthcare, is thus constructed as a major factor in parental health service choice (Woolfenden et al., 2000). This use of the Emergency Department as a primary care facility could be attributed to the meaning of the BCH 'brand' to families, as a specialist and dedicated Children's Hospital. Brand trust is defined as the sense of security held by an individual that a brand will consistently satisfy their needs and meet their expectations (Deighton, 1992). If families' perceptions are that BCH is the most trusted place for their child's care, this may present a barrier to uptake of new closer to home clinics, especially if parents are willing to pay a higher 'price' (e.g. travelling longer distances; paying extra costs for travel / parking; waiting longer to be seen) for a hospital-based service which they trust will meet their expectations, deliver high quality care and has a trustworthy reputation.

1.2.5 Outpatient Care

Outpatient services are one of BCH's largest areas of provision, utilising a significant amount of hospital resources and staff. These services continue to battle with costly non-attendance rates, leading some to question whether they need to be delivered in hospital at all (Taylor, 2010). Outpatient services have further been suggested to need a radical rethink, as changing how they are provided could lead to cost savings and greatly improve

patient experience (Patel, 2011). One outpatient service that BCH considers appropriate for delivery in the community is General Paediatrics. However, limited evidence means that it is unclear whether the aforementioned benefits of CCTH could be achieved in a paediatric context, and whether community-based clinics would be desirable to families. Given that paediatric services must overcome unique challenges in addressing the child's wishes as well as those of their parents, findings from adult settings may not be transferable.

1.2.6 General Paediatric Service

As a clinical speciality, General Paediatrics can be defined as: "the diagnosis from symptoms, signs and investigations of undifferentiated referred infants, children and young people" (Wacogne et al., 2006, p.1030). The General Paediatrician's role involves "initiat(ing) treatment which can be delivered personally or by another person or team, according to the needs of the child" (Wacogne et al., 2006, p.1030). The service therefore covers a variety of non-organ specific medical illnesses and psychological and social issues, ranging from urgent medical conditions to more long-term health needs. Health conditions treated by the General Paediatric team include, amongst others: asthma, infections, epilepsy, seasonal respiratory illnesses, allergy and constipation.

The General Paediatric department at BCH has nine General Paediatric Consultants. There are approximately 4,300 admissions per year to the General Paediatric service, and 9,000 outpatient attendances per year (West Midlands Deanery, 2012). Roles and responsibilities of the General Paediatric team include:

- Referrals from General Practitioners and the Emergency Department;

- Inpatient management of all acute and chronic general paediatric medical conditions (including child protection);
- Advice to other services within the Trust about general medical problems, child protection issues, and co-ordination of care for children with complex needs;
- Overall responsibility for general medical admissions to PICU, in close collaboration with the intensive care medical staff;
- Outpatient management of new and follow-up patients;
- Education, appraisal, and support of doctors in training, and teaching of medical students.

In addition to hospital inpatient and outpatient services, the General Paediatric team runs a new Paediatric Outpatient Referral, Triage and Liaison (PORTAL) service. This is a 'virtual' outpatient clinic, commissioned by HOB tPCT in 2011, to provide specialist online advice and guidance to GPs to assist them with decisions about treating paediatric patients. The idea is to prevent children going to hospital unnecessarily by providing GPs with specialist advice via the 'Choose and Book' appointment system, within 48 hours of the request. A mixed methods evaluation of this pilot service carried out by the CLAHRC PLACES Project team found that the service was effective in reducing outpatient attendances and facilitating knowledge transfer between primary and secondary care clinicians (Wordsworth et al., 2011). The pilot has been extended with further evaluation underway.

1.3 Satellite clinics

At present, the BCH General Paediatric team provides two 'satellite' clinics in community settings; one at Greet Health Centre (Heart of Birmingham teaching PCT, Sparkbrook locality) and one at Wychall Child and Family Centre (South Birmingham PCT, Northfield /

Kings Norton locality). In this context, satellite clinics denote consultant-led, secondary care outpatient services that are centrally managed, but delivered in settings outside of the main hospital site. In this case a health centre and a Sure Start family centre, although any community site could be included (e.g. GP surgery, community centre, school). Satellite clinics can be described as ambulatory, generally pre-planned care, although open access appointments can form part of the service. Referrals to these clinics are generally made by GPs to the main hospital, who then allocates them to local clinics based on postcode, medical condition and consultation with the family.

The Greet health centre clinic was initially established in response to discussions between the Heart Of Birmingham teaching Primary Care Trust (HOBtPCT) and BCH regarding how the two organisations could work together to improve services for children and young people, as well as reducing rates of non-attendance which were identified as high for families living in the area. The Wychall clinic was set up by one of the Consultant General Paediatricians who recognised that families from the Northfield / Kings Norton area of south Birmingham had to travel a considerable distance to the hospital, which was particularly difficult for those travelling via public transport with young children. In the 1990s paediatric health services had been transferred from Selly Oak Hospital in the heart of south Birmingham to the current city centre site of BCH, thus reducing access to specialist paediatric care for families living in those areas. Providing a General Paediatric outpatient clinic between the Northfield and Kings Norton areas of south Birmingham aimed to improve access and convenience for families, as well as reducing their travel costs.

1.3.1 Sparkbrook locality

Greet health centre is located in the Sparkbrook area of central of Birmingham. Healthcare for families living in this locality is organised and provided by the former HoB tPCT which covers the wards of Aston, Handsworth Wood, Ladywood, Lozells and East Handsworth, Nechells, Oscott, Perry Barr, Soho, Sparkbrook and Springfield (Heart of Birmingham teaching Primary Care Trust, 2009b). This locality has a multi-ethnic population with seven out of ten residents from a minority-ethnic group. The population is also disproportionately young, with approximately one third aged 19 years or younger (Heart of Birmingham teaching Primary Care Trust, 2009b). Children in this area tend to have multiple medical problems, some of which arise directly from deprivation, and some of which are normal healthcare problems exacerbated by poor access to services.

1.3.2 Greet community health centre

Located approximately 4.5 miles from BCH (see figure 1), Greet community health centre provides a range of primary and secondary care services to the local community. These include: rheumatology, ultrasound, MRI, X-ray, gynecology, minor surgery, cardiac rehabilitation and smoking cessation services. It also offers GP appointments and urgent care for those who need it but do not require a visit to the Emergency Department (Heart of Birmingham teaching Primary Care Trust, 2009a). A pilot outpatient clinic was established at Greet health centre by two Consultant General Paediatricians between September 2006 and February 2007. Since then, the clinic has continued to run, once per week by appointment.

1.3.3 Northfield / Kings Norton locality

Wychall family and children's centre is located on the border of Northfield and Kings Norton areas of south Birmingham. Healthcare for families living in this area is planned and provided by the former South Birmingham Primary Care Trust (SBPCT). This Trust covered the wards of Edgbaston, Hall Green, Harborne, Kings Norton, Longbridge, Moseley, Northfield, Quinton, Selly Oak, Weoley and Fox Hollies (NHS South Birmingham, 2010/11). Similar to Birmingham as a whole, SBPCT has a higher than national proportion of young people, particularly under 5's and 10 to 14 year olds. Although the rates of child poverty are lower than in HoB tPCT, there are 5 wards in SBPCT where >50% of families with children aged 0-16 claim benefits. These are: Kings Norton, Weoley, Bartley Green, Fox Hollies and Longbridge (South Birmingham PCT, 2003). Four of these are also the worst four wards in Birmingham for education deprivation, calculated by the number of children aged 16 or over not in full time education, rates of school absenteeism and percentage of children with English as a second language (South Birmingham PCT, 2003).

1.3.4 Wychall family and children's centre

Located approximately 7.4 miles from BCH (see figure 1), Wychall family centre brings together childcare, education, health, and employment services for families with children under five years old (Birmingham City Council, 2011). Their aim is to deliver a 'core purpose' which will:

“Improve outcomes and narrow the gaps, particularly in terms of identifying, reaching and supporting the families in greatest need to improve their: parenting capacity, health and wellbeing (including economic wellbeing), child development and school readiness. This is achieved through acting as a hub for the local community.” (Birmingham City Council, 2011, p.14)

Wychall family centre offers debt and benefits advice, Child and Adolescent Mental Health Services, parenting groups, job centre plus, information on tax credits and sexual health services. A General Paediatric satellite clinic was established there in January 2010 by a BCH Consultant General Paediatrician, who has subsequently retired. Another Consultant General Paediatrician has now taken over the clinic which runs once per week, by appointment. Initially a drop in clinic was also provided, but little demand led to its discontinuation.

1.3.5 Evaluation

Following the six month pilot at Greet health centre, a basic service evaluation was carried out. Patient survey data, conversations with parents and discussion between HOB tPCT and BCH since the inception of the clinic, indicated that the majority of attendees found the clinic to be ‘more convenient’ than the hospital in terms of parking (90%), transport (58%) and childcare arrangements (75%) (Buckle, 2007). A non-attendance rate of 10% was further reported for the clinic, in comparison with a concurrent rate of more than 30% at the main hospital site (Buckle, 2007). However, anecdotal reports suggest that attendance at the satellite clinic has worsened since the pilot study, and a recent analysis of data collected at the Wychall satellite clinic revealed that 12 out of 63 (19%) appointments were not attended in the year 2010 (Birmingham Children's Hospital NHS Foundation Trust,

2010). Evidence for paediatric satellite clinics therefore remains unclear and necessitates further investigation.

Figure 1: Map showing BCH and two satellite clinics



1.4 Summary

The aim of this study is to evaluate a new satellite clinic model implemented by Birmingham Children's Hospital for delivering consultant-led, General Paediatric outpatient care in GP practices and children's centres. There are several motivating factors for the hospital to place General Paediatric outpatient clinics in the community, including the conclusion of the Department of Health Darzi Review (2008b), which advocated the provision of services provided as 'close to home' as possible. Community-based clinics may also improve access to paediatric specialist care for families from differing ethnic and socio-economic backgrounds, thereby reducing health inequalities and non-attendance rates. In the longer term, providing outpatient services in the community would increase capacity at the main hospital which is currently limited. However, evidence regarding acceptability,

cost-effectiveness, health outcomes, attendance rates and satisfaction is unclear, especially in relation to a 'satellite' clinic model. The next chapter presents a more detailed account of the literature relating to CCTH and reviews it in relation to paediatric services, patient experience and theoretical concepts of place and space.

CHAPTER TWO

2 LITERATURE REVIEW

2.0 Introduction

In this review, literature relating to evaluations of Care Closer to Home (CCTH) as a new model of healthcare provision is examined. As Birmingham Children's Hospital (BCH) is considering a satellite clinic model for delivering community-based outpatient services, there is a focus on reviewing the evidence for 'specialist outreach clinics' within a UK paediatric healthcare context. However, due to limitations in the CCTH literature specifically relating to children's services, criteria for included studies was widened to also incorporate evaluations of adult specialist outreach clinics. This is followed by a review of literature exploring factors which might influence CCTH policy implementation and studies describing patient experiences of CCTH. Literature concerning paediatric CCTH is then discussed in more detail, before a summary of findings is given.

As improvements in patient satisfaction and experience are frequently cited as a justification for CCTH (DH, 2007), the second body of literature examined in this review relates to the emergence of patient satisfaction as an indicator of healthcare quality. Reflecting developments in policy and research, the concept of 'patient satisfaction' is critiqued in terms of its 'consumerist' nature. This leads to a consideration of 'patient experience' which is argued to be a more meaningful concept. As the findings from this project are intended to provide evidence on which to inform paediatric health service improvements, the benefits and limitations of different methods for capturing patient

experience are discussed, as are approaches for using patient feedback to make service improvements. Literature specifically relating to the inclusion of children's views in paediatric healthcare is presented, before findings are summarised.

Finally, in light of the central role given to 'place' in recent health policy reforms, and the resulting theoretical focus of this thesis, literature relating to the concept of 'Place and Space' within healthcare is reviewed. It is argued that the tendency to focus on CCTH as a philosophy of care has, in the past, led to a disregard of the importance of the physical place for health service-user and provider experience. However, as Moore et al (2013) identify, "all action has meaning only in the context of its surroundings" (p.151) and so, in this study, CCTH is considered a co-construction between philosophy and place. 'Place and Space' as theoretical concepts are thus examined in the third section of this review, both from phenomenological and social constructionist perspectives. Empirical studies exploring the role of place and space in healthcare are then considered, with a particular emphasis on children's health services where possible. A more detailed exploration of research concerning families' experiences of receiving specialist paediatric healthcare outside of a hospital setting is presented in the meta-synthesis of qualitative literature in chapter 3.

2.1 Search Strategy

A search of the available literature was conducted in the following databases: Ovid Medline, Science Direct, Health Management Information Consortium and Google Scholar. Various synonyms of keywords relating to the model of care (closer to home; outreach), patient experience and 'space' and 'place' were combined, with and without the terms 'child', 'parent' and 'family' to locate research. From this search, a number of articles were

identified. Abstracts were screened for relevance, and included if they discussed the provision and evaluation of a 'closer to home' model of care, patient experience and theoretical aspects of place and space. Despite a large body of literature however, it became apparent that children and young people were under-represented (Hargreaves and Viner, 2012, La Valle et al., 2012). Articles relating to adult services were therefore also included if they discussed patient experience in relation to measuring healthcare quality in the UK. In addition, online resources provided by The Kings Fund, the NHS Institute for Innovation and Improvement and The Excellence Framework for Patient Experience were searched, as were the reference lists of all included articles to identify further literature. Studies presented at relevant conferences (e.g. UK Health Services Research Network Symposium) were also included. This strategy identified a number of key texts including book chapters, primary research, systematic reviews, letters, Department of Health publications, commentaries and reports. These will now be reviewed.

2.2 Evaluations of Care Closer to Home

UK government policy has, in recent years, directed healthcare away from large hospital institutions and into local community settings, closer to patient's homes (DH, 2006).

Rationale for this initiative has included:

- Giving patients more choice, independence and control;
- Reducing the demand on hospital services;
- Reducing overall costs to the NHS;
- Improving the quality of care.

New service models were thus anticipated to deliver more clinically- and cost-effective care with higher rates of patient satisfaction. Alongside hospital-at-home, specialist outreach clinics (where hospital Consultants deliver outpatient care in community settings) have tended to dominate in the UK as a model for delivering CCTH (Gruen et al., 2009). This is perhaps unsurprising given the context of the polyclinic programme advocated by Lord Darzi in his review of the NHS (DH, 2008b). Other models gaining attention include General Practitioners with Special Interests (GPwSI) and 'virtual outreach' such as telemedicine (Royal College of Physicians, 2012). Evidence for CCTH will now be summarised, with particular focus on specialist outreach clinics.

2.2.1 Care Closer to Home demonstration sites

A range of initiatives have set about implementing CCTH policy recommendations, including the establishment of 30 demonstration sites moving health services from hospitals into the community, using five different models, within six adult clinical specialties (ear, nose and throat; trauma and orthopedics; dermatology; urology; gynecology, and general surgery) (National Primary Care Research and Development Centre, 2007). Using interviews with service providers, patient surveys and economic evaluation methods, Sibbald et al (2008) evaluated these demonstration sites in terms of factors that helped or hindered the design of new services and the impact of CCTH on patient access, quality of care and NHS costs. Although the authors found that different service models affected staff training, cost and service design in different ways, three main challenges for providing CCTH were identified:

- 1) Deciding on which services to move;
- 2) Finding suitable service delivery sites, purchasing new equipment and managing the loss of economies of scale;
- 3) Changing healthcare professional roles and providing adequate training and supervision.

Factors facilitating the development of new CCTH services included:

- 1) Securing support from key stakeholders;
- 2) Maintaining good working relationships across care sectors;
- 3) Having strong leadership, including local CCTH champions.

Observed patient benefits included: shorter waiting lists, reduced waiting times, increased patient satisfaction and improved access. The authors found no evidence to suggest adverse impacts on quality of care; however it was noted that health outcomes and objective measures of clinical competency were unavailable and therefore not included in the evaluation. In terms of the wider healthcare economy, the potential for CCTH to generate increased referrals to specialist services was also highlighted. The authors concluded by recommending that further consideration be given to quality, safety, cost and staff training.

2.2.2 Evaluations of Specialist Outreach clinics

As noted above, specialist outreach clinics have dominated as a model for delivering CCTH in the UK (Gruen et al., 2009). Nevertheless, service evaluations demonstrate mixed

findings for this approach. In a review of CCTH strategies, originally published by Roland et al (2006) and later summarised by Sibbald et al (2007), studies exploring the shift of acute services to community settings were grouped into five types:

- 1) **Transfer** of care to community-based practitioners: substitution of services delivered by hospital clinicians for services delivered by primary care clinicians (e.g. GPs with Special Interests);
- 2) **Relocation** of specialist outpatient care from hospitals to community settings without changing the people who deliver the service (e.g. specialist outreach clinics);
- 3) **Liaison**: Joint working between specialists and primary care practitioners;
- 4) **Professional behaviour change**: Interventions intended to change the referral behaviour of primary care practitioners;
- 5) **Interventions not involving primary care**: intermediate care services (e.g. community mental health teams, hospital-at-home).

A review of these approaches revealed that transferring secondary-care services to primary care practitioners eases outpatient demand, but negatively affects care quality as community-based practitioners may not have the skill set needed to manage cases previously cared for by the hospital. In contrast, relocating Consultants within community settings (specialist outreach clinics) and joint working between primary and secondary care sectors (liaison), can improve access to specialist care, without jeopardising quality. However this approach was found to be ineffective for reducing hospital outpatient demand, as well as leading to increased costs from the loss of economies of scale. Many of the studies included in this review focused on outpatient care and chronic disease management, concluding that shifting hospital-based services into community settings has

the potential to improve patient access to specialist care, but risks reducing quality and increasing costs.

Evaluations of the 'relocation' specialist outreach model (Bowling et al., 1997, Bond et al., 2000, Bowling and Bond, 2001) have shown that patients prefer community-based clinics as they deliver more satisfactory processes of care (e.g. convenience, waiting times and time on the waiting list), but that findings are less clear in terms of improvements to inter-professional communication and care co-ordination. A survey by Black et al (1997) for example, found that a lack of GP involvement in outreach clinics meant that the potential for knowledge transfer was often unrealised. This suggests that a shift in the provision of hospital services to primary care does not, in itself, influence how Consultants and GPs interact with one another. Nevertheless, over half of the GPs surveyed by Bowling et al (1997) felt that their knowledge had increased as a result of the outreach clinic, despite a lack of any formal training.

In addition to these evaluations, two systematic reviews of outreach clinics in primary care have been conducted; one synthesising UK studies on the benefits of holding specialist outreach clinics in primary care (Powell, 2002) and an international Cochrane review exploring the effect of specialist outreach clinics on access, quality, health outcomes, patient satisfaction, use of services, and costs (Gruen et al., 2009).

Powell (2002) included fifteen evaluations of adult and paediatric services in his review. Findings revealed outreach clinics to have benefits of improved GP-specialist communication as well as better patient experience and access. Drawbacks of the model included: administrative and accommodation costs and inefficient use of the Consultant's

time. Although studies indicated higher patient satisfaction and preference for outreach clinics, no differences were shown for self-reported health outcomes. However outreach clinics were found to be more expensive to run. These findings thus question whether improvements in the quality and efficiency of healthcare can justify increased costs in the absence of any significant impact on health outcomes (Bowling, 1997). In his conclusion, Powell suggested that it was up to healthcare commissioners and providers to decide whether the advantages of outreach clinics (in terms of patient access and experience) outweighed the additional financial costs.

In their review, Gruen et al (2009) identified 137 publications from a search of specialist outreach interventions, covering a range of specialties, countries and settings. Analysis of nine included studies again revealed that the 'simple shifted outpatient style' of specialist outreach clinics can improve access, but that evidence of impact on health outcomes was inconclusive. Specialist outreach as part of a more complex and multifaceted intervention (e.g. involving education or collaboration between clinicians) however, was associated with more efficient care, improved health outcomes and a decreased use of inpatient services. The authors thus concluded that any additional costs of outreach services may be balanced by improved access and health outcomes.

In support of these findings, a more recent UK survey and narrative review of four different models of CCTH (practitioners with special interests, specialist outreach clinics, telemedicine and intermediate care) (Royal College of Physicians, 2012) found that CCTH significantly improves patients' satisfaction with services, as well as improving their attitudes to and knowledge of their own health conditions and treatments. Although this

report found patient acceptability to be high for CCTH, patients who were assigned to telemedicine (consultations via videoconferencing link) maintained a preference for more traditional face-to-face consultations. Moreover, for the four models of care considered, CCTH was found to be as safe and clinically effective as hospital care. A survey of NHS staff on their views of providing specialist services in community settings also revealed healthcare professionals to hold generally positive views on CCTH, with many valuing the initiative as an opportunity to provide patients with convenient, accessible and integrated care. Nurses in particular described their enthusiasm for collaborating with and learning from specialists.

In sum, evaluations of specialist outreach clinics have produced mixed findings. These demonstrate that as a model of care, outreach can add value, by improving the processes of care (e.g. waiting times, convenience and access), but evidence for the effect on patient health outcomes is limited, and, when used as part of a simple intervention, costs are generally higher. However, many of the studies reviewed reported small scale projects with little indication of long term outcomes. Caution is therefore recommended in generalising the findings to other services and populations. In addition, rather than substituting hospital care, specialist outreach clinics were often provided as an additional service. This may account for some of the increases in demand and cost.

2.2.3 Factors affecting implementation

A report from the Audit Commission (2009) suggested that the shift from hospital to community-based care had been slower than predicted, and that despite being a key strand of government policy, the implementation of CCTH remains inconsistent across NHS

settings. In a rapid review of the literature on shifting diagnostic testing, day hospitals, and outpatient appointments from hospitals into the community, Singh (2006) identified that studies reporting successful implementation of CCTH had a number of features in common.

These included:

- Empowering people to take responsibility;
- Focusing on changing professional behaviour;
- Training to support staff in new roles;
- Increasing staff competencies and not assuming proficiency;
- Adequate investment in services;
- Adequate timeframes in which to test services;
- Realistic targets;
- Involvement of all key stakeholders;
- Whole systems approaches;
- Providing care based on levels of need;
- Not running (competing) services in parallel;
- Not assuming that shifts will reduce costs.

Echoing Gruen et al's (2009) findings, these factors indicate that in order to reduce reliance on secondary care, CCTH requires a multifaceted intervention rather than simple relocation. Singh (2006) also argued that an established culture of quality improvement and strong leadership are crucial to implementing the kinds of reforms required for successful

implementation of CCTH, as are the attitudes and behaviours of healthcare professionals. Investing time to examine barriers and facilitators to service re-design, including consideration of changing professional roles, were therefore identified as key success factors.

In a complementary document, Parker (2006) reviewed evidence of local NHS experiences of shifting care from the hospital to the community to identify examples of best practice. Capturing a range of models across the NHS, the report demonstrated that successful shifts in care involve a 'whole system' approach to new service development (for example bringing Consultants and GPs together from a range of specialties in order to develop Local Delivery Plans). In addition to the key factors identified by Singh (2006), Parker also recognised that high quality information technology systems create the right incentives for promoting integration across care sectors.

2.2.4 Patients' experiences of Care Closer to Home

The majority of evaluations of CCTH from a patient perspective have used surveys to try to quantify the effects of service reconfiguration in terms of the processes of care (patient satisfaction, access, convenience). Fewer evaluations have been carried out using methods to capture the qualitative aspects of these new models. One study which has, compared the experiences of patients receiving chemotherapy treatment in a traditional, hospital-based outpatient clinic and in a new, closer to home mobile chemotherapy unit (Mitchell, 2011). In this study, several participants described how a reduction in travelling time and efficiency of processes on the mobile chemotherapy unit enhanced their quality of life. As a less intrusive model of treatment delivery, the mobile unit was found to encourage a sense

of normality at a time when patients were experiencing considerable disruption and uncertainty. Chemotherapy closer to home thus helped patients to regain some control during their treatment period, including for some, being able to continue to work. As one participant describes:

“I usually have a 10 o’clock appointment so I leave here about half 9, twenty to They’re usually ready for me to go on the bus as soon as I get there, I have the treatment and I’m usually left there by 11. I drive myself, it doesn’t affect me, it doesn’t make me feel ill.” (Mitchell, 2011, p.22)

In contrast to the main hospital clinic, the mobile unit was also experienced as calmer and more sociable, due to smaller clinic numbers and natural light from the unit windows. The author concluded that as an alternative model of care delivery, the mobile Chemotherapy unit was highly acceptable to patients, improving a number of aspects of their treatment and recovery experiences. Similar descriptions of the impact and meaning of outreach services on patient’s lives are found in studies exploring haemodialysis (Bevan, 2007).

2.2.5 Paediatric Care Closer to Home

Many of the evaluations of CCTH to date focus on adult health services (Bowling et al., 1997, Black et al., 1997, Bond et al., 2000, Bowling and Bond, 2001, Sibbald et al., 2007, 2008) which may or may not be transferable to the provision of care for children and young people. Studies specifically evaluating the movement of paediatric specialist services into community settings however are few, particularly those exploring acceptability to parents, patients and health professionals. There are therefore gaps in existing knowledge about the appropriateness of specialist paediatric outreach clinics and the extent to which any of the apparent benefits are justified (McLellan, 1995).

Focusing on preventing inpatient admission and facilitating early discharge from secondary care, Parker et al (Spiers et al., 2012, Parker et al., 2011a) carried out an evaluation of UK service models providing CCTH for children and young people. This study comprised a systematic review (Parker et al., 2012, Parker et al., 2011b), national survey of CCTH provision, four in-depth qualitative case studies and a cost-effectiveness analysis. Findings of an updated systematic review of paediatric homecare (Parker et al., 2002) suggested that CCTH provides similar clinical outcomes for children whilst placing little extra burden on families. Paediatric homecare was also shown to reduce NHS costs particularly when inpatient admission was prevented or the length of a child's stay in hospital was reduced (Parker et al., 2012). This finding echoes studies comparing hospital-at-home with hospital-based care in adult services (Munton et al., 2011).

In attempting to describe the various models of paediatric CCTH in the UK, the authors noted that descriptions were "disappointingly vague on service delivery and organisational features of the service, giving little guidance for best practice" (Parker et al., 2011a, p.29). Nevertheless, a national survey did identify a range of services providing paediatric home care, with children's community nursing teams being the most common. Analysis of data from the case study sites also revealed that service providers viewed CCTH as a fundamental right of the child which was beneficial to families in supporting a sense of 'normality'. This enthusiasm for paediatric CCTH however was found to be frequently offset by difficulties at organisational and practice levels, which hampered service development. Interviews with parents also revealed their preference for paediatric healthcare at home, citing emotional support from healthcare professionals as highly valued, especially when taking on responsibility for their child's care (Spiers et al., 2011).

Although this national, mixed method study offers a valuable contribution to the under-developed evidence base for paediatric CCTH, the focus on ‘inpatient’ care delivered at home fails to address gaps in the literature regarding alternative settings for paediatric outpatient care. Moreover, only one child was recruited for the qualitative arm of the study; hence the views and experiences of young people on receiving CCTH remain unknown, as they may differ significantly from their parents (Lindeke et al., 2009).

2.2.6 Paediatric Outpatient Care

Although shifting care out of hospitals and into community settings is advocated in policy documents, there is a paucity of evidence describing or evaluating paediatric outpatient CCTH. This could be explained by the ‘low profile’ outpatient services have in comparison to other areas of clinical practice (Dodd and Newton, 2001) and the under-representation of children and young people in the literature more generally (La Valle et al., 2012).

One study that has explored the provision of Consultant-led paediatric outreach clinics (Spencer, 1993) has reported that such models of service provision could improve access, whilst “facilitating effective patient management and clinical decision making particularly in deprived areas where the need is greatest” (p.500). In this study, monthly clinics were established, taking referrals from GPs and health visitors for new and follow-up patients, creating a total of 18 clinics over a ten year period. In order to fulfill aims of mutual education between practitioners, GPs were often present during consultations, although it was acknowledged that this was sometimes impractical. A three-part evaluation of these specialist outreach clinics (new patient review, GP survey, patient questionnaire) revealed mixed findings. For instance, while access to specialist care was increased, moving clinics

closer to families' homes did not impact on non-attendance rates and, while parents appreciated the choice of setting, many preferred to continue to visit the hospital. This suggests that outpatient appointment non-attendance has deeper roots than distance to travel and that parental preference for their child's treatment may be different to those for themselves. Moreover, contrary to studies in adult services, close working relationships between specialists and generalists were developed, which resulted in knowledge and expertise being shared amongst practitioners for the benefit of children (Heath, 2008).

In addition to consumer outcomes of high satisfaction and levels of acceptability, a more recent study into the effectiveness of community-based child and adolescent mental health clinics (Day and Davis, 2006) also found clinical benefits for patients. Using a quasi-experimental design to compare an intervention outreach group with waiting list controls, findings revealed that children attending outreach clinics had significantly lower distress and problem severity, although improvements did not extend to parental stress.

2.2.7 Summary of Care Closer To Home Evaluations

This review demonstrates that outpatient CCTH has the potential to deliver patient benefits of improved processes of care (e.g. shorter waiting times, reduced travelling, improved access and satisfaction). Effects on patients' health outcomes and knowledge transfer between practitioners however are less clear, as is evidence that moving CCTH would result in cost savings for the NHS. A further problem identified is the methodological complexity of comparing diverse service models across patient groups in different social and economic contexts (Munton et al., 2011).

Relatively few studies have explored or evaluated the implementation of paediatric outpatient CCTH, resulting in evidence for the optimal paediatric outpatient service model remaining unclear. Moreover, very little research has explored the qualitative dimensions of shifting CCTH from a family perspective. Such an approach could offer new insights into service preference and utilisation, including a more comprehensive understanding of non-attendance at appointments. Qualitative literature on families' experiences of receiving secondary care outside of a hospital setting is revisited in greater depth in chapter 3.

2.3 Patient experience

Improvements in healthcare quality from a patient perspective is cited as one of the key benefits of moving CCTH (DH, 2006). Such improvements have been a high Government priority since the 1990s when a ten year improvement plan for health was outlined, promising more patient choice and greater user involvement in NHS service planning (Williams et al., 1998). At the same time a new, national patient survey was developed, requiring every NHS provider to capture their patient's satisfaction with the services they received. This programme was thus designed to "enable the health service to measure itself against the aspirations and experience of its users, to compare performance across the country, and to look at trends over time" (DH, 1997). Nevertheless, research has shown that capturing satisfaction ratings did not lead to the quality improvements that were expected (Cleary, 1999).

2.3.1 What is patient satisfaction?

Although commonly cited, there is little consensus on a working definition of the term 'patient satisfaction' (Edwards and Staniszewska, 2000). Sometimes it is used in relation to health outcomes (satisfaction with health status following treatment) and sometimes in relation to the processes of care (satisfaction with the way in which care was delivered). According to Coulter (2005) the concept of satisfaction reflects "three variables: the personal preferences of the patient, the patient's expectations, and the realities of the care received" (p.1). Despite an increase patient satisfaction research however, measures have been subject to considerable methodological and conceptual criticism (Coulter, 2005), suggesting they are neither sensitive nor useful (Delnoij, 2009). One of the problems with satisfaction as an indicator of quality is its ambiguity. As a multi-dimensional concept, 'satisfaction' is based on a relationship between preferences, expectations and concrete experiences, which may themselves all be influenced by patient characteristics and prior experiences. Moreover, a numerical score of satisfaction says little about a service-user's actual experience of care, or which areas they would like to see remain or improved (Edwards and Staniszewska, 2000).

Studies show that patient satisfaction surveys tend to report consistently high levels of satisfaction, with few patients expressing dissatisfaction (Williams, 1994). Several qualitative studies (e.g. Williams et al., 1998, Dougalla et al., 2000, Edwards et al., 2004) have also found that even when satisfaction is reported as high on surveys, in-depth interviews can expose negative experiences not reflected in the survey. There are several possible reasons for this. First, patients who experience dissatisfaction with one health

service provider may choose to access another provider who can meet their needs, suggesting that the proportion of dissatisfied patients in a healthcare setting at any one time could be quite small (Fakhoury, 1998). Second, patients may be reluctant to record or pursue expressions of dissatisfaction due to their dependency on a service, particularly if they perceive that negative evaluation would have a detrimental impact on their relationship with the service provider (Owens and Batchelor, 1996). Third, patient expectation that nothing will change as a result of their documenting dissatisfaction may also discourage them from doing so.

Authors exploring how patients construct their evaluations of care have further questioned the assumption that satisfaction surveys embody service-user evaluations at all. Williams et al. (1998) for example used patient satisfaction questionnaires and individual interviews within the same study, with the same participants to explore patient evaluations of a community mental health service. The authors found that while patients could describe negative healthcare experiences within interviews, they commonly reported high rates of satisfaction on surveys regarding similar aspects of care. The authors suggested that explanation for this might relate to patients' desires to avoid blaming individuals by making allowances for poor care. Using a similar mixed-methods approach but within elective orthopedic surgery, Edwards et al (2004) identified three factors that influenced the transformation of negative experiences into to positive evaluations. These were: "(i) the relative dependency of patients within the healthcare system; (ii) their need to maintain constructive working relationships with those providing care; and (iii) their general preference for holding a positive outlook" (p.159). Findings led to a recommendation of

using methods of inquiry which access the patients' untransformed or pre-reflective healthcare experiences, rather than their ratings of satisfaction.

Other limitations of satisfaction surveys highlight that questions may be restricted to those aspects of a service important to the inquirer rather than the patient (Edwards and Staniszewska, 2000). Consequently, questions within a survey may not correlate with patient values, and may potentially miss out issues that are important to patients. Finally authors have suggested that patients may not be aware of the standards they should be expecting (McIver, 1993) or have few expectations on which to base an evaluation (Owens and Batchelor, 1996).

Findings from these studies and others therefore critique satisfaction surveys for failing to meet minimal standards of conceptual or methodological rigour, rendering them inadequate as indicators of patient experience and unable to provide an accurate evaluation of healthcare quality. As a result, measuring the quality of healthcare from a patient perspective has moved towards eliciting more objective accounts of specific experiences of healthcare (Cleary, 1999, Coulter, 2006).

2.3.2 What is patient experience?

Patient experience is increasingly seen as the third arm of quality, alongside safety and clinical effectiveness (National Institute for Health and Care Excellence, 2012). As a particular facet of quality, patient experience is multi-dimensional; it is about both the functional (e.g. access, waiting, food, noise) and relational (e.g. respect, dignity, empathy) aspects of care (Iles, 2011). Informed by a recent King's Fund report, commissioned to

explore 'what matters' to patients in terms of their healthcare experience (Robert and Cornwell, 2011), the NHS National Quality Board in 2011 established a working definition of 'good' patient experience based on an adaptation of the Picker Institute 'Principles of Patient-Centred Care'. This included:

1. Respect for patient-centred values, preferences, and expressed needs;
2. Co-ordination and integration of care across the health and social care system;
3. Information, communication, and education on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;
4. Physical comfort and clean and comfortable surroundings;
5. Emotional support for such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances;
6. Welcoming the involvement of family and friends in decision-making and demonstrating awareness and accommodation of their needs as care-givers;
7. Transition and continuity as regards information that will help patients care for themselves;
8. Access to care.

This framework can be used to direct service improvement initiatives by, for example, helping to define what questions to ask patients in surveys and interviews. A newly developed National Institute for Health and Care Excellence (NICE) Quality standard for patient experience (2012), also details the components of good patient experience. Its 14 statements include aspects such as dignity and kindness, the right to care that is personalised to patient need, shared decision-making, and the right to a second opinion.

Nevertheless, although these guidelines provide a basis for understanding what good patient experience should look like, they fail to address the key issue of how to measure it and provide feedback in a meaningful way.

In order to identify the different components of healthcare experience that matter to patients, Entwistle et al (2012) conducted a critical interpretive synthesis of literature on health service delivery from a patient perspective. In this study, the authors found that patient's experiences could be divided into two categories: (i) what health services and staff are like and what they do; (ii) how patients feel as a result of their interactions with health services and staff. This extends existing frameworks of what matters to patients (e.g. Institute of Medicine, Picker institute) to include *why* such experiences might matter. Drawing on the capabilities approach (Sen, 2009), the authors concluded that patient's experiences of healthcare delivery matter because they affect the quality of people's lives. In their resulting conceptual map, the characteristics and actions of healthcare providers were thus related to patients' experiences of "being enabled (or not) to feel, be and do what they value feeling, being and doing - during healthcare contacts and beyond" (p.8).

2.3.3 Patient experience as a driver for quality

Using 'patient experience' as a driver for quality improvement has become prominent in recent reforms, emphasising experience as a core dimension of good quality care (National Institute for Health and Care Excellence, 2012). The fourth domain of the NHS Outcomes Framework for example, is "ensuring that people have a positive experience of care" (DH, 2011b, p.5). National initiatives aimed at improving patients' experience of healthcare have included NHS Choices, an information service that helps people to manage decisions about

their health and care, as well as PALS, a patient advice and liaison services which aims to work with patients and families to resolve any concerns they might have about their care. Despite these initiatives, further work is needed. This is signaled by the Government in its White Paper, 'Equity and excellence: liberating the NHS' (DH, 2010a) which stated that more emphasis needs to be placed on improving patients' experience of NHS care. The recent introduction of a 'friends and family test' further aims to make sure all NHS organisations maintain an ongoing focus to improve patient experience.

2.3.4 Approaches to measuring patient experience

In their review of what NHS organisations in England currently measure in relation to what matters to patients, the King's Fund identified a range of methods for collecting, analysing and reporting patient experience data across 12 case study sites (Robert and Cornwell, 2011). Methods included a variety of surveys, the development and use of real time data collection devices and the collection of patient stories through in-depth interviews. These will now be considered in turn.

2.3.4.1 Surveys

The Picker Institute has designed surveys to obtain data on specific dimensions of patient experience. Following criticism of patient satisfaction surveys however, patients are asked questions about their recent experience with a particular organization, service or clinician. In order to elicit information on what occurred (experience), rather than the patient's *evaluation* of what occurred (satisfaction), questions include asking patients to report on processes or events during a specific episode of care. Focusing on the details of patients'

experience in this way is suggested to help identify areas for improvement. Although patients are still restricted to answering fixed questions, the Picker patient experience survey is based on findings from in-depth qualitative research with patients (Coulter, 2005). This suggests that it may be more likely to include issues that are important to patients. Although these paper-based survey methods are a cheap and convenient method of sampling a large group, postal questionnaires can result in poor response rates (Brown et al., 2009) and may still miss out matters that are pertinent to specific patients or services.

2.3.4.2 Real time data collection devices

Increasingly NHS organisations are using technology-based devices such as computer screen kiosks and hand-held key pads to collect patient experience data in 'real time'. These devices have advantages of being able to capture immediate patient feedback on an ongoing basis, relatively quickly and inexpensively. They also have the potential to improve services as staff identify with the "freshness of the information and perceive it as having greater validity" (Brown et al., 2009, p.40), particularly if it is in the service-user's own words. Appraisals such as this have led to a requirement of all hospitals from 2009 to make use of real-time techniques to collect patient experience data for the purposes of driving quality improvements (DH, 2011b). However, like patient surveys, real-time data collection can constrain the types of questions asked of patients, prioritising issues from an organisational, rather than a patient perspective. As they are often shorter than surveys, concerns are also raised about the quality of data collected and how useful it can be for driving service improvements. Studies have subsequently highlighted the need to

complement real-time quantitative data with in-depth qualitative data, which provides a richer picture for how services can be improved (Brown et al., 2009, Cornwell, 2009).

2.3.4.3 Patient stories

Patient stories draw on the recognition that patient narratives offer possibilities as a powerful way to improve care by stimulating health service provider reflection and service change (Hurwitz et al., 2004). Robert and Cornwell (2011) highlight a number of observations regarding the value of patient stories. For example, raising issues that NHS organisations or teams were not already aware of and highlighting that patients' actual concerns do not necessarily correlate with staff perceptions of their concerns. The authors thus conclude that patient stories provide a more "vivid and immediate" (p.21) medium for communicating experiences, creating an emotional impact to motivate action.

In a review of four approaches to the use of narrative in quality improvement research (interviews; story gathering; case study; and collective sense-making), Greenhalgh et al (2005) suggest that the "richness and flexibility of the story form make it an enticing addition to the researcher's toolkit in the 'hard-to-research world' of quality improvement" (p.448). They further identify ten advantages of using patient narratives for improving health services (see figure 2). Different studies report using stories from patients or carers to make recommendations, for example, in areas such as critical-care (Todres et al. 2000), palliative care (Turner et al. 2000), breast cancer care (Mckinley et al. 2001) and in cardiac care (Gilbert & Walker, 2001). Although these studies vary methodologically, all use patient stories to stimulate ideas for improvement.

Figure 2: Advantages of using patient stories for improving health services

Ten unique selling points of stories in quality improvement research (compiled from various sources) Taken from Greenhalgh et al (2005)
1) Stories are perspectival. They are told subjectively from the viewpoint of the narrator, thus drawing attention to the individual rather than the institution.
2) Stories make sense of experience. The structuring devices of time and plot retrospectively align events and actions so as to modify mental schemas.
3) Stories are non-linear. They convey multiple and complex truths, depicting events as emerging from the interplay of actions, relationships and environments.
4) Stories are embedded in a context. A particular story about what went on in an organisation is nested within an over-arching meta-narrative of “what tends to go on around here”.
5) Stories have an ethical dimension. They depict both acts and omissions, reflecting society’s expectations about what a “good doctor” or “good daughter” should have done in such circumstances.
6) Stories bridge the gap between the formal codified space of an organisation (roles, job descriptions, lines of accountability) and informal uncoded space (relationships, feelings, “unwritten rules”, subcultures).
7) Stories offer insights into what might have been. The imaginative reconstruction of the end of a story allows us to consider different options for change.
8) Stories are action-oriented, depicting what people did (and what happened to them), and also igniting and shaping their future action.
9) Stories are inherently subversive since they embrace the tension between the canonical (i.e. an organisation’s standard routines and procedures) and the unexpected (i.e. new ways of thinking and working).
10) Leadership is related to storytelling. “Leaders are people who tell good stories, and about whom good stories are told.”

2.3.5 Linking patient experience to service improvement

Although NHS organisations use a variety of approaches to capture patient experience, all have been criticised for making little use of this information to drive-up quality (Robert and Cornwell, 2011). According to Berwick et al (2003) measures of patient experience can improve care quality through two means; selection or change. Selection occurs when public

exposure of poor quality care stimulates patients or their advocates (e.g. GPs) to select alternative, better performing providers. Change occurs when feedback from patients or commissioners stimulates providers to engage in their own quality improvement initiatives (Delnoij, 2009). Evidence on commissioners' actions to improve patient experience (for example via CQUIN) however, is limited and their influence over service quality is currently reported as under-developed (Robert and Cornwell, 2011).

Whilst considerable attention is paid to developing measures of patient experience, transforming feedback into service improvements remains a challenge for the NHS, and as the NHS Confederation observes (2010), delivering better, patient-centred care in hospitals may require a major cultural shift. Robert and Cornwell (2011) cite further challenges including political, cultural, educational, emotional and technical difficulties. Nevertheless, they also note that NHS organisations are at an early stage on their quality improvement journey. As well as capturing patient experience then, there is also a need to develop practical ways to implement patient-led service improvements. Some of the approaches already developed include: the Discovery Interview Process (Wilcock et al., 2003); Experience-based design (Bate and Robert, 2006); and the Patient and Family Centred Care Methodology (DiGioia et al., 2012). These will now be reviewed.

2.3.5.1 Discovery Interview Process

Developed by the Coronary Heart Disease Collaborative, Discovery Interviews involve gathering patient and carer stories to stimulate service improvement activities such as 'Plan-Do-Study-Act' (PDSA) cycles (Bridges et al., 2008). Data collection is in the form of individual interviews with the aim of enabling patients to directly tell their story. Prior to

the interview stage a 'spine' is devised (with input from service-users) to guide interviewees through key stages of their experience. Transcripts are then used in their 'raw' form to identify areas for service improvement. Although formal evaluation of the Discovery Interview technique is limited (Bridges et al., 2008), one study has used a range of methods to evaluate implementation of the process across 30 Coronary Heart Disease Collaborative sites in the UK (Matrix, 2005). Findings revealed that Discovery Interviews can have a positive impact on developing a patient-centred culture in the NHS, but that service improvements do not automatically occur wherever Discovery Interviews are implemented (Matrix, 2005). Other studies support these findings regarding patient-centred practice (Wilcock et al., 2003) and additional changes in hospital policy (Brown et al., 2004).

2.3.5.2 Experience-based Design

Bate and Robert (2006, 2007) call for approaches to health service improvement that position patients and providers as collaborators aiming to design experiences rather than services (Bate and Robert, 2007). Within a design framework, the Experience-based Design (EBD) approach aims to capture the experiences of various stakeholders (e.g. patients, carers, families and staff), by conducting observations and filmed interviews. Interviewees are asked about their care journey and also about the emotional journey they experienced whilst in contact with a particular service. Staff then watch the filmed interviews with service-users to understand their experiences and to identify 'touch points' for improvement and re-design. The methodology can be used in any setting, and can be applied to the whole or specific parts of the patient journey. Services piloting the EBD methodology include: head and neck cancer outpatient services (Bate and Robert, 2007),

district nursing services (Robert and Cornwell, 2011) and paediatric emergency care pathway (Birmingham Children's Hospital , 2012). Advantages of this method relate to the amount of material that can be generated for reflection from a small sample of individuals, and also the inclusion of input from service-providers as well as users.

2.3.5.3 Patient and Family Centred Care

Originally developed and implemented in the USA, Patient and Family Centred Care Methodology and Practice (PFCC M/P) (DiGioia et al., 2012, DiGioia and Greenhouse, 2012) tracks patients through a particular area of care and draws on this learning to improve patient and staff experience. Six steps are outlined to evaluate, co-design, and transform care in partnership with patients and families:

1. Select a care experience needing improvement;
2. Establish a guiding council;
3. Evaluate the current state;
4. Develop a permanent working group;
5. Create a shared vision of the ideal experience;
6. Identify improvement projects to address the gap between the current and ideal experience.

The authors advocate evaluating the 'current state' (step 3) by exploring care experiences through the eyes of patients and their families. This is suggested to be carried out using a variety of methods from the PFCC toolkit, such as shadowing service-users in real-time throughout their whole care experience. The person shadowing records their observations,

as well as patient responses to questions about how they are feeling or whether they understand what is happening. Similar to other approaches, it is argued that focusing on the emotive effects of a care experience creates a sense of 'urgency' for change (DiGioia and Greenhouse, 2011). To complete the cycle, changes are evaluated and the process repeated. As part of their 'Point of Care' programme, the King's Fund are currently working with NHS organisations to implement PFCC on projects to improve the experience of surgical and medical services at Alder Hey Children's Hospital and to improve the experience for children on neuromuscular and gastroenterology care pathways at Great Ormond Street Hospital.

2.3.6 Lifeworld-led healthcare

Although there are subtle differences in these methodologies, what is clear is the move towards gathering patient narratives of actual experiences, rather than using predetermined measures to obtain service-user evaluations. Nevertheless, a weakness of the methodologies summarised above, is the lack of a rich and robust qualitative data analysis phase, using a recognised theoretical framework (Greenhalgh et al., 2005). This could impact on how the findings are viewed, as well as leading to healthcare systems which "measure quality in ways that are superficial" (Todres et al., 2007, p.55). In order to achieve credibility, Todres et al (2007, 2009) reiterate the need for approaches with greater philosophical depth, that produce findings which are textured by the 'aesthetic qualities of living' (Todres, 1998).

Retaining the focus on humanised forms of care, a 'Lifeworld-led care' approach has been proposed to inform care at practice and policy levels using data that is grounded in the

qualitative experiences of people (Todres et al., 2007, Dahlberg et al., 2009). The strength of this framework lies in its philosophical foundation in phenomenological philosophy, emerging from the work of Edmund Husserl (1954/1970). Husserl was a philosopher and mathematician who became concerned about the inadequacy of quantitative measures for capturing the qualities of human experience. Building on his consideration of what makes up the human experience of life, five essential elements have been articulated: time, space, embodiment, inter-subjectivity and mood (Todres, 2005, 2007). The concept of 'Lifeworld-led care' embraces these existential characteristics of the human world to guide understanding of patients' "experiences of health and illness, their shared and individual journeys and their interactions with others" (Todres et al., 2007, p.58). Data collection focuses on obtaining detailed descriptions from participants of their experiences of the phenomenon under investigation and analysis incorporates descriptive phenomenological (e.g. Giorgi, 2009, Ashworth, 2003) or more interpretative approaches (e.g. Van Manen, 1990, Smith et al., 2009).

The Lifeworld framework is appropriate for exploring the experiential dimensions of healthcare, as understanding is grounded in both the shared and unique aspects of participant's experiences. As Shaw (2012a) points out, this emphasises the person as a unique individual, who also functions within the organisational and societal structures of a shared world. Studies using lifeworld theory have explored phenomena such as caring for a partner with Alzheimer's disease (Todres and Galvin, 2006), being dependent on haemodialysis treatment (Herlin and Wann-Hansson, 2010) and the experience of distress in hospital settings (Berglund et al., 2012).

2.3.7 Involving children and young people in healthcare

The Kennedy Report (2010) suggested that satisfaction with healthcare outcomes and processes should be the “single criterion for measuring the quality of the NHS’s services for children and young people” (p.88). Policies including: the National Service Framework for Children, Young People and Maternity Services (DH, 2004), Every Child Matters (Department for Education and Skills, 2004) and ‘You’re Welcome’ Quality Criteria for Young People Friendly Health Services (DH, 2011d) also support the involvement of young people in planning service improvements and decision making. Despite these recommendations however, children and young people (below the age of 16) have to date, been excluded from national NHS surveys exploring user satisfaction (Hargreaves and Viner, 2012). This has resulted in a large gap in the evidence-base used to inform paediatric health policy and service provision. As Hargreaves and Viner (2012) explain:

“The views of under 16s and their families have largely not been included in national surveys, contributing to less than 0.6 per cent of survey respondents since 2001 and none since 2004. Young people aged 16-24 are included in surveys, but they rate their care significantly lower than adults across all domains of emergency department and primary care, and most domains of inpatient care.” (p.4)

Nevertheless, recognising that children and young people are a specific population with unique care needs (Aynsley-Green et al., 2000), a number of smaller scale studies have explored paediatric patient involvement in terms of what different aspects of healthcare mean to children and young people (Coates-Dutton and Cunningham-Burley, 2009), as well as gaining their participation in the design of new healthcare environments (e.g. Coad and Coad, 2008, Coad et al., 2008, Cooke, 2004).

A recent evidence synthesis of children's views on health service provision (La Valle et al., 2012) carried out to inform the newly developed Children and Young People's Health Outcome Strategy (Children and Young People's Health Outcome Forum, 2012), identified a number of themes in relation to young people's experiences of primary and secondary care. These included that:

1. Healthcare staff often communicate with parents rather than in a way that children can understand;
2. Staff often do not treat children with respect;
3. Staff often fail to include children in decisions about their healthcare;
4. Children often feel they are cared for in unsuitable and unfriendly environments.

A focus group study conducted in Scotland with 25 paediatric service-users (Coates-Dutton and Cunningham-Burley, 2009) also found overlapping areas that were key to young people having a good patient experience. These were:

1. Access and waiting;
2. Better information about health and healthcare;
3. Environmental needs in healthcare settings;
4. Building relationships and trusting professionals;
5. Emotional impact of accessing healthcare;
6. Involvement in decisions and control over choices.

Consistent with findings from another study exploring what young people experience as positive in their local health service (Curtis et al., 2004), these themes emphasise the importance of the relational as well as the functional aspects of care for young people.

Studies exploring families' experiences of hospital outpatient care are few; however one study that has explored this topic (Byczkowski et al., 2010) used telephone interviews to survey sets of parents and adolescents on their experiences of attending hospital outpatient appointments. In their findings, the authors revealed that although adolescents' and parents' perceptions of care were generally consistent, adolescents described less involvement in decisions about their healthcare and felt less likely to receive information that they could understand. Adolescents also emphasised the importance of feeling able to confide in a trusted healthcare professional. The authors concluded their study by recommending that more time is allocated to adolescents' needs in consultations.

Finally, literature reviews on including children and young people in healthcare have concluded that even when studies cite consultation from paediatric service-users, there is little evidence of their full participation (Franklin and Sloper, 2005, Coyne, 2008, La Valle et al., 2012) and a distinct lack of evidence regarding the impact of young person involvement on service planning (Cavet and Sloper, 2004, Heaton et al., 2007, La Valle et al., 2012).

Despite these shortcomings in the evidence base, Cavet and Sloper (2004) note that the literature they reviewed was virtually unanimous in its support for the involvement of young people in decision-making and more recent reports suggest ways of giving children and young people a "louder voice in influencing how services are organised and delivered,

as well as a greater say over their personal health choices” (NHS Confederation et al., 2011, p.4).

2.3.8 Summary of patient experience literature

In the past ten years, NHS organisations have been guided towards using descriptions of patient experience for assessing healthcare quality. Current literature emphasises that improving services from a patient perspective requires more complex approaches than merely obtaining evaluations through service-user views. Rather, patients’ direct experiences of care are recognised as a unique and valuable source of information that should be placed at the heart of service transformation. This has led to the development of a range of new methodologies for capturing patient experience and delivering patient-led improvements. Although the involvement of young people in health service evaluation is widely supported in policy initiatives, there are major gaps in evidence regarding the inclusion of young people’s views and experiences (La Valle et al., 2012).

2.4 Place and Space

Despite the spatial nature of policy initiatives recommending that specialist healthcare should be provided closer to patients’ homes, reforms have proceeded with little regard for the location of services or people’s experiences of those locations. Moreover, there have been few attempts to systematically investigate those aspects of place which matter most in healthcare (Poland et al., 2005). Subsequently, place has been neglected in health service evaluations, which have instead opted to focus on the philosophy of care (Moore et al., 2013). However, shifting the place of outpatient clinic delivery from the hospital to the

community is likely to affect service use, patient experience and professional practice because 'place' is increasingly understood to hold complex, shared and unique meanings (Casey, 2001, Cresswell, 2009). Understanding the place of care and its ascribed meanings is therefore imperative to understanding the impact of health service de-centralisation on patients, families and staff (Kearns and Joseph, 1993).

Historically a distinction has been made between space and place, taking space to mean an abstract concept regarding the "void in which things (including humans) are positioned" (Casey, 2001, p.1). In contrast, place is the immediate environment of our lived bodies, transformed and given meaning by human activity. As Gesler (1991) describes, "place is studied with an eye for its meaning for people; space is analysed in terms of its quantifiable attributes and patterns" (p.165). Appreciation of the human experience of place thus adds a necessary and location-specific dimension to understanding space (Kearns and Joseph, 1993). Space transforms into place when it becomes meaningful, that is, when it is used, lived and experienced (Cresswell, 2009). Understanding what constitutes place-based meaning involves asking how it is that people make place out of space. In light of its potential value in health services research (HSR), the theoretical concept of 'place' is reviewed from phenomenological and social constructionist perspectives.

2.4.1 Phenomenological perspective

Different disciplines have developed different theoretical perspectives on place. One strand of the literature has roots in phenomenological philosophy and humanistic geography (Manzo, 2005). Phenomenology is the study of human experience with the aim of examining and describing events, meanings and experiences as they are known in everyday

life, but typically unnoticed beneath the level of conscious awareness (Husserl, 1954/1970, Seamon, 2000b). This perspective moves away from the objectification of place and its meaning (i.e. interpreting place as an objective environment *outside* of experiencers) (Million, 1996), towards a rich understanding of person-place intimacy that escapes any subject-object dichotomy. Much of this work builds on Husserl's notion of intentionality whereby consciousness is always consciousness *of* something and Heidegger's notions of 'dwelling' as a particular way of being-in-the-world, where people are inseparable from the world, and thus all knowledge and meaning is embedded and emplaced within it (Seamon, 2000b).

In the 1970s phenomenological geographers (e.g. Tuan, 1977, Relph, 1976, Seamon, 1979) directed attention towards the everyday, taken-for-granted nature of place and its significance as a feature of human life (Seamon and Sowers, 2008). Following these ideas, humanistic approaches moved away from spatial science towards an experiential, embodied perspective that focuses on place as experienced by human beings (Seamon, 2011). Tuan (1977) explains:

"What we cannot say in an acceptable scientific language we tend to deny or forget. A geographer speaks as though his knowledge of space and place were derived exclusively from books, maps, aerial photographs, and structured field surveys. He writes as though people were endowed with mind and vision but no other sense with which to apprehend the world and find meaning in it. He and the architect-planner tend to assume familiarity - the fact that we are oriented in space and home in place - rather than describe and try to understand what 'being-in-the-world' is truly like." (p.200-201)

Relph's (1976) concern is also the human experience of 'place', which he conceives a fundamental aspect of peoples' existence in the world. Relph (1976) thus describes place

identity in terms of (i) physical setting (ii) activities and events, and (iii) individual and group meanings of place, created through lived experience. To explain why place is so important in human experience, Relph turns to the essential lived structure of place as it has meaning in human life, which he argued could be understood through the concept of 'insideness'. For Relph, 'insideness' is the "degree of attachment, involvement and concern that a person or group has for a particular place" (Seamon and Sowers, 2008, p.45). Thus, the more profoundly 'inside' a place a person feels, the stronger their identity with that place will be. In contrast, a person can experience 'outsideness' when they feel separated or alienated from a certain place. Similar to Tuan's idea of 'rootedness' (how individuals derive a sense of belonging to places), and Heidegger's notion of 'dwelling', Relph argued that through varying intensities of 'insideness' and 'outsideness', people develop a sense of attachment or belonging to a place which gives meaning to their life. In describing the essence of place, Relph (1976) states:

"Place lies in the largely unselfconscious intentionality that defines places as the centre of human existence. There is for virtually everyone a deep association with and consciousness of the places where we were born and grew up, where we live now, or where we have had particularly moving experiences. This association seems to constitute a vital source of both individual and cultural identity and security."
(p.43)

Relph develops his ideas of insideness to examine the ways in which places may be experienced as authentic or inauthentic. He describes an *authentic* sense of place as a "direct and genuine experience of the entire complex of the identity of places - not mediated and distorted through a series of quite arbitrary social and intellectual fashions about how that experience should be, nor following stereotyped conventions" (Relph, 1976, p.64). Such

authenticity however, is suggested to be slowly becoming eclipsed by a less authentic attitude, which he terms *placelessness*. Placelessness develops from an acceptance of mass values (e.g. culture and communication) that weaken “the identity of places to the point where they not only look alike, but feel alike and offer the same bland possibilities for experience” (Relph, 1976, p.90).

Building on the existential phenomenologist idea of bodily intentionality (Merleau-Ponty, 1962), both Casey (1997) and Malpas (1999) extend Relph’s ideas by conceiving place as the ontological basis of human existence. In other words, place first becomes known to us through our lived bodies which inhabit it. For Casey then, place and body are inseparable as place is a necessary condition of all existing things. Malpas also emphasises an ontological inquiry into place, arguing that the formation of place identity is rooted in human subjectivity. This view of place presupposes an interplay between action, place, and experience, in which embodiment is “one’s extended, differentiated location in space [and] essential to the possibility of agency and so to experience and thought” (Malpas, 1999, p.133).

Critics of the phenomenological treatment of place suggest that it is: (i) essentialist (ii) static and bounded and (iii) structured around naive dualisms (e.g. inside/outside; authentic/inauthentic) that limit the range of place experiences (Massey, 1994). The essentialist claim has been proposed by social constructionists who argue that phenomenology presupposes that an essential structure will be exposed when non-essential qualities are stripped back. Thus, by focusing on the “experience of place as a foundational existential quality” (Seamon and Sowers, 2008, p.47), the structural, cultural

and historical circumstances that shape individual places and experiences are disregarded (Williams, 1998). However, this criticism could be argued to misinterpret a basic phenomenological recognition that human experience is multidimensional. In other words, it recognises individual variations (e.g. a person's historical and social situation) as well as shared characteristics that come from being human and living in a human world (i.e. the claim that place is an integral lived structure in human experience). Moreover, not all phenomenological approaches see place as static. Drawing on Relph's notion of insideness to examine every day environmental experiences, Seamon (2000b) describes place as the product of everyday, habitual mobilities. This perspective suggests that places exhibit an unplanned, yet ordered practice through the experienced dimensions of body, feeling and thinking.

2.4.2 Social Constructionist perspective

A social constructionist perspective of place concerns itself with how places are historically and socially constructed by the people who inhabit them (Morgan, 2010). Power is central to this understanding of place as it is considered inherent to the "construction, reproduction, and contestation of places and their meanings" (Cresswell, 2009, p.5). While phenomenologists try to demonstrate place as an essential constituent to our 'being-in-the-world', social constructionists (e.g. Kearns et al., 2003) argue that place is principally a social production. As Harvey (1993) illustrates, "the first step down the road is to insist that place in whatever guise, is like space and time, a social construct. The only interesting question that can be asked is, by what social process(es) is place constructed?" (p.5)

Geographers inspired by structuration theory have developed this process-oriented view of place. Pred (1984) for instance, argues that places and institutions are constructed by the activities of people which produce social structures saturated with power:

“Place is therefore a process whereby the reproduction of social and cultural forms, the formation of biographies, and the transformation of nature ceaselessly become one another at the same time that time-space specific activities and power relations ceaselessly become one another.” (Pred, 1984, p.282)

Pred’s theorization fore-grounded the importance of human agency in the formation of place, particularly in his ideas about the significance of power relations within historical, political and economic contexts. Such acknowledgment that power is spatially constructed is a testament to the work of social theorist Michel Foucault (1973), who wrote substantially about the constitution power and its function within institutions such as hospitals and prisons.

Massey (1994) further argues that places are actively constructed by the movement of people, commodities and ideas. Places to Massey then, are not fixed in space, or connected to single identities, rather they are produced through connections to the rest of the world, making them “more about routes than roots” (Cresswell, 2009, p.8). Massey (2005) thus discusses place as “unstructured, unbounded and freely connected” (p.187), emphasising the role of social relations, which, like places, are fluid, full of life and ever changing. Thus, human action does not simply occur in response to institutions, it is completely embedded within them (Hess, 2004). This contrasts greatly with Tuan and Relph’s earlier ideas of rootedness and inauthentic places.

Nevertheless, the social constructionist perspective also has its critiques. In seeking to clarify place purely as a social process for example, constructionists fail to account for the embodied, individualised nature of subjective experience and the link that the body makes between subjectivity and the objective material world (Malpas, 1999).

2.4.3 Place-related concepts

The interdisciplinary nature of understanding place as a concept worthy of investigation has led to the lack of a common definition or theory (Patterson and Williams, 2005).

Nevertheless, literature on the meaning of place has attempted to move towards conceptual clarity through notions such as 'place identity' (Proshansky et al., 1983), 'place attachment' (Hidalgo and Hernandez, 2001) and 'sense of place' (Hay, 1998). While some have argued that 'place identity' and 'sense of place' are both forms of 'place attachment' (Williams et al., 1992) others contend that each concept is distinctive. 'Place attachment' for example, focuses on evaluations of places, while 'place identity' concentrates more on how places inform the construction of personal identity (Moore, 2000). Early applications of these place-related concepts focused on positive experiences of residential settings, exploring place as a source of belonging and comfort (Manzo, 2003, 2005). Relph reminds us however, that "any exploration of place as a phenomenon of direct experience, must be concerned with the entire range of experiences through which we all know and make places" (1976, p.6). Because of this, research has expanded to look at 'special places' (Manzo, 2005) as well as places of recreation (Kyle and Chick, 2007). Even so, attempts to transform place-related concepts into constructs like 'place identity' have been argued to eradicate the "phenomenological essence of place as a psycho-social-environmental whole

larger than the sum of its parts” (Seamon, 1987, p.20) resulting in superficial understandings of the phenomenon.

2.4.4 Summary of Place as a theoretical concept

Despite a body of theoretical work exploring the conceptual nature of place in terms of its everyday lived dimensions, there remains little consensus on a systematic theory (Patterson and Williams, 2005). Rather, studies on place incorporate multiple theoretical perspectives (e.g. phenomenological, social constructionist) and variations of the place concept (e.g. place identity, place attachment, sense of place). Nevertheless, a common thread in all theoretical conceptualisations of place is the acknowledgment of a people-place connection, emphasising place as an operational, living construct, albeit complex and multi-layered, which is meaningful to human experience. Understanding how place relates to healthcare experience may be particularly important when considering the impact and implementation of service re-design initiatives such as CCTH.

2.5 ‘Place-based’ health research

Although the focus of this study is paediatric CCTH, there is a wider inter-disciplinary empirical literature reflecting the notion of ‘place’ as a meaningful concept. Research exploring the geographical nature of healthcare is thus increasingly moving beyond the mapping of the distributive features of health services, to a consideration of the extent to which healthcare experiences are structured by spatial dimensions (Andrews and Moon, 2005). Mounting recognition that the experience of healthcare cannot be detached from the place in which it is received (Lehoux et al., 2008) has also led to the importance of

establishing empirical evidence to substantiate 'place theories', partially in response to the drive to make health policy more evidence-based (Cummins et al., 2007). Empirical place-based health research will now be examined in two categories; (i) the hospital as a health place and (ii) community settings as health places.

2.5.1 The Hospital

Through their 'Enhancing the Healing Environment' programme, the King's fund (2009) recognise increasing evidence that the appearance and design of hospitals can influence wellbeing, such that a sensitively designed hospital environment can offer significant therapeutic benefits to patients and staff. These include: improved communication and interactions, easier navigation around buildings, increased feelings of calmness and improvements in staff morale (Francis et al., 2003). In a review of literature exploring the effect of hospital wards, treatment areas and waiting rooms on patient health, Dijkstra et al (2006) identified three dimensions of environmental stimuli: ambience, architecture and interior design. Findings showed that sunlight, windows and seating arrangements had positive effects on health, whereas sound, nature, spatial layout and television had inconsistent effects. The authors concluded that the physical healthcare environment can influence patient wellbeing, but that limitations in existing research make it difficult to generalise about the effects of specific stimuli.

Nevertheless, findings such as these have prompted recommendations for NHS trusts to invest in good hospital design. A report on the Psychological and Social Needs of Patients (BMA, 2011) outlined a range of evidence demonstrating the effect of hospital design on patient recovery times, levels of anxiety, blood pressure, and use of pain killers (e.g. Ulrich,

1991, 1984). The report also covered aspects such as single sex wards (a plus), noise (less is better), and social interaction (common areas are good). The authors concluded by recommending that healthcare organisations should prioritise the design of all future building projects, by adopting the 'Planetree model' of patient-centred care (Frampton et al., 2008). This approach stipulates that healthcare environments should:

- Welcome the patient's family and friends;
- Value human beings over technology;
- Enable patients to fully participate as partners in their own care;
- Provide flexibility to personalise the care of each patient;
- Encourage caregivers to be responsive to patients;
- Foster a connection to nature and beauty.

Work has also been undertaken demonstrating the effects of the physical healthcare environment on members of healthcare staff. In their review however, Tanja-Dijkstra and Pieterse (2011) found little high quality research, leading to only one study meeting their inclusion criteria. In this study Christenfeld et al (1989) found improvements in mood and job satisfaction in staff members working on a renovated hospital ward (inclusive of light-coloured tiles, warm wall colours and furniture rearrangements) compared with those working on an un-renovated ward. Although this finding points to a positive influence of workplace design on healthcare staff, evidence is currently insufficient to make conclusions about the influence of the healthcare environment on work-related outcomes.

Taking a different approach, Radley and Taylor (2003a, 2003b) used photo-elicitation methods in conjunction with patient interviews to explore the effects of the hospital ward on rehabilitation, post-surgery. During their stay in hospital, participants were asked to photograph salient aspects of their environment that would provide material for discussion. In their findings the authors expressed how participants' pictures at first appeared 'disappointingly' ordinary (e.g. photographs of a chair, window, and bed). When talking to participants about their images however, it became clear that they were replete with embodied experiences of recovery. For example, in justifying two photographs of looking into and out of a bathroom, one participant told their story of trying to change a dressing, but "panicking and struggling with the bleeding" (p.85) before being assisted by a nurse. The photographs to her thus signified the beginning and end of a painful and traumatic event. Another of the participants described her photograph of a window both in terms of liberation and imprisonment. Supplemented by patient narratives then, the images of the hospital environment in this study served as a powerful reminder of how the hospital, as a 'landscape of care' can effect patient recovery and wellbeing (Gelser et al., 2004).

McKeever et al (2002) also considered the effect of the physical environment, this time on mothers of severely ill infants being cared for in hospital isolation rooms. Analysis of interviews again illustrated how place, space, and time affected the women's experiences, with negative aspects of the restricted and bounded room defined in physical terms and positive features characterised in relational terms. This indicated that whilst mothers often experienced the isolation room as "a prison cell", it was also viewed as a protective "sanctuary" that optimised the child's prospect of life (p.1025).

Gesler's (1991) concept of the 'therapeutic landscape' provides one framework for understanding the relationship between the physical healthcare environment and patient wellbeing, proposing that specific places can have therapeutic effects on healing and health. The concept of the 'therapeutic landscape' has so far been used to explore the hospital in terms of its design features (Gelser et al., 2004, Kearns and Barnett, 2000), as well as the emergence of 'homelike' birthing rooms within hospitals, describing the transformation of the traditional 'sterile' hospital birthing space into a softer and more personal environment, as a reflection of the shift in "medical philosophy that no longer views childbirth as pathological" (Fannin, 2003, p.513). The idea that hospitals also provide attachments for users, was clearly observed in a very different study exploring public opposition to the possible closure of St Bartholomew's Hospital in London (Moon and Brown, 2001). Findings from a discourse analysis of policy, media and campaign materials revealed that resistance related to recognition of the hospital not only as a place of medical expertise, but also as symbol of medical tradition within the city of London.

Together these studies demonstrate the effect that the physical hospital environment can have on patient and staff wellbeing, suggesting that the healthcare setting is more than just physical appearance and functioning, and that the geographical location of care often has "less significance in its therapeutic role than the physical, social and symbolic organization of the space itself" (Smyth, 2005, p.488).

2.5.2 The Community

Interest in 'health places' has also led to consideration of the impact of environmental factors (e.g. parks, built environment, industrial areas) on individual and community health

(Cummins et al., 2007). More recently, the built environment within community settings has also received research attention.

In two studies of primary care settings, Rapport et al (2007, 2009) show how the workspace is constructed in order to maintain healthcare professionals' sense of professionalism and to position patients within a passive role. Using biographic and photographic data, Rapport et al (2007) found that GP workspaces had often evolved rather than been planned, and in an extension of professional identity, ranged from "the embodied to the disembodied, the sacred to the profane, the technological, clinical and modern to the homely life space" (p.543). The authors interpreted this relationship between workspace and practice, as a reflection of staff morale, motivation and professional seniority. Rapport et al (2009) also explored the extent to which community pharmacy spaces were associated with professionalism and meeting public need. Findings in this study revealed that pharmacists inhabit different areas of the pharmacy (e.g. sales area, dispensary and consultation rooms) in diverse ways. For example, the dispensary was constructed as the nerve centre of the pharmacy, with its order and precision epitomising the essence of *being* a pharmacist. In this way then, the dispensary was not only used as a convenient place for the dispensation of drugs, it was also used to preserve professional identity and to evade members of the public. Emerging policy initiatives which dictate greater transparency and accountability through an 'opening-up' of the dispensary space were thus shown to hold implications for the pharmacist's construction of self.

Professional groups however, do not always agree on the best design of new services and spaces. This is demonstrated in studies by Lehoux et al (2007, 2008) examining the design

of new satellite and mobile dialysis units in Canada. They found that the professionals involved in the design and implementation of the units constantly sought to measure up to the 'ideal standards' of fixed hospital units, while having to acknowledge the constraints of smaller, community-based environments. This duality between an 'ideal' world and a 'real' world was linked to the way in which healthcare professionals selectively addressed clinical norms and patients' expectations. In exposing such professional tensions within and between groups, the authors argued that new clinics were developed not only to provide closer-to-patient services, but also to streamline clinical tasks. This finding is supported by Gelser et al (2004) whose evaluation of the UK hospital building programme led to the conclusion that many health places are designed to maintain the social and political interests of medical professionals:

"Many hospital designs in the UK have been based mainly on expert discourses that emphasize efficiency in terms of costs and clinical functionality. These values reflect the priorities of key participants in the design process and their assumptions about the relationship between healing and environment... For instance, it is apparent that certain stakeholders (usually the most powerful groups) are able to manipulate the social space of the hospital so that distinctions between medical 'experts' (e.g., doctors and Consultants), medically trained staff (e.g. nurses), non-medical support staff (e.g. porters, security, kitchen staff) and non-staff (e.g. patients and visitors) are maintained." (p.118)

The ability to transport medical technologies into the home setting also means that forms of healthcare that would previously have been provided in institutions can now be delivered in the home (Poland et al., 2005). The home has thus been re-conceptualized as a complex site of care, laden with emotional attachments, meanings, histories, symbolism and even social conflict (Dyck et al., 2005, Andrews, 2006, Moore et al., 2010). Studies on

the provision of hospital care in patient's homes have considered what it means to be a patient or homecare nurse (Liaschenko, 2003), as well as ethical issues such as the appropriateness of transferring values (e.g. professional boundaries and privacy issues) from hospital to home (Peter, 2003). Within a paediatric context, Lindahl and Lindblad (2011) conducted a meta-synthesis of qualitative literature on family members' experiences of everyday life when a child is dependent on a ventilator. Findings revealed that the presence of medical technologies and healthcare professionals changed the essence of home as a private and personal space, noting how the home becomes open to "public inspection and judgment" (p.259) when a child requires long-term medical intervention to survive. These findings echo those from other studies of the home as an informal care setting, suggesting that while patients often display a strong preference for homecare over hospital care (Shepperd et al., 1998), their experience of 'homeliness' can be disturbed by medical technologies and healthcare professionals (Angus et al., 2005, Moore et al., 2010), thus the meaning of home can change over the course of illness, from a therapeutic to a non-therapeutic place (Donovan and Williams, 2007).

While knowledge of the home as a therapeutic environment for the patient is well documented (Williams, 2002, Martin et al., 2005), less recognised is the impact that moving care into the home has on carers. In a study of her own mother's long term care at home, Cartier (2003) discusses her concerns in terms of the financial burdens of 'place-switching health services' (from hospital to home), gendered aspects of care-giving and management of the 'no-care zone' (transition of service provision from one sector to another). This 'no-care zone' has also been explored by Martin et al (2005) in terms of 'intermediate' care for older people. The authors' observed that by aiming to prevent hospital admissions and

facilitate early discharge, intermediate home care was rationalised on the basis of promoting autonomy and independence for older people. However, analysis of healthcare professional interviews led to questions about these assumptions, especially in cases where the home was experienced as restrictive or confining. The therapeutic nature of an environment is therefore argued to be dependent on a person's "physical, psychological and social meanings of place" (Martin et al., 2005, p.1893). This finding is supported in a study of older people's experiences of hospice day care (Moore et al., 2013), demonstrating that, within the context of health and illness, individuals purposefully re-construct places as therapeutic, in order to achieve a sense of 'homelikeness' (Svinaeus, 2001) within themselves.

2.5.3 Summary of 'place-based' health research

In light of changes to healthcare delivery, such that services are being shifted out of hospitals and into community settings, new conceptualisations of place are emerging. As a result, empirical studies have begun to consider healthcare settings as more than their physical location and material environment. Rather they are starting to be understood as meaningful, social places which provide experiences, attachments, symbolism and identity for their users (Andrews, 2006). This understanding has led to mounting consideration of the meanings attached to where care is delivered, and how different stakeholders participate in the creation of new health places (Lehoux et al., 2007). Nevertheless, there remains a dearth of knowledge regarding how place contributes to healthcare experience and how healthcare contributes to place experience (Kearns and Joseph, 1993, Williams, 1998). As Williams (2002) observes, despite the clear direction of policy, little "health

services research has adopted a place-centred theoretical perspective” (p.141).

Consideration of place “as an operational ‘living’ construct”(Kearns and Moon, 2002, p.609) may therefore contribute to a fuller understanding of how families experience paediatric outpatient care closer to home and why they experience it as they do.

2.6 Conclusion

This literature review shows that very few studies have explored the experience and impact of moving paediatric outpatient clinics into community settings. However, the concepts of ‘patient experience’ and ‘place’ are central to reforms in health policy, including those considering health services for children and young people. There are therefore, major gaps in the evidence-base regarding the design, implementation and evaluation of acceptable and effective ‘closer to home’ paediatric health services. Although patients’ direct experiences of care are increasingly recognised as a unique and valuable source of information, evidence for the systematic inclusion of young people’s experiences in service improvements is also lacking. By enhancing understanding of the meanings that places hold for service-users and providers, it may be possible to understand how and why families and staff experience CCTH as they do. Such information could have implications for service design and utilisation. The next chapter starts to address one of these gaps in knowledge by synthesizing the qualitative literature on families’ experiences of receiving specialist paediatric care outside of a hospital setting, with the purpose of generating new, conceptual understandings of the experiential and geographical dimensions of receiving community-based paediatric care.

CHAPTER THREE

3 FAMILIES' EXPERIENCES OF RECEIVING SPECIALIST PAEDIATRIC CARE OUTSIDE OF A HOSPITAL SETTING: META- SYNTHESIS OF QUALITATIVE LITERATURE

3.0 Background

As previously discussed, the National Service Framework (NSF) for children, young people and maternity services (DH, 2004) has sought to ensure that children and young people who are ill receive timely, high quality and effective care as close to home as possible, recommending that families receive “services which are coordinated around their individual and family needs and take account of their views” (DH, 2004, p.87). Together with advancements in treatments and technologies, changing beliefs about medical power and expertise, and a need to reduce costs in the NHS, such reforms have led to the shift of an increasing number of specialist paediatric health services being delivered outside of the traditional hospital setting (DH, 2005, 2007).

3.1 New models of service delivery

Achieving policy objectives for paediatric healthcare has prompted the development of new models of service delivery. In England, the predominant model is the community children’s nursing team (Parker et al., 2011a), which provides specialist home-based care to children and young people (0-18 years) with a range of acute and chronic illnesses (DH, 2011a). Such care prevents hospitalisation by providing families with the equipment, resources and support they need to care for children in their own homes (Cooper et al., 2006). Other models of Care Closer To Home (CCTH) include specialist outreach clinics,

where hospital-based healthcare professionals go out into the community to deliver services (Heath et al., 2012); virtual outreach or teleconferencing services; as well as paediatric assessment units (Spiers et al., 2012). These aim to improve access to specialist paediatric healthcare, while preventing unnecessary inpatient admission and reducing hospital length of stay.

Systematic reviews exploring the clinical and cost-effectiveness of paediatric CCTH (Parker et al., 2012) and in home (Cooper et al., 2006) report that the approach provides similar clinical outcomes for children and may be more cost-effective than hospital care. While these reviews contribute valuable knowledge to the under-developed evidence-base for paediatric CCTH (Parker et al., 2011a), less is known about the experience of services, from a user perspective. Findings of this kind would facilitate the design and delivery of innovative and acceptable services, which take into account service-user views and experiences (DH, 2011d).

3.2 New places, new experiences

The literature review in this thesis (chapter 2) revealed that increasing diversity in healthcare settings has led to 'place' being recognised as more than just physical location or material environment (Rapport et al., 2007). Rather, the place of service delivery is starting to be understood as a meaningful, social space which provides experiences, attachments, symbolism and identity for its users (Andrews, 2006). While 'place' is a recognised concept in disciplines such as medical geography, less consideration for the meanings attached to where care is delivered, and how different stakeholders participate in the creation of new health places has been given in healthcare policy and practice

(Lehoux et al., 2007). This is important as understanding both how 'place' fits into the landscape of healthcare and how families and staff experience different places, may shed light on how and why families experience CCTH as they do, which could in turn influence service improvement strategies. As yet, there has been no application of the theoretical concepts of 'place and space' for investigating paediatric CCTH.

3.3 Introduction to Meta-synthesis

Sandelowski and Barroso (2003) define a meta-synthesis as "a systematic approach to the collection and analysis" of solely qualitative studies and "the use of qualitative methods to synthesize those findings" (p.154). It is modelled on traditional systematic review methodology in that it includes a systematic search strategy, screening of retrieved studies and quality appraisal (Shaw, 2012b). Unlike meta-analysis however, the aim is to broaden conceptual understandings and provide new insights into a particular phenomenon, in this case, families' experiences of receiving paediatric care outside of a hospital setting.

As one approach to meta-synthesis, meta-ethnography is an effective method for synthesising findings from qualitative research studies in healthcare (Campbell et al., 2011). The process involves combining and contrasting findings from individual studies so as to develop new insights that are "greater than the sum of the parts" (Campbell et al., 2003, p.672). The output of a meta-ethnography is therefore a new, 'higher order' interpretation or theory that satisfactorily accounts for the available body of evidence (see figure 5).

Due to the methodological and theoretical diversity in qualitative research, quality appraisal of studies in meta-ethnography is contentious (Dixon-Woods et al., 2005); however, in order for the findings to contribute to an evidence-base for service re-design, consideration of quality is necessary.

Figure 3: Steps of a Meta-Ethnography

Noblit and Hare's phases for conducting a meta-ethnography (1988)
<ol style="list-style-type: none"> 1. Getting started: Identifying an intellectual interest that qualitative research might inform. 2. Describing what is relevant to initial interest: An exhaustive search for relevant accounts can be undertaken followed by selection of research relevant to the topic of interest. 3. Reading the studies: Repeated reading and noting of metaphors is required and continues as the synthesis develops. 4. Determining how the studies are related: Putting the studies together requires a list of key metaphors, ideas or concepts (and their relations) used in each account, and juxtaposing them. This leads to initial assumptions about relations between studies. 5. Translating the studies into one another: Metaphors and/or concepts in each account and their interactions are compared with the metaphors and/or concepts and their interactions in other accounts. These translations are one level of meta-ethnographic synthesis. 6. Synthesizing translations: Various translations can be compared with one another to determine if there are types of translation or if some metaphors/concepts are able to encompass those of other accounts. In these cases, a second level of synthesis is possible, analysing types of competing interpretation and translating them into each other to produce a new interpretation/conceptual development. 7. Expressing the synthesis: For the proposed synthesis to be communicated effectively it needs to be expressed in a medium that takes account of the intended audience's own culture and so uses concepts and language they can understand.

3.4 Aim

The aim of this review was to examine the qualitative evidence for providing paediatric CCTH and to derive new, conceptual understandings of families' experiences of receiving specialist paediatric care outside of a hospital setting.

3.5 Methods

This meta-synthesis proceeded in four stages. A systematic search strategy was developed; records retrieved were screened for relevance, appraised and then synthesized using the principles of meta-ethnography (Noblit and Hare, 1988). Throughout the review, care closer to home (CCTH) is used to refer to any 'out of hospital' setting.

3.5.1 Systematic search and screening

Five databases representing the disciplines of medicine, social sciences and health services research (Medline, Embase, Cinahl, Assia, Health Management Information Consortium) were systematically searched using synonyms of keywords and specific database index terms relating to the population (families; parents, children and young people), type of care (closer to home, at home) and method (qualitative, interview). Synonyms of search terms were combined using the term OR and concepts were combined using the term AND (Boolean logic) (see appendix 1.1 for example search strategy). Google scholar was then searched to identify grey literature (Borg Xuereb et al., 2012) and the reference lists of all papers which met the inclusion criteria reviewed for relevant material.

3.5.2 Inclusion criteria

Studies were included if they investigated families' experiences of receiving specialist paediatric care outside of a hospital setting, through the use of qualitative methods, were conducted in the UK, reported in English and published between 2003 and 2013. The country of study and time limits were chosen deliberately to reflect the development of

CCTH policy initiatives in the UK. No restrictions were applied to the model of care used to provide CCTH.

Where two papers reported data from the same study, a decision was made about how different their content was, in order to determine their inclusion. Care was taken to ensure that findings from the same study were not repeated within the synthesis. Any duplication of reported findings were therefore removed during the data management stage. Studies that reported service provider views as well as families' experiences (Carter et al., 2012, Kirk and Glendinning, 2004, McIntosh and Runciman, 2008, Runciman and McIntosh, 2003) were included, however data pertaining to staff views were excluded at the data management stage and subsequently did not feature in the analysis. Where supplementary data were referred to, for example in online appendices and reports (Carter et al., 2012, Spiers et al., 2011), these were included.

3.5.3 Critical appraisal

Prompts developed by Dixon-Woods et al (2004) were used to critically appraise the quality of included studies, whilst remaining methodologically neutral (see table 6 for an example). The purpose of this process was to consider the trustworthiness of the review findings, rather than to exclude papers on the basis of quality (Shaw, 2012b).

3.5.4 Data synthesis

Studies were read and re-read before data were extracted and recorded on standardised forms (see appendix 1.2). As well as basic study information, data were extracted on key themes, ideas and concepts as expressed by the participants (first-order constructs) and

also by the authors (second-order constructs). Information about study setting, methodology and participants was also extracted to provide a context for data synthesis. Synthesis of studies was carried out through the interpretative activity of translating studies into one another. This meant comparing and contrasting first and second order constructs across studies to identify third-order constructs, which represented the collective meanings of findings from individual studies.

In practice, first and second order constructs (author generated themes supported by participant data) were compared within a matrix (see table 2) so as to identify any common or recurring concepts and to determine how the studies were related (Britten et al., 2002).

Table 2: Example taken from Matrix of 1st and 2nd order constructs

	Theme 1	Theme 2	Theme 3
Spiers et al (2011)	<p>Parents' responsibilities during care closer to home <u>Having responsibility for nursing tasks</u> Degree to which parents felt supported in their care giving varied. However, all preferred CCTH over hospital care.</p> <p><u>Having no responsibility for nursing tasks</u> Regardless of level of responsibility, all parents valued support from CCTH staff.</p>	<p>Being supported Being supported socially and emotionally was highly valued by parents. Community nurses appeared to be the primary source of such support.</p>	<p>Relationships with staff Parents perceived their relationships with staff to be an important and integral aspect of the child's care. Relationships were often, though not always, described positively.</p>
Carter et al (2012)	<p>What Is Working Well? <u>Effective communication</u> Nurses acted as a central intelligence; robust "leadership" helped team members negotiate the uncertainty and challenges of working across traditional boundaries</p> <p><u>Enabling Families to be at Home</u> Services that work well centre on the needs of children and their families, enabling care to be provided at home where possible.</p> <p><u>Relationships and Working in Partnership</u> Services work well when relationships, based on trust and respect are developed between nurses and families and where nurses work in a solution-oriented way. Central to this is tailored and context specific training, delivered "in a way I can understand".</p>	<p>What Could Work Better? <u>Lack of Services and the Pressure to Cope</u> Some families felt there were "massive expectations" of them to provide CCTH without adequate support and guidance. Inequity and gaps in services meant that, for some families, life was disrupted regularly and unnecessarily</p> <p><u>Standard Working Hours</u> Many families had difficulties accessing support outside of normal working hours.</p> <p><u>Equipment and Resources</u> Equipment was a widespread concern, ranging from not having enough to substantial delays in delivery.</p> <p><u>Quagmires of Communication</u> Communication was cause for concern in some settings, especially in relation to discharge from hospital.</p>	<p>Visions for the future <u>Parents Supported to be Parents, Not Caregivers</u> The Community Children's Nursing Specialists should facilitate care at home that enables parents to be parents rather than have their parenting role subsumed by the need to be a caregiver.</p> <p>Equity and accessibility meant that families should be able to receive high-quality services regardless of their geographical location.</p>

Once the relationship between the included studies was established as related or 'reciprocal', findings from the first three papers were coded, before these codes were collapsed into a number of broader categories. These codes and categories then made up an initial coding framework, which was subsequently applied to two more papers before being refined. This process was repeated until no new codes were generated. The final coding framework (see table 3) was then applied to all findings in order to generate new themes. Themes were compared across papers using a matrix containing research articles in rows, themes in columns and summarised data within the cross-tabulated cells. This process enabled constant comparison between study findings, as well as reconstructing the coded data into something more than the parts alone, thus generating a new, fuller understanding of the phenomenon (a "line of argument" synthesis).

Table 3: Coding Framework

Category	Codes
Transformation of the meaning of 'home'	Medicalization of home by technology and healthcare professionals
Transformation of the meaning of 'parent'	Transforming from lay person to expert; from service-user to service provider; blurring of parent/carer roles; parents training in technical aspects of care; change in parent-child relationship; sleep and social disruption
Maintaining a sense of normality	Restoring and maintaining normality; managing and minimising disruption; effects on other family members; balancing care with other activities of daily life; preference for a place called 'home'
Support and coping strategies	Emotional, psychological, practical or technological support; managing crisis; respite; access to support
Working in partnership	Relationships between healthcare professionals and families; co-ordination and integration of care; access to services, equipment or resources

3.6 Findings

3.6.1 Included Studies

Searches yielded 248 articles excluding duplicates. Titles and abstracts were screened, and 230 papers excluded due to having a quantitative design (40) or irrelevant topic (190). 18 full text papers were then screened against the inclusion criteria and a further 15 removed due to an irrelevant topic or not being conducted in the UK. References of the remaining 3 papers were then reviewed and an additional search of Google Scholar carried out using the same search terms. This yielded a further 14 articles, of which, 6 were excluded following retrieval of full text, due to an irrelevant topic or not being conducted in the UK. The remaining 11 papers were screened against the inclusion criteria, where a further 2 papers were removed. This review is based on the findings of the 9 remaining articles, reporting 7 different studies (see figure 4).

Included papers described a range of models for providing paediatric CCTH, including community children's nursing; hospital outreach services; and children's assessment units (see table 4). The majority of papers reported families' experiences of receiving community children's nursing care within the home, reflecting the most common model in the UK (Parker et al., 2011a). Methods used to guide data analysis included the Framework approach (Ritchie and Spencer, 1994), Grounded Theory (Strauss and Corbin, 1998) and Thematic Network Analysis (Attride-Stirling, 2001).

3.6.2 Quality

Papers included in this review varied in quality, with only three providing enough information to fully satisfy the quality criteria prompts (Spiers et al., 2011, Carter et al., 2012, Kirk et al., 2005). Common problems included a lack of detail on methods of data analysis and lack of raw data as evidence to support analytical claims (See table 5).

Accounts of reflexivity were also limited, with authors of only three papers considering how their role as a researcher could have influenced data generation and analysis (Spiers et al., 2011, Kirk and Glendinning, 2004, Kirk et al., 2005). Such transparency is necessary in qualitative research to produce trustworthy findings (Shaw, 2010). Details on maintaining rigour more generally were provided in all but two studies (Carter et al., 2012, Malik et al., 2006). Examples included: double coding of data by two independent researchers, identification and examination of disconfirming evidence, prolonged engagement in the field, and keeping an audit trail.

Figure 4: Flow chart outlining number of articles retrieved, and included or excluded at each stage of review process

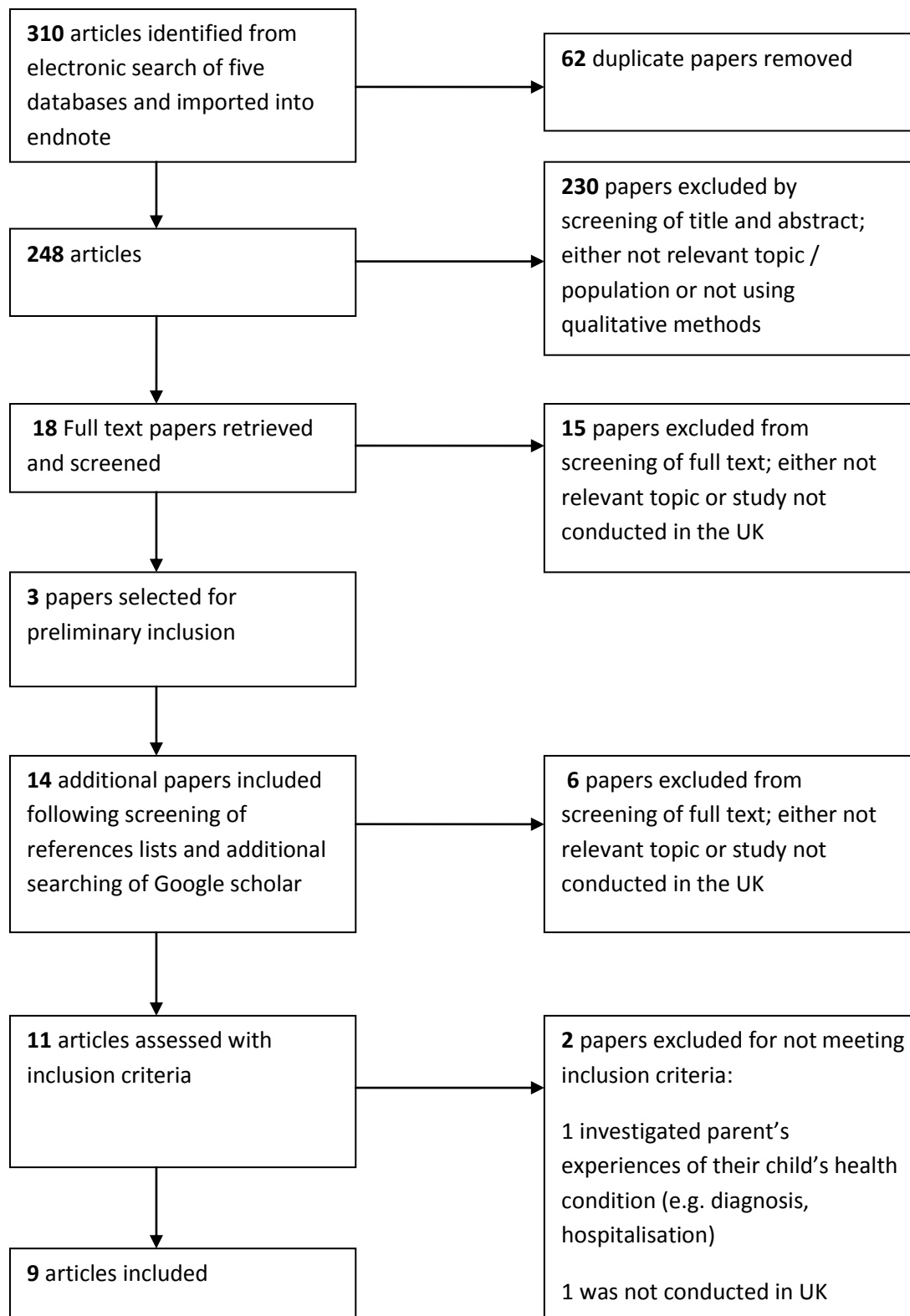


Table 4: Study Characteristics (*Papers from the same study)

Author, title, journal	Aim	Model of Care Closer to Home	Sample	Method
Spiers, G., Parker, G., Gridley, K. & Atkin, K. (2011) The psychosocial experience of parents receiving care closer to home for their ill child. <i>Health & Social Care in the Community</i> 19, 653-60	To explore the implications of CCTH through understanding the experiences of those who use such care.	2 Community Children's Nursing Services, 2 outreach nursing services, 1 children's assessment unit. All provided specialist, long-term and acute care in home and outpatient settings in England.	27 parents and one extended family member	In-depth, semi-structured interviews conducted face-to-face with parents. Data analysed using a Framework approach
Carter, B., Coad, J., Bray, L., Goodenough, T., Moore, A., Anderson, C., Clinchant, A. & Widdas, D. (2012) Home-based care for special healthcare needs: community children's nursing services. <i>Nursing Research</i> 61, 260-8	To elicit the perspectives on and experiences about Community Children's Nursing Services in England in relation to things that are working well or that could be improved and the vision for services.	9 regional locations in England providing a range of acute and long-term specialist Community Children's Nursing Services to children in their own homes.	82 parents and grandparents; 27 Children and young people	Arts-Based Participatory Appreciative Workshops; E-contributions (emails & blogging); Semi-structured interviews. Data analysed using a Thematic network approach.
Malik, A., Godson, J. & Tilford, S. (2006) A qualitative pilot study to compare physiotherapy provision through Sure Start and hospital-based services. <i>Practice</i> 18, 195-206	To investigate factors operating at the healthcare provider, child and parent interface that could affect the efficiency and effectiveness of a home-based physiotherapy service.	Home-based physiotherapy service to children run as part of a Sure Start programme and hospital-based service in a multicultural city in the north of England.	7 parents	Focus groups and semi-structured interviews. Data analysed using Grounded Theory techniques.
*Heaton J., Noyes J., Sloper P. & Shah R. (2005) Families' experiences of caring for technology-dependent children: a temporal perspective. <i>Health & Social Care in the Community</i> 13 (5) 441-450	To examine the temporal organisation and time consequences of the care regimes for technology-dependent children and their families.	Health services in England providing care to families with a technology-dependent child at home.	46 parents; 13 technology dependent children; 15 siblings; one grandparent	Semi structured interviews. Interviews with children facilitated by the use of time-line drawings. Participants could also keep a written and/or photographic diary. Data analysed using A Framework approach.

*Heaton, J., Noyes, J., Sloper, P. & Shah, R. (2006) The experiences of sleep disruption in families of technology dependent children living at home <i>Children and Society</i> 20, 196-208	To examine the effects of the care regimes for technology-dependent children and their families on sleep disruption.	Health services in England providing care to families with a technology-dependent child at home.	46 parents; 13 technology dependent children; 15 siblings; one grandparent	Semi structured interviews. Interviews with children were facilitated by the use of time-line drawings. Participants were also given the option of keeping written and/or photographic diaries. Data analysed using A Framework approach.
*Kirk S. & Glendinning C. (2004) Developing services to support parents caring for a technology-dependent child at home. <i>Child: Care, Health and Development</i> 30 (3) 209– 218	To explore the experiences of families caring at home for a technology-dependent child; and to identify perceived problems and good practice in the purchasing, delivery and co-ordination of services.	Hospital nursing support services in the home for children who are technology dependant.	33 Parents	In-depth interviews. Data analysed using constant comparison method.
*Kirk S., Glendinning C. & Callery P. (2005) Parent or nurse? The experience of being the parent of a technology- dependent child. <i>Journal of Advanced Nursing</i> 51 (5) 456–464	To discover how parents experience caring for a technology-dependent child.	Hospital nursing support services in the home for children who are technology dependant.	33 Parents	In-depth interviews. Data analysed using the constant comparative method (Grounded Theory)
Runciman, P. & McIntosh, J. (2003) Evaluation of the PATCH nursing service: Partnership and training supporting children with complex needs at home. <i>Primary Healthcare Research & Development</i> 4, 307-318	To examine parents and agency workers perceptions / experiences of the PATCH (Partnership and Training Supporting Children at Home) service	PATCH project - an intersectional initiative between health, social and education services in Lanarkshire, Scotland which provided support at home from two experienced children's nurses for parents of children with complex disability.	12 Parents	Semi-structured interviews. Data analysed using 'transcript-based' analysis.
McIntosh, J. & Runciman, P. (2008) Exploring the role of partnership in the home care of children with special health needs: Qualitative findings from two service evaluations. <i>International Journal of Nursing Studies</i> 45 (5) 714–726	To report empirical work relating to conceptual understandings of 'partnership' in the home care of children with special health needs.	Two out of hospital nursing services for children with special health needs in different Scottish Board areas.	17 parents	In-depth interviews; Data analysed using inductive and deductive 'transcript-based analysis'.

Table 5: Prompts for appraising qualitative research (Dixon-Woods et al., 2004)

	Are the research questions clear?	Are the research questions suited to qualitative inquiry?	Are the following clearly described?			Are the following appropriate to the research question?			Are the claims made supported by sufficient evidence?	Are the data, interpretations and conclusions clearly integrated?	Does the paper make a useful contribution?
			sampling	data collection	analysis	sampling	data collection	analysis			
Spiers, Parker, Gridley & Atkin (2011)	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Carter, Coad, Bray, Goodenough, Moore, Anderson, Clinchant, & Widdas (2012)	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Malik, Godson & Tilford (2006)	YES	YES	NO	YES	NO	NO	YES	NO	YES	YES	YES
Heaton, Noyes, Sloper & Shah (2005)	YES	YES	YES	YES	YES	YES	YES	YES	NO	YES	YES
Heaton, Noyes, Sloper & Shah (2006)	YES	YES	YES	YES	YES	YES	YES	YES	NO	YES	YES
Kirk & Glendinning (2004)	YES	YES	YES	YES	YES	YES	YES	YES	NO	YES	YES
Kirk, Glendinning & Callery (2005)	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Runciman & McIntosh (2003)	NO	YES	YES	YES	NO	YES	YES	YES	YES	YES	YES
McIntosh & Runciman (2008)	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES	YES

3.6.3 Synthesis of findings

Reciprocal data analysis generated five third-order themes (see table 6). These were: transformation of the meaning of parent; transformation of the meaning of home; maintaining a sense of normality; support and coping; and working in partnership. Each theme will now be described in detail, using verbatim quotations from first and second order constructs.

Table 6: Matrix of third order constructs

	Transformation of home	Transformation of parent	Maintaining normality	Support and coping	Partnership working
Spiers et al (2011)		•	•	•	•
Carter et al (2012)		•	•	•	•
Malik et al (2006)			•	•	•
Heaton et al (2005)	•	•	•	•	•
Heaton et al (2006)	•	•	•		
Kirk & Glendinning (2004)	•	•	•	•	•
Kirk et al (2005)	•	•			
Runciman & McIntosh (2003)			•	•	•
McIntosh & Runciman (2008)		•	•	•	•

3.6.4 Transformation of the meaning of ‘parent’

In caring for their child at home, parents were often required to assume responsibility for being “both their child’s parent and a skilled caregiver and provider of technological support and medication” (Carter et al., 2012, p.265). As a result, many experienced a

transformation in the meaning of parent from nurturer to clinical care provider. For some this meant a change in their identity and a change in their relationship with the child.

Technical care relating to medical devices was principally provided by the children's mothers, with diverse levels of support from other family members and service providers (Heaton et al., 2005). Such activities included: "administering oxygen; changing tracheostomy tubes; administering intravenous infusions; suctioning airways; passing nasogastric tubes; and giving injections" (Kirk et al., 2005, p.460). To perform this role, parents were required to undertake professional training. Most parents accepted this new responsibility without complaint:

"I never felt under any pressure whatsoever to, to go for this sort of training... I mean it just, they, you know, they were great in that respect they really were. They instilled some confidence into me." (Mother; Spiers et al., 2011, p.656)

Others however, found it more challenging or resented the accountability, especially when there was a requirement to administer complex treatment regimens:

"I do think it does put a lot of responsibility on the parents, you know, to have to give a lot of the medication, you know, at home." (Mother; Spiers et al., 2011, p.656)

"A parent should not be expected to do free slave labour 24/7... not good enough to treat families this way." (Parent; Carter et al., 2012, p.265)

The combination of technical training and experiential knowledge that parents gained whilst caring for their child at home meant that they often acquired a more personalised understanding of their child's specific needs and condition than the healthcare professionals they encountered. Whilst this allowed for the provision of bespoke care

(Kirk et al., 2005), it also meant the potential for tension with professionals, particularly when parents perceived that healthcare professionals were threatened by their expertise (Kirk and Glendinning, 2004).

Maintaining a healthcare provider role simultaneously with the kinds of care associated with parenting in general (Heaton et al., 2005) was particularly difficult for parents when the procedures they were required to administer caused pain or distress to the child. Consequently parents often found themselves managing both their child's and their own emotional reaction to treatments:

“The NG tube, you've got to get it up and wriggle it down, and he's crying and he's dead distressed, and it'll go the wrong way or curl in his mouth. You end up in tears and he ends up in tears.” (Mother; Kirk and Glendinning, 2004, p.212)

“It is so distressing to him and I'd, I'd end up giving up and not being able to do it. Cos it'd upset me to distress him.” (Mother; Spiers et al., 2011, p.657)

To manage their dual roles parents tried to distinguish between being a parent and being a nurse by emotionally detaching themselves from the service provider role when not giving care and prioritising their parental role wherever possible. The aim of this strategy was to protect the parent-child relationship, and prevent parents from being defined by the healthcare activities they carried out.

“Now I can be his mum... I can get with him and I can sit on the floor with him and we can watch tele(vision) with the others all together. Or we can go out together; we are just going to be a family. But then, come 8 o'clock, I've got to do his chest and I've got to do his physio and I've got to do his (nasogastric) feeds. And then you're not his mum, you're his carer again.” (Mother; Kirk et al., 2005, p.460)

Some parents however, experienced difficulties in seeing their children in the same way as they had prior to the onset of the medical condition. One Mother described how healthcare professionals helped her and her family to adapt to their new situation:

“We had been told so many things about (son) you kind of looked on him as a wee bit freaky at times... (the CCTH nurse) came along and got us looking at him in a completely different way again, so it’s given us an awful lot more confidence with him and I think we are a lot more positive about the future as well.” (Mother; Runciman and McIntosh, 2003, p.315)

Finally, parents described their lack of choice in becoming responsible for their child’s healthcare. For most, an overwhelming desire to have their child home from hospital overshadowed any concerns about coping. Having experienced CCTH however, parents discussed their struggle to separate their role as a carer from other activities of daily life. This had both emotional and financial implications, as many mothers had felt it necessary to give up work, and often felt too exhausted to engage in social activities (Kirk and Glendinning, 2004, Heaton et al., 2006).

3.6.5 Transformation of the meaning of ‘home’

For those parents of technology-dependent children receiving care in the home, the essence of home was transformed by the presence of technological equipment (e.g. ventilators, dialysis machines) and medical supplies (e.g. syringes, medications). In addition, the “continual or frequent presence of home carers or professionals” (Kirk et al., 2005, p.459) meant that essential constituents of ‘homeness’ such as privacy, personalisation and control, were redefined by the medical technologies and professionals that the child with

complex health needs depended on. Home was thus transformed into a functional environment. As one mother describes:

“She’s got a cupboard in her bedroom that’s totally full of everything she needs. Needles, syringes, gauze, everything we need for her. So it’s like a medical cupboard. Actually her bedroom is like a mini-hospital. There is everything you can think of that we’d use in hospital is there.” (Mother; Kirk et al., 2005, p.459)

Traditional home spaces were also re-organised to accommodate the child’s care needs.

For example one family transformed their main living area into the child’s bedroom, demonstrating how the whole family’s life was re-structured around the child’s condition:

“We had him in the lounge area in the other house, you know, his bed and his oxygen and his vent(ilator), all his stuff all in our lounge. The kids couldn’t have their friends in because it wasn’t then our lounge, it was A’s bedroom.” (Mother; Kirk et al., 2005, p.459)

Sleep too, was often disrupted by “machine alarms going off; the need to administer medications or other treatments during the night” (Kirk and Glendinning, 2004, p.213) and the need to monitor the child, for example, in case of breathing difficulties (Heaton et al., 2005). Some families made changes to their sleeping arrangements, such as sleeping in the child’s room in order to respond more quickly (Heaton et al., 2006). Others described only being able to sleep peacefully when technological equipment was not in use by the child, or when overnight carers were there. However, with no guarantee of a good night’s sleep, the presence of carers often meant added intrusion of privacy (Heaton et al., 2006).

Homes therefore, were not only altered by medical supplies, but also by the regular comings and goings of various health and social care professionals. As such, the home also

became “a public space where life was conducted alongside comparative strangers, with interactions open to public inspection and judgement” (Kirk et al., 2005, p.460). Freedom to be oneself and to engage in normal family interactions such as quarrels, displays of affection and entertaining of friends were also constrained by this intrusion of privacy and fear of being judged. As one mother describes:

“You haven’t got the freedom to talk about anything you want to because someone is always around. It’s very compromising. I want to keep things to myself, really, and there are certain things you can’t do.” (Mother; Kirk et al., 2005, p.460)

3.6.6 Maintaining a sense of normality

Parents of children receiving CCTH tried to maintain a sense of normality as much as possible for their whole families. For many this meant being at home in the place where the child was “happiest”, and where familiar and expected routines meant that they remained a part of “normal life”. As one child describes:

“I could sleep at home. I couldn’t sleep in the hospital. She came two times I think to my house... She came the second time and took my stitches out... right here [shows chest]... I liked it at home best of all. She gave me a star for being good and having a clean cut where my operation was.” (Child; Carter et al., 2012, p.264)

It was important to families that they continue with normal family routines, for example ensuring that the child attended school and that siblings’ needs were also met. Reducing the need for hospital visits and admissions allowed families to manage their other commitments alongside the sick child’s needs:

“In 2007/8 she had 14 hospital admissions lasting 1 day to 5 days. Since the CCN came during 2009 she has had only two.” (Mother; Carter et al., 2012, p.263)

“I prefer the home service because of childcare responsibility for a younger daughter who is nine months old.” (Parent; Malik et al., 2006, p.200)

For parents of children with more complex needs, balancing life and care could be more difficult. Nevertheless, parents often made a “determined effort not to allow their lives to be dominated by the demands of the technology and over time incorporated this into a more balanced way of life” (Kirk and Glendinning, 2004, p.213). For example, where possible, treatments were re-structured so as to fit in with social schedules and other institutional timetables, thus allowing life to carry on as usual (Heaton et al., 2005).

Despite the challenges of increased responsibility and intrusion from medical technologies and professionals, all families preferred CCTH to hospital-based care. This was because it was more flexible; allowed the family to stay together; enabled the child to remain in a familiar environment and reduced risks of infection. Some parents felt that they would like even more care at home, resulting in requests for a more frequent CCTH service, which extended beyond the current range:

“If there was a way that we could do more at home, even like you say with the temperatures, checking through the night and stuff like that, then we’d be happy to take on that responsibility.” (Father; Spiers et al., 2011, p.656)

“I would like a physio to visit every week at home.” (Parent; Malik et al., 2006, p.199)

Apart from crises, and occasionally during crises, home was constructed as simply the “best place” for the sick child to be:

“I think the best thing is that you don’t have to worry about taking her to hospital or the GP surgery, where she could catch more infections. All in all this service keeps my child out of hospital and at home with me.” (Mother; Carter et al., 2012, p.263)

3.6.7 Support and Coping

Adequate training in the child’s treatment regimen was imperative for parents undertaking new responsibilities of delivering treatment and care. Nurses based in the hospital and in the community were in charge of providing this training in a way that parents could understand. Such tuition eased the burden of responsibility for parents by increasing their knowledge, self-efficacy and independence. As Carter et al (2012) explain:

“Central to this support was the tailored and context specific education, training, and information that nurses delivered “in a way I can understand” to the children and their families in their homes. One mother who was “getting in a right muddle” about medication explained: “I went to the GP twice and to the Practice Nurse once and I could see the receptionists raising their eyebrows when I said “I don’t understand this!” Then the [nurse] came and helped me... made me a chart and this helped loads.” (Carter et al., 2012, p.264)

The resulting “sense of mastery over medications, interventions, and technology” (Carter et al., 2012, p. 264) meant that CCTH, both for short- and long-term conditions, could be sustained more easily by families who felt more confident in their ability to cope. Where CCTH nurses held responsibility for training other carers, parents also appreciated their thoroughness and respect for the mother’s way of caring for the child:

“I knew that it had been a thorough going over of all the different points, the pump, the hygiene bit... everything I would have done was covered you know the way I did it... She just didn’t come and take over... but very much involved me... So I knew that when I left (the trained carers) at home they would be doing exactly what I did so you know that was quite reassuring to me to know that I am confident in leaving

them and they won't be cutting corners or doing things differently." (Mother; McIntosh and Runciman, 2008, p.721)

As well as providing advice on the technical aspects of care, CCTH nurses appeared to be the primary source of emotional support for families, guiding and reassuring them in their abilities and encouraging discussion and resolution of concerns as they arose:

"I think... it's really good because you get to know them, so... and any concerns you might have you can talk to them about it, and it just seems that it's another form of support really." (Mother; Spiers et al., 2011, p.657)

"I am very happy with the service as it helps me to relieve my chinta (worry). I always worry more when I am on my own and talking to the Physiotherapy assistants is very helpful." (Parent; Malik et al., 2006, p.199)

Isolation from other parents of children with similar conditions (that parents were able to access in hospital settings) may have contributed to parents' dependence on CCTH staff for support:

"I think it would be nice if there was some sort of support group, you know, parent support group." (Mother; Spiers et al., 2011, p.657)

In addition, CCTH staff frequently provided support to families regarding social issues. For example, the bi-lingual Sure Start physiotherapists were able to give additional "advice on transport issues, housing advice and help with completion of Disability Living Allowance forms" (Malik et al., 2006, p.199). This was particularly valued by those non-English speaking families who do not access services in traditional ways.

Moreover, many parents described how community nurses acted on behalf of families to ensure provision of appropriate services, equipment, transport and funding. Such an

'advocacy' role was particularly important where liaison with other agencies was required or where quick action was needed to avert a crisis. Availability of CCTH nurses in this capacity reduced the number of visits to GPs and to hospitals, as well as providing more 'direct' access to specialist care (Runciman and McIntosh, 2003). This type of support also helped to relieve parental stress, as one Mother explains:

"I did all the phoning and running around early on up until the (named nurses) came on board but now they are taking over from me - it will take away the strain of having to chase somebody up by phone or just to know where to go. A lot of times I didn't know where to go and I was phoning other people and you get passed on "Oh it's not my problem" and all the rest of it." (Mother; McIntosh and Runciman, 2008, p.722)

Where such advocacy roles were not in place, parents often felt frustrated and disappointed by poor co-ordination of services and frequent changes of staff:

"I sometimes felt that I had to do everything myself, I was coordinating everything... I really did feel on my own, very isolated when B was very young. I felt I was cut off from (the hospital) and I was really quite disappointed in the after-service there." (Mother; Runciman and McIntosh, 2003, p.311)

"It's alright people think that you're a parent, you're just here to care for your child whatever happens, to fight for what they need, but a lot of the time I felt that I was the kingpin in what was happening, people were asking me... I felt that I was the person coordinating all the care and it was a mega weight when you're under stress... it gets a heavy load to carry." (Parent; Kirk and Glendinning, 2004, p.213)

Moreover, in cases where support was perceived to be inadequate and particularly when formal care packages were deficient due to shortages in staff and resources, parents experienced feelings of distress and abandonment. Carter et al (2012) provide a good

example of such a case, noting that similar stories were shared in many of their data collection workshops:

“One mother, who contributed via e-mail at 3:00 in the morning, explained how she was covering the night-time care of her ventilated child for the third night running as the caregivers trained to care for her child’s needs were “off sick with flu” and there was no other coverage available. For the following two nights, this mother sent e-mails to say that she was still covering her child’s night-time care and that she was tired, frightened, and angry.” (Carter et al., 2012, p.264/265)

Where training had been insufficient, parents also felt trapped and unable to continue with life as normal. For example, one set of parents “talked of being ‘stuck in’ and ‘sitting in the house taking shots each at going out’ because they did not know ‘how to go mobile’ with their baby and her feeding pump” (Runciman and McIntosh, 2003, p.312). Crises in parental confidence were further expressed when the child’s condition changed or worsened.

Relationships with CCTH staff were therefore highly valued by parents, and services were thought to be effective when continuity of care allowed relationships based on mutual trust and respect to be developed. Such familiarity with healthcare professionals meant that they were sometimes referred to as a friend, or as part of the family:

“She was just like my best friend, you know, she was fantastic, and she still keeps in contact now. So we, we’ve built up a really good friendship.” (Mother; Spiers et al., 2011, p.657)

Parents often felt reassured by access to a reliable person who knew their child, and who could offer help, advice or information; someone who ‘was there for them’. This promoted a sense of security and confidence, which in turn aided coping.

“I mean (named nurse) was the first nurse that I actually trusted... she was the first person that managed to get Katie settled and fed without having a military operation. So she was the first person that I felt comfortable, if I had to go for a cup of tea, I was quite happy to leave her.” (Mother; McIntosh and Runciman, 2008, p.721)

For families with children with complex or long-term needs, the importance of regular breaks from the responsibility as primary care provider was made very clear by parents. This included staying with relatives or in hospices, or having formal carers come into the home. Parents were also accepting of staff without professional qualifications if they were familiar with the child and their treatment (Kirk and Glendinning, 2004). However caring for a child at home without the support of nurses and carers would have been unsustainable:

“(Named nurse) walked through the door and said “right, this is enough”. She took over [child’s name] she said “I’ll do it one afternoon a week for four weeks. I’ll do it, I’ll come down and let you out or let you have a bath.” (Mother; McIntosh and Runciman, 2008, p.722)

3.6.8 Working in Partnership

Using their expertise in the health system and allegiances with service gatekeepers, nurses often facilitated networks between professionals across a range of services and settings. As Carter et al (2012) note, regardless of the delivery model, services which were “underpinned by highly effective and collaborative communication among the nurses, families, and caregivers resulted in the nurses being able to act as informed and trusted links between the family and the range of agencies from whom they gained support (e.g. pharmacies, general practitioners, acute and tertiary healthcare, the child’s school and

social care agencies)"(Carter et al., 2012, Supplemental Digital Content 6). CCTH nurses thus often become a 'first point of contact' for families, as one Mother summarised:

"For new families, I feel that it is indispensable, it will take away the strain of them having to chase somebody up by phone or just to know where to go. A lot of times, I didn't know where to go and I was phoning other people and you get passed on. "Oh, it's not my problem" and all the rest of it. I feel it's a really good service; it's going to be good for the future." (Mother; Runciman and McIntosh, 2003, p.315)

For some families however, poor communication across the hospital-community interface resulted in incomplete care packages and delays, particularly for those who received services from different organisations. This often resulted in parents feeling "confused about the responsibilities of different professionals"(Kirk and Glendinning, 2004, p.215). Even professionals themselves were sometimes unclear about whether GPs or hospital Consultants were medically responsible for children receiving CCTH.

Communication issues were also embedded within the discourses used by different agencies (e.g. health and social care), with some professionals "speaking different languages and using different tools" (Carter et al., 2012, p.265). Information sharing was thought to be impeded by the absence of shared information systems. However, one intervention which had managed to reduce fragmentation was a child health record, containing a detailed picture of the child's daily life, care requirements, behaviour and preferences. This document enabled the child's needs to be communicated in a clear and systematic way, regardless of the recipient (Runciman and McIntosh, 2003).

The amount and types of support provided with home-based healthcare seemed to be determined more by location of the family home, rather than family or child needs.

Families in rural areas or who lived very far away from the hospital were particularly vulnerable to receiving inadequate support and guidance (Carter et al., 2012, Kirk and Glendinning, 2004). Services that were only able to deliver care in standard working hours (8 hours a day, 5 days per week) also had little fit with the needs of children and their families. Some families therefore found it very difficult to access help from CCTH staff 'out of hours', either because the service was not available, or because it had to be booked in advance. Access to equipment and supplies was also a major concern for families, ranging from not having enough, to delays in receiving it.

3.7 Discussion

This meta-synthesis contributes to the evidence-base for paediatric CCTH, broadening other reviews (Lindahl and Lindblad, 2011, Parker et al., 2012) by including any health service provided outside of the hospital setting, to children with a range of clinical needs. It therefore has distinctive and significant implications for understanding the experience of paediatric CCTH from a user perspective, the provision of future services, as well as highlighting gaps in the literature-base.

3.7.1 Families' experiences of CCTH

The ability to deliver paediatric Care Closer to Home means that a sense of normality can be maintained when children require short or long-term medical intervention and the families' desire to keep children out of hospital can be met. The decision to care for children closer to home however often requires parents to take on responsibilities for the child's care that in hospital would be shouldered by a trained healthcare professional. Thus

the parent becomes part of the multi-disciplinary healthcare team. Where the child has complex or long-term needs, this can result in parents' perception of their role as 'nurturer' and 'protector' being challenged by the adoption of new healthcare-provider activities, particularly when there is a requirement to administer treatments that cause pain for the child. Parents can find this parent-carer duality difficult to manage, resulting in changes to their personal identity, to the parent-child relationship and to families' interactions with healthcare professionals. These findings are supported by international studies, reporting parents' experiences of caring for children with chronic illness (Sheerin Coffey, 2006) as well as those who are ventilator-dependent (Wang and Barnard, 2008).

The transformation of home, particularly for families with a technology dependent child is also demonstrated in the literature (Lindahl and Lindblad, 2011). In line with findings of this review, other authors report that the physical and social re-construction of the family home around the child's medical condition, can lead to it symbolising the very place that families aim to avoid – the hospital (Moore et al., 2010). The sense of "at-homeness" in terms of familiarity and belonging, regeneration, the freedom to be oneself, warmth, and a sense of control (Seamon, 1979) is thus challenged when children receive CCTH for complex medical conditions. Nevertheless, these empirical findings do give life to theoretical conceptualisations of the home as a complex site of care, laden with emotional attachments, meanings, symbolism and even social conflict (Dyck et al., 2005, Andrews, 2006), suggesting the need for further investigation of the particular "nuances and subtleties" (Pontin and Lewis, 2008, p.34) of where care is delivered.

For families in the studies synthesised in this review, paediatric CCTH provided an opportunity to reduce the frequency and duration of hospitalisation, allowing families to continue their everyday life as normal. Thus, despite the extra burden of responsibility and potential for disruption in family functioning, all families expressed a preference for care closer to or at home. A recent study of families' experiences of 'hospital at home' care for children with cancer in Denmark (Hansson et al., 2012) confirms that CCTH reduces strain on the family as a whole. From a user perspective therefore, the value of CCTH reaches beyond keeping the child out of hospital, to maintaining the well-being of other family members, enabling them to stay close together and to retain a sense of normality and security.

As well as technical advice and training, parents of children receiving CCTH discussed the necessity of support, and respite from the responsibility of being a carer for their child. This not only demonstrated additional needs of the family, but also the extended role of healthcare professionals when care is delivered closer to and in patients' homes. Findings suggest that the negative feelings of isolation and loneliness that families experience when physically separated from the hospital may be eased by generating a sense of "togetherness" with healthcare professionals (Todres et al., 2009). One way to improve access to the kinds of technical, emotional and practical support required by families when a child is receiving CCTH, might be the introduction of tele-home care and video-conferencing (Young et al., 2006). Such a service would provide guidance and reassurance to help parents manage their responsibilities in a separated world, in a cost-effective and less intrusive manner. Continuity of healthcare professional however would have to remain

a priority, so that families are able to build and maintain the kinds of on-going relationships with staff that they value highly.

Finally, many of the parents talked about their experiences of CCTH service delivery as a partnership between the family and various health, social care and education agencies, with varying degrees of success. This finding is supported by nurses' accounts of providing specialist paediatric care to families at home (Pontin and Lewis, 2008, 2009).

Communication within and between agencies was seen as imperative for enabling CCTH, as was flexibility in service provision and co-ordination of care around the child's needs. All too often however, services in this review appeared to be fragmented and determined by geographical location or the needs of service-providers, particularly in terms of limited working hours. Such inequity in access to care and lack of understanding about the experiences of care provision in a paediatric homecare settings are also documented in Australia and Canada (Wang and Barnard, 2008, Young et al., 2006).

3.7.2 Implications for policy, practice and research

A number of recommendations for policy and practice can be drawn from the findings of this meta-synthesis. In particular, services providing CCTH for children and young people, should:

- Negotiate the transfer of roles and responsibilities before hospital discharge.
- Have an integrated approach across services and agencies with common systems to provide coordinated care (e.g. shared care-plans, computer systems, and training materials).
- Be equitable across geographical boundaries.

- Provide adequate technical, emotional and social support to families to promote a sense of “togetherness”.
- Be responsive and flexible to families’ needs.

More research is needed to expand understanding of CCTH from the perspectives of families with children who have a range of shorter-term conditions and those who have experience of different types of CCTH service delivery model, other than community children’s nursing care delivered in the home.

3.7.3 Trustworthiness

Like any qualitative analysis, trustworthiness in the findings of a meta-synthesis is generated through transparency of each stage of the research process (Yardley, 2000). In this review, trustworthiness was maintained through documentation and clear audit trail of all decisions made. The aim and methods of the review, including inclusion criteria of studies were recorded within a synthesis protocol prior to commencement of the review. Detailed, reflexive notes were also kept throughout regarding the searching process, article content and interpretation of findings. Moreover, ideas were discussed and developed with other members of the research team throughout the process.

3.7.4 Limitations

The main limitation of this review is the lack of evidence regarding models of CCTH other than paediatric home-care for children with very complex and long-term needs. Methods of data analysis in the papers were also incomplete, often not providing enough raw data to back up claims (see table 5). Furthermore, most researchers used a one off data collection

design, which may not account for changes throughout the duration of families' experiences. Nevertheless, findings do raise a number of significant issues for policy and practice.

3.8 Conclusion

Minimising disruption to the family routine was a highly valued benefit of CCTH that meant it was preferred by all families for the delivery of specialist paediatric healthcare. By its very nature however, this approach changed the experience of specialist paediatric healthcare, requiring a transfer of roles and responsibilities from healthcare professionals to parents. CCTH services must therefore provide adequate psycho-social, as well as technical support.

Together with the literature review (chapter 2) findings from this meta-synthesis suggest that gaps remain in the literature regarding families' experiences of models of CCTH other than paediatric homecare. Such studies would provide useful information on the acceptability of these types of services and facilitate their design from a user-led perspective. The next chapter introduces the methodological approach taken in the empirical studies, which begin to fill some of the gaps identified in the evidence-base regarding paediatric outpatient CCTH.

CHAPTER FOUR

4 METHODOLOGICAL APPROACH

4.0 Introduction

In this chapter the methodological approach taken to exploring paediatric CCTH from service-user and provider perspectives is described and justified. The chapter begins with a discussion of the research paradigm, including the ontological and epistemological framework which guided the choice and use of methods; phenomenological interviews with families and a descriptive phenomenological method of analysis (Giorgi, 2009) and semi-structured interviews with NHS staff and stakeholders using a thematic Framework method of analysis (Ritchie and Spencer, 1994). A rationale for the use of different qualitative methods to analyse family and staff data is also presented.

4.1 The research paradigm

A research paradigm is a framework of beliefs or values within which research takes place (Joubish et al., 2011). These beliefs are principles for understanding and explaining how the world is made up, specifically, the nature of reality (ontology), the nature of knowledge (epistemology), and beliefs about how we gain knowledge (methodology). These assumptions dictate the mode of inquiry and justify the methods used, as Guba and Lincoln (1994) explain:

“A paradigm may be viewed as a set of basic beliefs (or metaphysics) that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the ‘world’, the individual’s place in it, and the range of possible relationships to that world and its parts, as, for example, cosmologies and

theologies do. The beliefs are basic in the sense that they must be accepted simply on faith (however well argued); there is no way to establish their ultimate truthfulness.” (p.107)

Within the context of evidence-based policy or practice, the design and delivery of health services have traditionally been investigated within a positivist paradigm. This assumes the existence of an objective reality against which researchers can compare their claims and ascertain truth (Fulop et al., 2001). Whilst such assumptions have been widely challenged, they reflect the “persistent view that only 'facts' constitute evidence and that these are best derived from research involving numbers” (Ritchie, 2003, p.26). Such a focus on inputs and outputs however leads to a very limited view of 'evidence', which may overlook the 'taken-for-granted' practices in healthcare (Popay and Williams, 1998) or fail to take into account what it is actually like for a patient to be a patient (Todres et al., 2009, Ashworth, 1997).

To overcome the shortcomings of positivism, advocates of interpretive approaches have followed ideas from philosophical phenomenology (Sandberg, 2005). This suggests that the human world is more than a set of empirical markers which represent truth; it is saturated with context-dependent experiences and meanings, as Merleau-Ponty (1962) indicates:

“I am not the outcome or the meeting-point of numerous causal agencies which determine my bodily or psychological make-up. I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation. I cannot shut myself up within the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless.” (p.ix)

The ontological and epistemological assumptions underpinning interpretive research are therefore different to those underpinning positivism (Sandberg, 2005). Interpretivism rejects the notion of an absolute, objective reality, instead conceiving person and world as interrelated through their lived experience of the world (Husserl, 1954/1970). Hence, the human world is never a world in itself; it is always an experienced world, a world that is related to the conscious subject (Sandberg, 2005). As Giorgi (2009) explains, a reality separate from our knowledge of it is unintelligible as “nothing can be known or spoken about that does not come through consciousness” (p.4), thus knowledge is constituted through a person’s lived experience of reality. This view provides a philosophical rationale for considering human experience a valid source of knowledge, worthy of scientific study in its own right (Todres, 2005). On a practical level, interpretive and in particular, phenomenological approaches, tend to converge with qualitative research methods, as its philosophical underpinning offers a “certain logic for legitimating qualitative discriminations with rigor” (Giorgi, 2009, p.5). Being open to the possibility of experiential knowledge, generated through the use of qualitative methods, may then offer new insights for health services research (HSR), contributing towards a more humanised health service which values the “quality of the journey as well as the destination” (Todres et al., 2009, p.75).

4.1.1 A pluralistic approach

In this study, two approaches to qualitative data collection and analysis were taken; phenomenological interviews with families and a descriptive phenomenological method of analysis (Giorgi, 2009); and semi-structured interviews with NHS staff and stakeholders

using a thematic Framework method of analysis (Ritchie and Spencer, 1994). This pluralistic approach was selected as a means with which to address two research questions with two participant groups (Morse, 2009) thus allowing for a broader and more complex picture of the research topic from differing perspectives (Frost, 2011).

Phenomenology can be described as both a philosophical approach and a range of methods concerned with how things appear to us in our experience, with a focus on the lived world and its meanings (Langdrige, 2007). Such an approach implies an epistemology for human science research in which meaning is primary (Dahlberg et al., 2008). It was therefore considered the most appropriate approach for exploring the meaning of CCTH for families and their experiences of receiving outpatient care in different settings. However, not all service-provider participants had direct experience of paediatric CCTH and nor were their experiences a primary focus for the study. Rather, the inclusion of NHS healthcare professionals and stakeholders was based on a desire to access service-provider views and experiences of the CCTH policy and its implementation. An approach which enabled both exploration of individual participant views as well as comparison between groups of individuals (e.g. Executives and Consultants) was therefore required and led to the selection of the thematic Framework approach (Ritchie and Spencer, 1994). Moreover, although thematic Framework analysis is grounded in the qualitative paradigm, it does not hold the kind of theoretical and epistemological commitments found in other methods such as constructionist or interpretive approaches (Braun and Clarke, 2006). This philosophical flexibility helped to overcome some of the epistemological, ontological and methodological challenges of combining different qualitative approaches in the same study (Shaw, 2012b).

The ontological and epistemological foundations of phenomenology will now be examined more closely, before focus is turned to the Thematic Framework method.

4.2 Philosophical underpinning of phenomenological inquiry

4.2.1 What is Phenomenology?

The phenomenological movement was founded by Edmund Husserl (1859-1938) as an alternative to methods of the natural sciences for examining human phenomena. In doing so, Husserl sought to change the nature of philosophy by focusing on the part humans play in constructing their world as it is experienced (Willis, 2001). He thus rejected the idealist position that the mind creates meaning in the world (Racher and Robinson, 2002, Dahlberg and Dahlberg, 2004) and the positivist position that an objective, knowable reality exists beyond the human mind. Instead, Husserl argued that ‘things’ (people, objects, ideas etc...) are only brought into existence and given meaning when they are perceived through human experience. Consequently meaning is simultaneously both discovered and created, so that when we experience something, we immediately grasp its meaning. As Davis (1991) states:

“The meaning of things is not inherent in objects, but is actually located in the individual’s inner life... The researcher’s task is to understand reality as it is, actively and consciously created by subjects, not as a pure entity that exists out there.” (p.5)

Husserl’s phenomenology centres on human experience of the world as it appears in consciousness. It is grounded in the principles of eidetic science, which “defines essential objects and relationships of society not through consensual meanings, but through the things themselves” (Lindlof, 1995, p.35). The ontological position of phenomenology

assumes that the only reality which exists is the one we interpret through our experience, and the epistemological position regards knowledge as being created through lived experience of reality (Sandberg, 2005). Moustakas (1994) elaborates:

“Husserl’s phenomenology... emphasizes subjectivity and discovery of the essences of experience and provides a systematic and disciplined methodology for derivation of knowledge. Husserl’s approach is called “phenomenology” because it utilizes only the data available to consciousness - the appearance of objects... It is logical in its assertion that the only thing we know for certain is that which appears before us in consciousness, and that very fact is a guarantee of its objectivity.” (p.45)

Having said this, Husserl recognised that human perceptions of things in the world are constantly influenced by all kinds of prior understandings. He therefore called for a science which returned to *‘the things themselves!’*, to phenomena exactly as they appear to us preceding any “culturally pre-set prejudices and ways of thinking” (Willis, 2001, p.3). In developing his philosophy, Husserl introduced a number of concepts including; the natural attitude (everyday way of being in the world), intentionality (that consciousness is always directed towards something), lifeworld (lived world that exists prior to any abstraction or categorisation), essence (the nature of a phenomenon that makes it what it is), phenomenological reduction and epoché (setting aside presuppositions so that new meanings can emerge). Husserl’s terminology will now be considered in detail.

4.2.2 Natural attitude

Husserl took his starting point from what he called the ‘natural attitude’. The natural attitude is an ordinary, everyday way of being in the world; “the common sense attitude we all have as we live our daily lives doing the ordinary things we do” (Giorgi and Giorgi, 2009,

p.170). From a phenomenological perspective this everyday 'natural' attitude is problematic, as it is saturated with pre-reflective judgments known as 'posits'. Posits are implicit and explicit "common sense beliefs and assumptions about the nature and existence of things in the everyday world" (Preist, 2002, p.52) including for example; inferences, assumptions, theories, and pieces of information we never doubt, but never try to prove. According to Husserl (1936/1970), the task for phenomenology is to go beyond our 'taken-for-granted' knowledge in the natural attitude and to reveal objects of 'pure essential consciousness'.

4.2.3 Intentionality

Also central to Husserl's philosophy is the phenomenological notion of intentionality. Intentionality is the principle that whenever we are conscious, we are always conscious *of* something (Langdrige, 2007, 2008). Rather than consciousness being an inner awareness of our own ideas, formed in a mind separate from the world as it really is, the mind and objects in the world are conceived as interdependent. This means that things in the world do appear to us directly and the way they appear to us is a necessary part of their being, rather than just some perception of the mind (Sokolowski, 2000). In existential terms, intentionality narrates the relationship between us as human beings and our world. Because we are *beings-in-the-world*, we cannot be described as separate from our world, just as our human world cannot be described separate from us (Crotty, 1998). This notion discredits the Cartesian tradition of subject-object dualism and refocuses on the way that consciousness is turned out *onto* the world as it intentionally relates to objects. Although

intentionality is a philosophical concept, it can be applied in a research setting through the consideration of lived experience as a source of knowledge.

4.2.4 Lifeworld

The idea of the lifeworld was developed by Husserl to express the beginning place from where we divide up our experiences into more abstract categories and names, as Todres (2005) describes, the lifeworld contains “the flow of experiential happenings which provide the ‘thereness’ of what appears, prior to categorising it into packages” (p.104).

Existentialists developed this idea of a pre-reflective world by asserting characteristics that are essential to all human experience, including; temporality (time as it is humanly experienced); spatiality (places, things and environments that have meaning in the lived world); inter-subjectivity (how we are in the world with others); embodiment (how we bodily live in meaningful ways in relation to the world and others) (Todres et al., 2007).

4.2.5 Essence

According to Husserl, every object has an essence. An essence is something that is essential; an invariant, necessary condition or core meaning which makes any phenomenon what it is. These qualities give an experiential phenomenon its distinctiveness, as Van Manen (1990) indicates, an essence is that thing “which makes something what it is, and without which it could not be what it is” (p.177). For example, as all birds lay eggs, it is a necessary condition of a thing being a bird that it belongs to an egg-laying species. The essence of a phenomenon in its appearing to human consciousness can be identified by

putting aside all of our prior understanding of the phenomenon, as if seeing it for the first time.

4.2.6 Phenomenological reduction

The aim of the phenomenological reduction is to isolate the pure phenomenon from what the researcher already knows about it. This is only possible however, if the researcher abstains from any judgment about the truth, including beliefs, assumptions, preconceptions and biases related to the phenomenon under investigation. The word reduction means to restore something to its more primordial mode (Langdrige, 2008). Husserl (1954/1970) described the phenomenological reduction as being off the ground and looking down upon the world with greater clarity; “it is from this very ground that I have freed myself through the epoché; I stand above the world, which has now become for me, in a quite peculiar sense, a phenomenon” (p.152). Having presented the natural attitude as the perspective of everyday life, for Husserl, the process of the phenomenological reduction is an attitudinal modification, which frees the phenomenologist from the implications of positing.

4.2.7 Epoché

Epoché is a way of allowing phenomenologists’ to break with their familiar acceptance of a particular phenomenon (Merleau-Ponty, 1962) through ‘bracketing’ prior knowledge and allowing the phenomenon to appear directly through experience. Underlying this attempt to suspend any culturally derived understandings and elicit new meanings, is a “deeply rooted suspicion of culture and the understandings it imposes” (Crotty, 1998, p.81). Whilst acknowledging that it is culture which allows us to emerge from our immediate

environment and reflect upon it, for Husserl, our culture is limiting as it imposes specific meanings and excludes others of which we might not yet be aware. According to Husserl then, our symbols in the world hide potential, new fuller or renewed meanings by standing between us and our immediate experience, so that we may miss what we actually see, hear, feel, smell, taste or even imagine (Caelli, 2000).

Phenomenology is about rejecting habitual, taken-for-granted meaning systems and taking a fresh look by calling into question current, accepted knowledge and critically examining our involvement with the phenomenon under study (Dahlberg and Drew, 1997).

Consequently, Husserl's philosophy searches for objects of experience rather than being content with a description of the experiencing subject (Crotty, 1998).

4.3 Phenomenology as a research methodology

Following Husserl's ideas, the aim of phenomenology as a research methodology is to gain a deeper understanding of the meaning of everyday lived experiences. Several approaches have evolved, including Descriptive Phenomenology (Giorgi, 2009), Hermeneutic Phenomenology (Van Manen, 1990), Reflective Lifeworld Research (Dahlberg et al., 2008) Interpretative Phenomenological Analysis (Smith et al., 2009), and Embodied Enquiry (Todres, 2007). Despite their epistemological differences, Finlay (2012) and Willis (2001) propose that these approaches have fundamental commonalities in terms of the phenomenological processes engaged. These include "(a) embracing the phenomenological attitude, (b) entering the lifeworld through descriptions of experiences, (c) dwelling with horizons of implicit meanings, (d) explicating the phenomenon holistically and dialectically, and (e) integrating frames of reference" (Finlay, 2012, p.3). In order for research to be

considered phenomenological therefore it must involve a rich description of the lived experience, adoption of an open phenomenological attitude and a search for essential meanings (Willis, 2001).

Some scholars (for example Crotty (1998) and Paley (1997)) however, critique the move from phenomenological philosophy to methodology. For them, the phenomenology of the phenomenological movement is a first person exercise in which each of us must explore our own personal experience, not the experience of others. Thus transformation of philosophical phenomenology into a method for research is problematic because it loses the “objective character and critical spirit, so strong in the phenomenological tradition” (Crotty, 1998, p.85). Giorgi (2009) responds to this criticism by explaining that to follow Husserl’s method is to perform phenomenological philosophy. However, to carry out scientific research the method needs revising. Thus, Giorgi argues that the descriptive phenomenological research method retains the status of phenomenology, by describing a phenomenon as it is consciously experienced and discovering the meaning of those experiences as free as possible from unexamined preconceptions.

4.3.1 Description versus interpretation

While all phenomenology is descriptive in the sense of aiming to describe rather than explain, scholars distinguish between descriptive and interpretive or hermeneutic phenomenology. In the descriptive form (i.e. Husserl-inspired), researchers aim to describe the essence of a phenomenon, staying close to that which is given in all its richness and complexity. The epistemological claim is that findings reflect a careful description of precisely the features of the experienced phenomenon as presented to consciousness. The

approach also aims to uncover what is there, but not immediately obvious (Giorgi and Giorgi, 2003). Thus, it requires transformation from overt statements provided within the natural attitude to underlying meanings within the phenomenological reduction (Willig, 2007). In drawing out implicit meanings however, some scholars argue that descriptions of the lifeworld cannot avoid aspects of interpretation (Ashworth, 1997). This follows the Hermeneutic tradition in assuming that lived experience is always an interpretative process (Racher and Robinson, 2002). Moreover, because all lived experience is grounded in our embodied being-in-the-world, it is not possible to separate our prior understandings as if to see the world for the first time. This clearly presents a challenge to Husserl's descriptive approach, resulting in what Dahlberg and Dahlberg (2004) term the 'description-interpretation' controversy. In comparison to interpretive approaches, pure description as an outcome of qualitative research has also been criticised for being naive and unsophisticated (Neergaard et al., 2009). Nevertheless, both Langdrige (2008) and Willis (2001) deny that there is anything simplistic about generating phenomenological description and attempting to get back to the *'things themselves'*.

4.3.2 Giorgi's Descriptive Phenomenological method

Giorgi's (2009) descriptive phenomenological method was selected for this study as it offers a transparent and systematic guide through the analytic process. What is appealing about descriptive phenomenology for HSR is the nod towards objectivity through researcher openness (i.e. being as free as possible from unexamined preconceptions) and the movement from individual subjective experiences towards an essential general structure of the phenomenon.

In Giorgi's method (2009), data is collected from other people on their concrete experiences of the phenomenon under study, through interviews or written accounts. In this study, data were collected from parents and young people on the experience of receiving paediatric outpatient care in different settings via individual interviews. Once descriptions of the experience have been collected, four steps of analysis are performed within the phenomenological attitude; (1) the researcher obtains a sense of the whole description through reading and re-reading of the transcript; (2) data are split into units of meaning; (3) the researcher interrogates each unit for meaning and transforms it into phenomenologically sensitive expressions; (4) an essential general structure is formed, which describes features that are typical or essential to the experience of the phenomenon.

Although there is some debate as to whether Husserl's phenomenological reduction and epoché are useful or even possible, scholars such as Colaizzi (1973) and Wertz (2005) suggest that it is both possible and desirable to bracket immediate and spontaneous understandings of the world through a process of reflexivity (Wertz, 2005). This suggests that self-reflection is consistent with a Husserlian application of the epoché in which the researcher actively identifies their own expectations and understandings of the phenomenon, in order to put them aside and focus on the participants' understanding. As Finlay (2012) points out, "researchers have to know what it is they are striving to bracket in order to be open" to new meanings (p.8).

4.3.3 Rationale for use

Within healthcare, researchers have embraced phenomenology as a way to examine, explore, describe and understand human experience (Caelli, 2000). Descriptive

phenomenology in particular has much to offer HSR as a human science (Todres, 2005). In particular it provides a means of informing care at practice and policy levels on the basis of concrete descriptions of people's lived experiences. Within the context of patient and public involvement, descriptive phenomenology also has advantages of focusing on meaning rather than measurement. The method thus goes beyond the consumerist ideals of patient satisfaction, to purposefully accessing the richness and fullness of patient experience (Todres, 2005, Polkinghorne, 2005). The method does not rely on respondents to come up with articulated views, but makes use of their multilayered and complex lived experience as a source of knowledge. Finally, not only do the findings from descriptive phenomenological studies imply strong knowledge claims (Giorgi, 2009), they also permit movement from individual experiential accounts to a general, shared structure of the phenomenon (whilst retaining idiographic variations). Descriptive phenomenology might then be one approach to ensuring that the qualitative dimensions of healthcare are considered from a service-user perspective, in a systematic, transparent and rigorous way that meets the needs of an evidence-based model (Shaw, 2012a).

As already discussed however, not all service-provider participants had concrete experience of delivering general paediatric outpatient clinics, and so a different, thematic Framework method (Ritchie and Spencer, 1994) was selected to explore NHS staff and stakeholders' views, as well as their individual experiences. This approach will now be considered in more detail.

4.4 Thematic Framework method

Located within a larger family of analysis methods often termed ‘thematic analysis’, the Framework method (Ritchie and Spencer, 1994) aims to identify commonalities and differences in qualitative data, before drawing conclusions derived from connections within and between different parts of the data. Although the method is not explicitly associated with a particular epistemological, theoretical or disciplinary perspective (Braun and Clarke, 2006), its systematic approach and requirement for assertions to be supported by evidence (raw data), commonly situate it within a positivist framework (Guest et al., 2012). That is not to say however, that it cannot also be “incorporated into a more interpretive analytic approach” (Guest et al., 2012, p.18). The strength of this method then, lies in its pragmatic focus on using the most appropriate tools for answering for the research question (Hiles, 2012). Such methodological flexibility is crucial when carrying out health research in a ‘real world’ setting (Dures et al., 2011).

4.4.1 Rationale for use

The thematic Framework method was selected for analysing staff and stakeholder interviews based on its potential to facilitate comparison of data *across* individuals and groups (e.g. community-based and hospital-based participants) as well as *within* individual cases (Ritchie and Spencer, 1994). Its distinctive feature is the matrix output; using rows, columns and ‘cells’ of summarised data to assist analysis by case and by code (Ritchie and Lewis, 2003b). ‘Cases’ can either refer to individual interviewees or predefined groups or organisations. While in-depth analyses of key themes can take place across the whole data set, the views of each participant also remain connected to other aspects of their account

within the matrix, so that the context of the individual's views is not lost. This is a core principle and advantage of the method. Moreover, the method has a well-defined procedure, which assists management of voluminous data and is open to the development of themes both from the research questions and from the narratives of participants (Rabiee, 2004). This means it is possible to explore specific issues such as the design and location of services, but also leaves space to discover other, new and unexpected aspects in the data. The method involves five key stages; familiarisation, identifying a thematic framework, indexing, charting, and interpretation. These will be explained in more detail in chapter 5.

4.4.2 Summary of methodological approach

This chapter has provided a background to the epistemological and ontological framework of this study and how it informed the methodological approach. Different qualitative methods were selected in response to different research questions and participant groups (Hiles, 2012, Morse, 2009). A phenomenological approach with families was selected because of its focus on eliciting meaning from experience-near descriptions of the CCTH phenomenon. A thematic Framework approach with staff and stakeholders was selected because of its focus on eliciting and comparing participant views and experiences, both within and between individuals and groups. The next chapter describes in detail the methods of data collection and analysis.

CHAPTER FIVE

5 METHODS OF DATA COLLECTION AND ANALYSIS

5.0 Introduction

Methods are the practical activities of research, including sampling, data collection, data management, data analysis and reporting (Carter and Little, 2007). In this chapter the methods used to collect and analyse data in the family and staff interview studies are described and justified. In line with the epistemological characteristics of this research however, it is not possible to regard the researcher as completely detached from the research process, and so reflexive consideration of the researcher's position is required (Holloway and Wheeler, 2010). In order to demonstrate reflexivity and take ownership of my role within data collection and analysis, this chapter is written in the first person tense (Gilgun, 2005, Berger, 2013).

5.1 Identifying and accessing the research sites

Official permission to enter the main hospital site was conferred by my substantial contract of employment as a trainee health psychologist and doctoral researcher on the wider CLAHRC PLACES Project. Although this did not guarantee full access or co-operation from individuals to participate in the study, my NHS Trust employee status and physical placement within the Children's Hospital (and one of the research sites), did provide a basis on which to build relationships with key individuals and negotiate access to participants (Wanat, 2008).

As part of my NHS Trust induction for example, I was required to meet with a number of paediatric Consultants, service managers and executive team members involved in the planning and running of General Paediatric clinics. During these meetings I gathered information on the organisational structure of the hospital and on the design, location and development of community-based clinics. During this time I was also encouraged to attend a number of Chief Executive briefings at the hospital, meet with the Emergency Department clinical lead and invited to shadow a Consultant-led outpatient clinic within the main hospital. In addition, I joined a general paediatric Consultant team during a hospital ward round. These experiences allowed me to become familiar with the physical surroundings of the hospital and significantly enhanced my understanding of different paediatric clinical specialities, including the general paediatric service that this study is focused on.

During my first few months of employment at the Trust, I further started to develop an awareness of the social structure and culture of the main hospital, including the working relationships and professional alliances and tensions between individuals and groups within the organisation. Such 'insider' knowledge was extremely valuable for deepening my understanding of the research area, shaping the research questions and methods and providing a context for the collected data.

In addition to becoming familiar with the main hospital site, I also visited both community-based outpatient clinics. Following an informal email to the manager of the family centre introducing myself and explaining the research, I was invited to the centre to have a guided tour. This enabled me to become familiar with the location and setting

of one of the community-based clinics and facilitated my understanding of the functioning of a family centre and its purpose within the community.

I also contacted and met with one of the practice-based commissioners at the third research site, a community-based clinic delivered in a primary care health centre. This gave me an opportunity to gain information on existing health service commissioning practices, the history of the clinic set-up, and on the local population's needs. This is described in an extract from my research diary:

"Today I met with the Practice-based commissioner at the GP centre... she said she was looking for a good package from the hospital, where patients can be seen, treated and discharged within their community. 'We're not looking for a drag and drop service' she said, integration seems to be the key then?" (Meeting notes, 05/07/2010)

Taking time to develop relationships with the two Consultants delivering community-based satellite clinics also facilitated access to their clinics for recruitment purposes.

5.2 Selection of participants

Although the term '*sampling*' is typically used in qualitative research to refer to participant selection, Polkinghorne (2005) advises that the term be used with caution, as it implies that the people selected are representative of a specific population. Instead, the term '*selection*' is suggested to more closely describe the method for choosing participants. In this study, different strategies were used for selecting family members and staff and stakeholders. These will now be discussed.

5.2.1 Selecting parents and young people

The aim of this study was to find out what it is like for parents and patients to attend general paediatric outpatient appointments in different places. Participants were therefore selected because they could provide “substantial contributions to filling out the structure and character of the experience under investigation” (Polkinghorne, 2005, p.139). In other words, I purposefully set out to locate and select individuals with the specific experience of attending general paediatric outpatient clinics in my three research settings.

In his phenomenological method, Giorgi (2009) recommends including at least three participants with experience of the studied phenomenon as differences between participant’s accounts make it easier to distinguish those aspects of the experience that are invariant across different accounts and those which vary (Finlay, 2009, Langdrige, 2007). As Giorgi (2008a) explains; “at least three participants are included because a sufficient number of variations are needed in order to come up with a typical essence” (p.37). Collecting a number of variations of the same experience is therefore recommended so that the researcher may “better intuit and see essential structures by finding them in a number of variations of the experience” (Todres, 2005, p.110).

In light of this, parent and young person participant selection was guided by the principles of purposive and maximum variation sampling strategies. I purposefully selected parents and patients who had the common experience of attending general paediatric outpatient appointments in one of three settings, but who varied on a range of demographic characteristics including age, sex and ethnicity, employment status and distance of home from the main hospital (Polkinghorne, 1989). In line with recommendations on sample sizes

for phenomenological studies (Morse, 2000), I aimed to select at least six parents and six young people with experience of hospital outpatients and six parents and six young people with experience of community-based clinics. Although there is no official lower age limit at which children can participate in qualitative research (Shaw et al., 2011), the depth and detail of recounted experience needed for descriptive phenomenological analyses would have been difficult to achieve with very young children, and would have required different, more creative methods of data collection (Shaw et al., 2011). A lower age limit of (approximately) 8 years was therefore set for young people participants.

5.2.2 Selecting NHS staff and stakeholders

The aim of this study was to elicit a broad range of views on moving general paediatric outpatient CCTH, from the service-provider perspective. I therefore required participants who had informed views and experiences on healthcare policies and the planning and running of new clinics. This could include hospital-based clinicians and managers as well as other NHS stakeholders such as GPs, commissioners and primary care service managers who could provide a wider context perspective by offering views from outside the hospital trust. The views of GPs were considered particularly important for the study as through their interaction with families and through their referral and commissioning practices under new government proposals (DH, 2010a), they would be instrumental in the success of new community-based services.

In order to obtain the variety of views and richness of data required for this study, at least 30 participants were needed (Morse, 2000). A purposive sampling technique was used to select participants specifically for their knowledge and experience of paediatric health

services (Carter and Henderson, 2006). Being based at the hospital, this seemed like a good place to start. Using the knowledge and contacts gained during my initial induction period and through discussion with my research team, I identified a core of ten “key informants” (Marshall, 1996) from a range of clinical and managerial backgrounds. Key informants usually occupy a position of responsibility and influence within the research setting and can be distinguished by their professional role, knowledge of the research topic and their willingness and ability to communicate knowledge (Tremblay, 1989).

From there, a ‘snowball sampling’ method was used to identify others with potentially informed views. Snowballing strategies start with an initial contact (in this case the ten key informants) who are then asked by the researcher to indicate other respondents whom they believe may be able to contribute to the research topic (Carter and Henderson, 2006). This technique was particularly valuable for identifying participants outside of the hospital setting. Participants continued to be selected and interviewed up to the point at which no new information was elicited (Bradley et al., 2007).

5.3 Materials

To recruit participants, various materials were developed to advertise the study and invite people to participate. These included: a recruitment leaflet and poster, invitation letters, information sheets and consent forms (see appendix 2). Age-appropriate documents were developed for young people in consultation with the Medicines for Children Research Network (MCRN) guidance for researchers on designing Patient Information Leaflets (MCRN Young Person’s Advisory Group, 2010). By adhering to MCRN recommendations on leaflet design and content (e.g. what the study was about, why it was being done, where it was

taking place, when it would begin and finish and who was leading the study), information sheets were made clearer and easier to read for young people. To make leaflets more user-friendly, I also folded A4 sheets to make four small 'pages' (Alderson, 1995) and used colour, pictures and photographs as well as subheadings, short lines and small paragraphs.

The Children's Hospital MCRN Young Person's Advisory group was then invited to review all materials for the study and make comments on draft copies (see appendix 3). Generally feedback was positive, but where amendments were suggested, changes were made. For example, more explanation was given in response to the following comments: "CLAHRC is a bit confusing"; "Put in brackets what paediatric means."

5.4 Gaining access to participants

A favourable opinion from the West Midlands NHS Research Ethics Committee (REC) was given for the family recruitment strategy, which included approaching families in general paediatric clinic waiting areas, sending letters to families who had received a general paediatric appointment and advertising the study on posters and leaflets (see appendix 4).

Access to families waiting in the main outpatient department was negotiated with the outpatient manager and clinical lead for the service. Access to the satellite clinic waiting areas was negotiated with the two Consultants who ran the two clinics and with the managers of both clinic centres.

Negotiation to access patient waiting areas was facilitated by my 'employee' position within the hospital and the relationships I had taken time to establish at the beginning of my employment. In addition, many of the key members of staff with whom I negotiated

access to waiting areas had already taken part in the 'staff and stakeholder' study. They were therefore familiar with me and the 'PLACES' project. Consequently, gaining access to clinics was a relatively straight forward process, achieved predominantly through email and telephone interaction. A relationship with the outpatient department manager also meant that I was able to access useful information for recruitment, such as times and dates of general paediatric clinics, how many clinics were running at one time, the Consultants running each clinic and the room numbers that Consultants occupied. For the satellite clinics I was able to find out how many patients were booked into a clinic each week by contacting the Consultant's secretary. This enabled recruitment to focus on the busiest clinics, allowing me to maximise my time, whilst covering of a range of Consultants.

Access to NHS staff and stakeholder participants in the hospital was also facilitated by my position as a hospital employee and by the personal contacts I had made since the start of the project. This meant I was able to access and utilise the hospital intranet for advertising the study, work email addresses and extension telephone numbers. Even though I was operating from within the organisation, many of the participants were still protected by gatekeepers who informally controlled access to them (Neuman, 2000). For example, I had to negotiate access to many of the Consultants with their secretaries who often presented with extremely limited availability and frequent rescheduling of appointments. Access to GPs and other community-based stakeholders was also more difficult, particularly as I was unknown to potential participants and therefore had a limited basis on which to form relationships. Although I attempted to contact GPs by phone, I was often held back by receptionists who would offer to pass on messages, but

denied access to the GP directly. I therefore wrote letters; emails and faxes directly to local GPs.

5.5 Recruiting interview participants

5.5.1 Recruiting families

Approaching families to participate in the study in main outpatients was a challenge.

Logistically, difficulties came from the outpatient department set-up; a large, open area filled with families waiting for a number of different clinics. As it was difficult to establish which families were specifically waiting for a General Paediatric appointment, I took a strategy of talking to all families in the waiting area and trying to find out which service they were attending before explaining the study. Many families however, were unsure about which service they were waiting for. I tried to overcome this by asking them which Consultant they were seeing. This often resulted in them giving me their appointment letter to look at, which enabled me to establish their eligibility before explaining the study.

Another strategy was to enlist the help of one of the support staff whose role included checking appointment letters and directing families as they entered. After explaining that I was interesting in talking to families specifically with a general paediatric appointment, one of the support staff was able to indicate some eligible families as they came in, although this was also not ideal. Satellite clinic recruitment was easier in that it was clear which families were waiting for a General Paediatric appointment.

After establishing eligible families and introducing the study, I gave each family an information sheet to read, and, if they were interested and willing, I noted down their

contact details. Some families were apprehensive about giving their personal contact information. In this case I could only reassure them, but be respectful of their decision to decline. After 24 hours had passed, all interested families were contacted to see if they wanted to participate and to schedule a time and a place for interview. At this point, some families declined to take part, some were recruited and some were not contactable. Letters were sent to the families whom I was unable to reach by telephone.

5.5.2 Recruiting NHS Staff and Stakeholders

A list of email addresses and telephone numbers for the hospital-based key informants was obtained, which allowed the research team administrator to contact them. Emails comprised a brief introduction to the study, a participant information sheet and an invitation to take part in the research. If they agreed, this was followed by arrangement of a time and place for interview at the participant's convenience. Potential participants also received a follow-up telephone call if they did not respond to the initial email invitation. At the end of each interview all participants were asked to suggest other people who they thought would be valuable to speak to regarding the study. This strategy was useful for recruiting participants that didn't know me (such as GPs), as it enabled a more personalized approach to recruitment, by conveying to potential participants that they had been personally recommended by a colleague as someone who might be interested and willing to take part in the study. These individuals were also invited to participate via email with telephone follow-up.

5.6 The interview process

Interviews are the most commonly used method of data collection in qualitative research (Polkinghorne, 2005) and are appropriate for seeking access to the participant's "understanding of the world and their experience" (Taylor, 2005, p.40). Face-to-face interviews were selected as the method of data collection for this study as they provided a situation in which participant's views and experiences could be explored, illuminated and probed (Kvale, 1996). Establishing rigour in qualitative interviewing requires data collection methods to be grounded in the philosophical principles of the methodological approach (Giorgi, 2008b, Marshall and Rossman, 1995, Englander, 2012, Wimpenny and Gass, 2000). I therefore aimed to elicit concrete, detailed descriptions of participant's experiences of paediatric outpatient care during data collection for the family study. This was consistent with phenomenological philosophy underpinning the descriptive phenomenological approach (Englander, 2012).

5.6.1 Phenomenological interviews

Prior to the start of data collection, I developed a schedule of 'experience-near' interview questions. 'Experience-near' questions ask participants to describe concrete experiences of a phenomenon, encouraging specific situations and details (Van Manen, 1997). After the first pilot interview however, I found this interview schedule to be constricting, unnecessary, and at times, leading rather than facilitating. I therefore revised the schedule in order to take a much less structured approach (see appendix 5). To get respondents talking, I started each interview with a 'grand tour question' (Leech, 2002) (e.g. Can you tell me a bit about why you/your child attended the outpatient clinic?). This was followed by an

invitation to the participant to describe (in as much detail as possible) their experience of their last outpatient appointment. Any subsequent questions were tailored to participant responses, mainly serving to clarify understanding and prompt for more detail. The use of a less structured interview style had benefits of eliciting spontaneous, in-depth and pre-reflective descriptions of the outpatient experience. I also found this method produced a more conversational interaction which led to richer and more nuanced accounts. There are of course disadvantages to unstructured interviews specifically because they can be difficult to manage, and at times I did find that interviewees could go off track. In such cases I tried to steer the participant back towards a description of the experienced phenomena, whilst remaining mindful that interviewees descriptions of their experiences were set within the broader context of their lifeworld (Todres and Galvin, 2012). Young people were also encouraged to draw pictures of their outpatient appointment if this helped them to articulate their experience. However, these pictures were used purely as data elicitation technique rather than as data themselves.

The first interview I conducted was a pilot interview and not used within the final data set. This interview was invaluable for the main data collection phase as it made me appreciate that as the researcher I was responsible for setting-up the interview correctly. This meant ensuring participants had attended the appropriate clinical service (the pilot interviewee turned out to be a parent of a child who had attended an audiology clinic running concurrently with General Paediatric clinics), asking participants to minimise distractions, stating needs of interview (i.e. to focus on description of experience) and being equipped with materials for eliciting experiences with younger children.

5.6.2 Semi-structured interviews

Semi-structured, face-to-face interviews were selected as the method for generating data with NHS healthcare professionals and other professional stakeholders. This method was chosen because of its flexible approach to data collection, providing an opportunity to probe meaningful responses in order to gather in-depth data, whilst ensuring that topics important to the research area were covered (Britten, 1995). The aim of the interviews was to explore the 'insider' service-provider perspective, capturing participants thoughts, perceptions, feelings and experiences of providing paediatric CCTH, in their own words (Taylor, 2005).

Semi-structured interviews were guided by a flexible schedule of questions, structured around topics such as CCTH initiatives, current outpatient services and delivering outpatient services in community settings (see figure 5 / appendix 5). Questions were open-ended and responsive to individual participants, meaning that the order and wording of questions were tailored and additional prompts or questions used where appropriate. The schedule ended by asking participants to discuss where they thought general paediatric services should be delivered and finished by asking if there was anything else that they wished to add. The interview schedule was piloted with two paediatric registrars, resulting in refinement of question wording and adding in a question about CCTH policy recommendations. Following the introduction of proposed radical changes to NHS organisation with a new coalition government, a question about the impact of the new white paper, 'Equity and Excellence: Liberating the NHS' (DH, 2010a) was also added in.

Figure 5: Topics covered in staff interviews

Topics covered by semi-structured interview schedule
<ul style="list-style-type: none">• Closer to home policy• Delivering secondary care services in community settings• Local Children’s Hospital context• Perceptions of family views and experience• Location and design of services• Access and attendance to appointments• Working across the primary-secondary care interface

5.6.3 Interview setting

Individual interviews were carried out at a location that was most convenient for the participant. For families this could have been in the interviewee’s home, in a private room in the Children’s Hospital, a private room at the University of Birmingham or in a community setting (e.g. a children’s or community centre). For staff this could be in their usual place of work, or in a meeting room in the hospital Research and Development (R&D) department. Increasingly social scientists see the “concept and agency of place to be an important influence on human activity” (Anderson et al., 2010, p.599), arguing that interviews are “structured by the spatial context in which they are conducted” (Sin, 2003, p.306) and that the place of the interview necessarily holds implications for power relations (Elwood and Martin, 2000).

Most parent and young people participants chose to be interviewed in their homes. This had advantages of being a more relaxed and familiar environment, providing context of the participant’s lifespace (Sin, 2003), and redistributing power from the researcher to the

respondent (Elwood and Martin, 2000). Negotiating my role as a 'friendly' outsider (Jordan, 2006) often resulted in me being welcomed as a guest by families, being offered cups of tea and introduced to family members. Nevertheless, this setting also came with practical disadvantages, namely disruptions to the interview in the form of telephones, children, doorbells etc. Three interviews took place at the hospital, two in a room in the R&D department and one in a room in Main Outpatients. This environment provided fewer distractions, but felt more impersonal, which may have influenced participant's responses.

The majority of staff participants chose their office as the interview site. Conducting interviews within the participant's workspace presented practical difficulties, including interruptions from colleagues entering the room, telephones ringing and beeps sounding. When this happened audio recording was paused and resumed following the interruption.

5.6.4 Informed consent

At the beginning of each interview, informed consent / assent to take part in the research was obtained from the participant. To do this, specific informed consent 'agreements' were developed, stating that participants were voluntarily willing to partake, understood the purpose, procedures and any risks or benefits of participation, their right to stop recording at any time and processes used to protect confidentiality (Kvale, 1996). Written consent was obtained from parents who were participating themselves and from the parents of participating children and young people. Informed, written assent (agreement to participate) was also obtained from children and young people who were participating themselves (Phelan and Kinsella, 2013, Fargas-Malet et al., 2010). In accordance with 'Seeking Consent: working with children' (DH, 2001) and following specific National

Institute for Health Research (NIHR) training in informed consent, the principles of Good Clinical Practice (GCP) were followed when obtaining consent from all participants. As it was considered important for staff and stakeholder views to be understood within the context of their professional role, all staff participants were fully informed that their job titles would remain transparent throughout reports and gave written consent to this effect.

5.6.5 Interview techniques

During the interviews I drew on a range of techniques learned from previous experience of conducting qualitative interviews and from formal training. The first was to build a rapport with the participant (Giorgi, 2009). I tried to do this by introducing myself as a researcher based at the Children's Hospital, giving a brief description of the project, and explaining how their interview would assist the study. As Taylor (2005) points out, the way participants respond to questions may be influenced by perceptions of the role and status of the interviewer. I therefore tried to demonstrate that I had some knowledge of paediatric services, but less than the respondent. I also assured participants that any information they provided would only be used for the purposes of the study. Throughout the interview I tried to appear friendly and curious (Leech, 2002), apprehending the phenomena by reflecting back my understandings to check for shared meaning (Taylor, 2005). I also pushed participants to explain commonly used, descriptive words (e.g. 'can you describe what you mean by...' or 'can you give me an example of...'), thus bracketing my own assumptions, in order to reveal the experience as it appeared to the participant (Jasper, 1994). In addition, I used interpersonal skills (e.g. active listening) to convey my interest and tried to explore non-verbal cues, which may have indicated that a participant

was struggling to find the appropriate words to describe their experience (Gendlin, 2009). Finally, although uncomfortable at times, I tolerated silences, working at the participant's pace by slowing down and speeding up where necessary.

In between interviews I often listened back to audio-recordings. Although not always possible due to time constraints, I found this to be a valuable method for reflecting on my interviewing technique and on the quality of the descriptions being elicited. Throughout data collection this resulted in refinement of my interview style. As Englander (2012) explains, it is "only through an openness and reflection on one's previous interviews that one can become a better (and more present) interviewer" (p. 28).

5.6.6 Closing the interview

At the end of each interview, participants were asked if they wanted to add any other details that had not already been covered. Recorders were then switched off and socio-demographic information obtained. Participants were debriefed on what would happen to the findings and how they could contact the research team to ask questions or withdraw participation up to two weeks later. Commonly, at the end of the interview and after participants had declined to add anything else and the recorder had been switched off; participants would continue the discussion or raise new issues. When this happened, I tried to note down everything that was said either in the room or straight after. These notes were taken into consideration during analysis, but not used as verbatim quotations.

5.7 Recording

Following informed consent a digital voice recorder was used to record all verbal exchanges between myself and the interviewee. Descriptive as well as reflective notes were hand written during and straight after each interview. These included notes on what I had seen, heard, experienced, and thought about during an interview, including impressions of the setting and the interviewee's non-verbal behavior.

5.8 Transcription

All interview recordings were transcribed verbatim. Long pauses and laughter were noted within the text, but other non-verbal sounds were omitted as the content of participants' responses was of primary interest. This transcription process started the course of data familiarisation, allowing me to make additional notes as I transcribed and remembered the interview. I found that listening to the interviews helped to transport me back to the situation, allowing me to recall the setting and my impressions. At this point I also took time to re-read through my reflective diary and make further notes. Following initial transcription, all the interviews were listened to again and transcripts checked for errors.

5.9 Ethical considerations

A favourable opinion of the proposal for the family study was given by the West Midlands REC and BCH R&D. Participants were informed that the interviews would be audio-recorded and that transcribed excerpts from their interview may be used in reports and publications arising from the study. All participants were given code numbers and any identifying information was altered or omitted from transcripts. All audio recordings were transferred

to a password protected computer and then on to a secure server. They were then deleted from the portable audio device. Interviewees were informed that they were under no obligation to answer particular questions and could terminate the interview at any time. Participants were also made aware that they could withdraw their participation retrospectively without explanation up to two weeks after the interview. Contact details of the research team were made available had participants wished to contact us. Given the possibility that participants may not have read the consent form in its entirety these issues were reiterated prior to the beginning of each interview.

When meeting participants at their homes for interview, a lone worker policy was followed. This involved me informing a member of the research team of the participant's name, address (location of interview), time of interview and expected duration. I carried a fully-charged mobile phone at all times and a designated team member was contacted before I went in to the house for interview and when I left. Transcripts and socio-demographic information were stored securely in a locked filing cabinet and labelled against their interview number. The contact details of all participants were stored separately from the data in a different locked filing cabinet in a locked room.

During data collection, I encountered several ethical problems regarding the disclosure of information and complaints. For example, in one interview I became aware that a parent had potentially misunderstood clinical advice given to her by a Paediatric Consultant. This presented a dilemma in that I was unsure exactly what the Consultant had said, but felt reluctant to break the participant's confidentiality by speaking to the clinician directly. I therefore decided not to question the advice during in the interview, but discussed the case

with my research team who advised me to feedback generally to Consultants on ‘potential sources of misunderstanding in the clinical encounter’. On another occasion, it became apparent that a participant wished to complain about the care they had received. In this case, I explained the role of the hospital Patient Advice and Liaison Service and encouraged them to contact the service regarding their complaint.

As the staff study was classified by the National Research Ethics Service (NRES) as a service evaluation, NHS ethical approval was not sought. Nevertheless, consent from the hospital R&D department was obtained and the principles of GCP adhered to at all times. All interview participants were informed of what the study was about, and what their involvement would entail. They were also given an indication of what would happen to the data, including its use in any reports, publications or presentations both at the hospital and at external conferences. As already stated, consent was sought prior to the interviews being conducted and the audio recorder being switched on. Identifying information such as names, events and places were removed from the data, but job titles remained transparent, which respondents were made aware of and consented to. Completion of the data collection process also included a debriefing of all participants, where the next steps in the research were explained. Participants were given a debriefing sheet containing written contact details of the research team, and encouraged to contact the team to discuss questions or to withdraw participation.

5.10 Reflexivity

Reflexivity encourages researchers to identify and reflect on how their decisions, bodies and actions influence all aspects of the research inquiry (Horsburg, 2003, Ellingson, 2006).

As the researcher's presence and form of involvement is integrated into respondent's accounts (Polkinghorne, 2005), relationships between the interviewer and interviewees are particularly important factors to consider when taking a reflexive approach to qualitative interview research (Shaw, 2010). In light of this, a reflexive account of the data collection and analysis process will now be described.

In this study I presented myself to families and staff as a hospital employee, and as a researcher interested in finding out what it is like for participants to receive or deliver paediatric outpatient care in different settings. This enabled me to present myself as a hospital 'insider' but removed from the direct delivery of patient care. When approaching families in the main outpatients, I often felt uncomfortable and self-conscious, as if I was intruding somehow on their appointment and their lives. At times, this made me feel anxious, but once I had engaged the family in conversation, my anxiety tended to ease and most families were happy to chat about the project and their experience. When talking to families I became very aware of how I presented myself and the project. My clothes, body posture, tone of voice and the words that I used could all have impacted on the willingness of families to take part. I was careful to manage the potential power imbalance through physically positioning myself at the same level as participants, whether this meant standing, sitting or crouching (Phelan and Kinsella, 2013). I tried to be as informal and relaxed as possible when explaining the study, being mindful to engage both parents and young people and trying to strike a balance between being encouraging but not coercive. At the same I was conscious that families could be called into their appointment at any time. There was some pressure therefore, to make the interaction as concise as possible. While this could have undermined attempts to build a rapport with potential participants, it was a

practical necessity of the recruitment strategy. Satellite clinic recruitment was easier in that it was clearer regarding which families were waiting for a paediatric appointment, meaning that I was sure the people I was talking to would be eligible to take part in the study.

Positioning myself as a hospital 'insider' may also have influenced why particular participants agreed to take part in the research. For example, some respondents were eager to tell me that their participation was a way of 'giving something back' to the hospital. Others saw the interview as a kind of informal exchange of services. Lofland and Lofland (1995) describe this 'trade-off' as a legitimate component of the research process, in which interviewees seek something in return for their participation. For example, it became apparent that for some participants the 'trade-off' was having someone listen to their account of something that was important to them (Primeau, 2003), for others, it was the desire to express dissatisfaction with the care they had received or to use the interview to access further clinical advice or appointments.

Bracketing my own preconceptions throughout data collection and analysis was also challenging. In listening to participants' experiences, I understood that I needed to set aside my theoretical knowledge of patient satisfaction, as well as my experiences of recruiting in the main outpatient department and satellite centres, and of being an outpatient myself in the past. This process required me to engage in personal reflection outside of my position as a researcher. For example, when listening to a 15 year old male describing his experience of living with epilepsy; his fears of having seizures, the feelings of being mollycoddled by protective family members and that his mind had been slowed down by medication, all resonated with my own personal experiences of being adolescent and epileptic. It was only

by becoming aware of this familiarity with what I was hearing that I felt able to separate my own experience from that of the participant.

Maintaining control of the interview was also difficult when participants, in particular senior members of staff tried to dominate the interaction by questioning me, for example by saying '...and what do you think?' When this happened, I tried to regain my role as the interviewer by giving a very neutral answer and deflecting attention back to the participant. There were also instances whereby staff and stakeholder respondents challenged my interview style, questions or the research topic itself. In these cases, although anxious, I tried to remain professional and restate the purpose of the study. As the research progressed however, it became clear that the issues being discussed during interviews uncovered a number of frustrations with the hospital organisation and the wider health service. Even though I tried not to engage in debate with interviewees, it was sometimes difficult to abstain from colluding with them, especially when they wanted to tell me things 'off the record' or asked me to tell them things 'off the record', generally regarding other interviewees views on organisational reform.

5.11 Methods of data analysis: family study

The first step of the descriptive phenomenological data analysis process was to assume the attitude of the scientific phenomenological reduction. When reviewing data therefore, I tried to acknowledge and set aside my personal experiences and theoretical knowledge. I also tried to refrain from making judgments about the importance of different features of the experience by treating them with equal importance (Moustakas, 1994). Within this

phenomenological attitude, I then followed Giorgi's (2009) steps of descriptive phenomenological data analysis.

5.11.1 Obtain a sense of the whole

After adopting the phenomenological reduction and whilst setting aside any preconceptions, I read and re-read each transcript until I became immersed in the text and felt that I had obtained a general sense of what the data was about as a whole experience.

5.11.2 Determination of meaning units

Having grasped the essence of the whole, I slowly re-read through each transcript with a focus on discriminating units of meaning within the description. This was carried out by marking with a slash in the text every time I experienced a significant change of meaning. As the phenomenological reduction was also assumed, the meaning units were determined from a phenomenological health services research perspective. This did not occur with every sentence, as a unit of grammar is not necessarily sensitive to revealing meanings within the experience (Giorgi, 2009); instead it occurred every time there was a shift of meaning within the text relevant to the outpatient experience. At the end I was left with transcripts which had been broken down into a series of meaning units guided by the data itself (see figure 6). This step also helped to make the data more manageable.

Figure 6: Example of a transcript split into meaning units

“Right, well we went in the car, we park in the car park just around the corner, not exactly sure what it’s called, but it is expensive, if I can I will park outside, I’ve managed to get outside on one of the outpatients appointments which isn’t too bad, it’s not too expensive to park there. / Actually sorry, thinking back, the last time I went my husband dropped us off and I caught the bus back and it was easier then thinking about it, the last time my husband dropped us off / and it was a Saturday morning appointment. / I expected it to be quiet, but it was very very busy, very busy. / We had to wait quite a long time, and that is my experience of the outpatients, I have had to wait a long time, the clinics are usually running late, I think the last time we went it was oh gosh, it was about an hour we had to wait, it really was quite a long time so, / but when we walked in, we pulled a ticket, it’s quite an easy system, you understand the system, it’s not like you know there’s no problems there, pulled a ticket, wait then they call you up to the desk /” (Parent 4, BCH)

5.11.3 Transformation of data

Following the identification of meaning units, I set about transforming participants’ raw data from their natural attitude into more phenomenologically sensitive and meaningful expressions of the outpatient experience. The aims here were to reveal meanings that were lived but not explicitly articulated and to move from very specific descriptions of concrete situations to more general expressions of the experienced phenomena (Giorgi and Giorgi, 2003). To achieve this, I went back to the start of each transcript (now delineated into meaning units) and transformed each unit from first person to third person expressions, so as to make it clear that I was carrying out analysis on another person’s experience and not my own (Giorgi, 2009). I then interrogated each unit for meaning, drawing out dimensions that were significant to the phenomenon and re-describing them in language relevant to

the discipline of health services research (HSR). I also re-described each meaning unit in a way that did justice to the concrete situation, but expressed the experience in a more general way (Todres, 2005), always being careful to recognise and abstain from imposing any theoretical concepts or hypotheses. At this stage I arranged the meaning units and transformations into a table with meaning units in the left hand column and corresponding transformations in columns two and three (see table 7). This helped to manage the data and aid transparency so that transformations could be traced back to the original data.

Data transformation was further facilitated by reflecting and engaging in a process of free imaginative variation, whereby data is imaginatively changed or modified until a common thread appears. As Giorgi (1997) states, “in this step, statements of the subjects are transformed by the researcher to be in accord with the researcher’s disciplinary intuition, which become stabilized after the process of free imaginative variation” (p.247). In other words, parts of a phenomenon are changed to see if it remains identifiable with the part changed or not. In doing so, “one becomes aware of those features that cannot be removed and thus what is essential for the object to be given to consciousness” (Dahlberg et al., 2008. p.243).

Following transformations, meaning units that seemed to belong to together were clustered, before the clusters were rearranged to create a preliminary pattern of understanding (Dahlberg et al., 2008).

Table 7: Example of data transformation, Parent 10 family centre

Original Text	Description by meaning unit (3rd person transformation)	Scientific Attitude: Health services research (meaning transformation)
(25) Like, it's not like a proper like, whereas like obviously at the hospital they can do like a full MOT basically, like check your ears, nose, throat, all that sort of thing, whereas that one you can't.	P10 states that her son can have a full body medical check-up at the hospital, which is not possible at the family centre.	Attending appointments at the hospital enables clinicians to conduct a comprehensive medical examination, which is not possible at the family centre.
(26) I mean obviously they've probably got the equipment put away somewhere, but it's not like	P10 expects that medical equipment is available at the family centre if needed.	Medical equipment is believed to be available at the family centre if needed.
(27) it's just a room basically with a doctors bed, like thing in and then a computer and chairs and toys and that is about it and it's not like a hospital or a doctors place sort of thing, it's like a nursery,	P10 states that the consultation room has a bed, a computer, chairs and toys. For P10, the centre is more like a nursery than a hospital.	Informal surroundings and home-like artefacts lead to the family centre feeling more like a nursery than a hospital.
(28) which to be fair I was a bit shocked when I first went there to be honest because I was like 'woah' obviously you know, why am I coming here, I thought it was like, not realistic sort of thing	P10 states that she was surprised when she first went to the centre for her son's appointment. She thought it was strange and unrealistic to deliver outpatient appointments in such an environment.	Delivering paediatric outpatient appointments in such a non-medical setting is odd and unfitting.

5.11.4 Formulation of essential general structures

Once the data had been split into parts, transformed and clustered into groups, the text was once again treated as a whole. Individual structures of the outpatient experience were synthesised into a general structure for main hospital parents; main hospital young people; satellite clinic parents and satellite clinic young people. Following this, parents and young people's essential structures were synthesized to form a general structure for families experiences of paediatric outpatient care received in a traditional hospital setting and in

new 'closer to home' community settings. The aim of these structures was to present a statement of the invariant themes that ran through each participant's experience of the phenomenon, thus determining those parts that were typically essential in the general description. The two structures were then compared and particular variations highlighted.

5.11.5 Trustworthiness

Although scholars have argued that reliability and validity remain appropriate concepts for attaining rigor in qualitative research (Morse et al., 2002), new criteria have been proposed for assessing the 'trustworthiness' of qualitative study findings in terms of their 'credibility', 'dependability', 'confirmability' and 'transferability' (Lincoln and Guba, 1985). Strategies to fulfill these quality criteria include researcher reflexivity, member checking, thick description, searching for disconfirming evidence, audit trail and peer debriefing (Creswell and Miller, 2000).

To establish trustworthiness throughout this study, I maintained consistency between methodology and method (Englander, 2012, Wimpenny and Gass, 2000), using Giorgi's (2009) descriptive method which is grounded in Husserl's phenomenological philosophy. I also tried to keep my descriptions grounded in the original data, verifying experience with the data by constantly checking my understanding with the data itself. This meant that the analysis was driven by a search for meanings as lived by the participants within the disciplinary perspective of HSR. In addition, I kept a reflective diary of my thoughts and impressions, beliefs and potential biases. This encouraged me to reflect on my own social, cultural and historical context and helped me to bracket my experiences, expectations and existing knowledge as the study progressed. I documented all decisions made throughout

different stages of the research and kept the whole analysis process transparent by clearly demonstrating how I moved from individual participant data, through transformations to a general structure. Finally, I regularly met with other members of the research team to discuss and review my data analysis, which served to challenge my assumptions and pushed me to justify analytic decisions.

Licolln and Guba (1985) argue that member checking is one of the most important strategies for maintaining credibility in qualitative research. This technique consists of taking findings back to study participants for verification. The problem with this however, as Giorgi (2008b) points out, is that participants describe their experiences from the perspective of the natural attitude, but the analysis is performed from the disciplinary (HSR) perspective. This means that the findings are necessarily replete with the discipline's orientation, which may differ from the experience as recalled by the participant. Giorgi (2008b) elaborates:

“The purpose of the research is not to clarify the experience that the individuals have for their own sake, but for the sake of the discipline... the research is undertaken in order to understand certain disciplinary phenomena in a more adequate way. Whether or not the individual participant agrees with the findings is beside the point.” (p.5)

Moreover, as findings have been synthesised from across many participants' experiences to form a general structure of the phenomenon, there is no reason for individual participants to be able to see their own, very specific experience within the findings (Morse et al., 2002).

5.12 Methods of data analysis: Staff and stakeholder study

Transcripts from staff and stakeholder interviews were analysed according to the five stages set out by Ritchie and Spencer (1994); familiarisation, identification of a thematic framework, indexing, charting, mapping and interpretation. Each process was used to guide the analysis of service provider data, and will be discussed in turn.

5.12.1 Familiarisation

First I became familiar with the whole data set by thoroughly reading through each transcript and by listening to audio recordings on numerous occasions. I also made notes in the margins of the transcripts, re-read my research diary notes and discussed the interviews with other members of the research team. This step was essential for facilitating my understanding and navigation of each interview as a whole.

5.12.2 Identification of a thematic framework

Following familiarisation, transcripts went through several iterations of coding in order to identify a thematic framework. In practice, this meant reading and re-reading each transcript before assigning a short paraphrase or label (code) to each passage of text identified as meaningful; summarising what was in the passage and describing what was interesting or important about it. As can be seen in figure 7, the left hand margin was used to label each passage of text and the right hand margin used to note additional thoughts and ideas. After completing this process on three transcripts, the codes or labels I had ascribed to each passage on each of the three transcripts were listed and compared. This led to the formation of an initial coding framework, that was, a set of codes each with a

brief description of their meaning. Using this framework I then coded the next set of three transcripts, whilst making note of any new codes which did not fit the existing set. The initial coding framework was then revised to incorporate new and refined codes. This process of applying and revising the coding framework was repeated until no new codes were generated. Codes which seemed to be related were then grouped together to form categories, each with a brief explanatory description. These categories and codes formed the final thematic framework (see table 8 / appendix 6).

Figure 7: Example of open coding

<i>Coding labels</i>		<i>Notes and ideas</i>
Professional role	<u>Paediatrics has more in common with General Practice than most specialties, but obviously in General Practice you're looking at the whole person, not just the disease</u> and obviously the good quality Paediatrician does that and <u>if you're seeing people nearer to their home setting</u> , then you can see, you know an <u>outpatient department is a bit remote</u> and I'm not saying it's inhumane but <u>if you are in a setting you're comfortable in, you're going to be more relaxed</u> , you	Family centred care; holistic versus disease model; 1° vs. 2° care
Place & Space	might be <u>more honest and open and give better quality answers particularly if there are social issues. It would be good for Consultants to be, you know recognised in a certain area</u> and I think they would appreciate that as well. So no I think, obviously <u>ways in which care could deteriorate are in terms of records</u> because obviously if	Local = more holistic - families in their environment not doctors; more relaxed; shift in power?
Patient experience	the Consultant doesn't have the notes, that's a disaster, so I don't know what the <u>IT set up</u> would be like, that would, you know obviously if the <u>Consultant can access notes remotely</u> whatever you're planning, that would be very, very important. (GP 5)	Experience differs according to setting – impact on consultation / outcomes?
Primary-secondary care		Construction of Consultant as detached?
Quality of care		Notes, technology, IT systems affect quality of care, risks
Technology		

Table 8: Example of a category from the final thematic framework

Working Practices	
Professional role	<i>Perception of own or other's roles, including empowerment, professional pride, GP commissioning, GPs with Special Interest (GPwSI)</i>
Relationship between primary and secondary care	<i>Barriers, gaps, advantages and drawbacks, working relationships</i>
Knowledge and skills transfer	<i>Education, information, explanations, teaching, training (student doctors, GPwSI)</i>
Joined up working	<i>Instances of working together from two or more different disciplines, working across care sectors</i>
Changes in working practices	<i>Impact / outcome in terms of changes to working practice (e.g. Saturday clinics), changes to clinician workload, Consultant travel</i>

5.12.3 Indexing

Once the final thematic framework had been developed, it was systematically applied to all transcripts. This was assisted by the use of a qualitative data-management package (QSR NVivo version 8). As shown in figure 8, transcripts were imported, re-read and each meaningful passage of text highlighted and assigned a code from the thematic framework.

Figure 8: Example of application of the thematic framework to part of a transcript

So do you think that access would be easier then for people in community settings?

“Yeah, I mean of course it would be. Of course it would be. But, but this goes back to the point I was making before that, what, what, ideally what you try and do with access is to improve the access, so if you just transfer a clinic from a, from a hospital setting into a community-based setting you’ll improve the access for some people and reduce it for other people. You know ideally what you’re trying to do is to complement and supplement it, so you know, you can have some services that are in, in a hospital basis, but you also replicate some of those opportunities and access in a community-based setting. But to do that will potentially cost, cost resources, so you know, is it cost effective to do it? I think that, that it is just, I keep coming back to it, but that’s the one big issue I think that we’ve not really thought through around the care closer to home. It’s got to be part of the much bigger picture around the sort of self-care and self-management, because if it’s not it will be more expensive.” (Executive5)

Equity in service provision

Ideology of CCTH

5.12.4 Charting

Once all transcripts had been coded using the final thematic framework, data were charted into a matrix for each category using Microsoft Excel. The NVivo package was particularly useful at this stage as it meant that passages of text from across the whole data set that had been coded with the same label could be retrieved quickly and easily. Each matrix comprised of one row per participant and one column per code. Coded data were then abstracted and summarised using verbatim words and charted for each case and each code within that category. This required a balance between reducing the data and retaining the original meanings and feel of the participant’s words. Charted data also included references to interesting or illustrative quotations (see table 9). Whilst charting, I kept notes on any

impressions, ideas and interpretations of the data. These were then discussed with the research team and contributed to the final, interpretation stage.

Table 9: Extract from the ‘Philosophy of Care’ matrix (Q’s indicate potential quotes and underlining indicates verbatim text).

	Ideology of CCTH	Patient-centred approach	Equity in service provision	Equivalence to hospital care
Manager 1	Gen Paeds doesn’t need to be in hospital; with right infrastructure CCTH makes sense [p1, 24].	Need to deliver services based on what families need; at the moment <u>focused on what's easier for us</u> QQQ [p16, 467].	For some people a city centre hospital is CTH than a clinic in the community [p620, 21].	Need to <u>instil confidence</u> that they're getting same level of care, but CTH [p2, 33].
Consultant 7	CCTH is a good recommendation; only patients who need specific investigations should attend hospital for outpatients [p1, 7].	<u>Preservation of the institution</u> (hospital), <u>rather than needs of the population they actually serve, seems to be the predominant interest</u> QQ [p3, 69].		<u>Make it clear to patients it's exactly same service</u> in satellite clinic, <u>they are seeing me</u> (same Consultant) [page 1, 16].
Executive 5	The more we keep patients out of hospital, the better; don't want patients in hospital if don't need to [p1, 14]. CCTH is part of <u>bigger picture around self-care and self-management</u> [p11, 350].		If just transfer clinic from hospital to community setting, <u>improve access for some, but reduce it for others</u> QQ [p11, 340].	

5.12.5 Mapping and interpretation

Thematic analysis (Braun and Clarke, 2006) was carried out on the managed data set by reviewing the matrices, identifying patterns and making connections within and between codes and cases. This process was influenced by the original research objectives and by concepts generated inductively from the data (Fereday and Muir-Cochrane, 2006, Pope et al., 2000). During the interpretation stage I tried to go beyond description of particular cases to explanation of reasons for the emergence of particular phenomena. In cases where interesting ideas felt worth exploring and developing in more detail, structured memos were written (see appendix 7 for an example). Memos contained a definition of the issue or topic, specific codes that related to the topic, a summary of raw data, discussion of any deviant cases and further points for consideration (Charmaz, 2006). These memos substantially contributed to the development of key themes.

5.12.6 Trustworthiness

Trustworthiness in the findings was demonstrated through regular meetings between the research team enabling exploration of participants' responses and discussion of deviant cases to be discussed. A diary was also kept throughout data collection and analysis. This enabled an audit trail of pragmatic and analytic decision making to be maintained throughout the research process and demonstrated transparency of progression from raw data through to interpretative findings (Creswell and Miller, 2000). The interview schedule was also piloted during development to ensure face validity. Finally, preliminary findings were presented to the General Paediatric team, who provided their comments and contributed to the refinement of interpretations (Fereday and Muir-Cochrane, 2006).

5.13 Summary of methods

In this chapter I have described the methods used to collect and analyse data to answer research questions from the perspectives of service-users and providers. Consideration was also given to issues of ethics, reflexivity and maintaining trustworthiness throughout the process. Findings from the phenomenological family study are presented in the next chapter, followed by findings from the staff and stakeholder interview study in chapter 7.

CHAPTER SIX

6 FAMILY STUDY FINDINGS

6.0 Introduction

In this chapter, findings from interviews with parents and young people who have experience of receiving specialist paediatric outpatient care at the hospital or in one of the two community-based clinics are presented. The aim was to understand what the paediatric outpatient care experience was and how it changed in different settings. The chapter begins with a description of the participants, before presenting the general structure of the experience of receiving General Paediatric outpatient care at the Children's Hospital and then at 'Closer to Home' community clinics. These are followed by an analysis of the constituents of the general structure including quotations from the interviews, demonstrating commonalities and variations within participant's accounts. In line with the descriptive phenomenological tradition, findings are written in a way that attempts to retain the 'texture' of the human experience as well as maintaining structural accuracy. Thus the style of writing within this chapter is deliberately used to provoke a sense of recognition and empathy within the reader (Todres, 1998). Discussion of how the place of healthcare delivery influences the paediatric outpatient experience concludes the chapter.

6.1 Research question

In this chapter the following research question is addressed:

- What are the experiences of families of receiving specialist paediatric outpatient care in different settings?

6.2 Description of participants

For this study, 13 parents and 14 young people (YP) were interviewed. As discussed in the methods chapter, this number was selected in line with recommendations for phenomenological studies (Morse, 2000) and to facilitate distinction between those aspects of the experience that are invariant across accounts, and those which vary (Finlay, 2009, Langdridge, 2007). Characteristics of the participants can be seen in tables 10 and 11. Seven parents and eight young people were interviewed about their experiences of receiving outpatient care at the hospital, and six parents and six young people were interviewed about their experiences of receiving outpatient care at one of the two community-based clinics (family centre and health centre). Parent participants were not related to the young people participants, thereby providing a wider variety of experiences. There was also a wide range in participants' ethnicity, age and how close in proximity they lived to the Children's Hospital. That all parent participants were female reflects the prevalent pattern of mothers as the predominant carer and most likely to accompany their child to an outpatient clinic appointment (Darbyshire, 2003).

Table 10: Characteristics of parent participants

Parents									
Part No	Age	Child Age	Gender	Ethnicity	Employment	Miles to BCH	Clinic	Recruit	Interview place
P1	38	11	Female	White British	Part time	5	BCH	FTF	Home
P2	38	2	Female	White British	Part time	7	BCH	Letter	Home
P3	43	15	Female	South Asian	Part time	4	BCH	Letter	BCH
P4	38	7	Female	White British	Part time	5	BCH	Letter	Home
P5	39	4	Female	White British	Part time	5	BCH	Letter	Home
P6	28	3	Female	South African	Part time	9	BCH	Letter	Home
P7	46	14	Female	South Asian	Un-employed	3	BCH	Letter	Home
P8	44	14	Female	White British	Un-employed	6	Wychall	FTF	Home
P9	28	7	Female	White British	Student	9	Wychall	FTF	Home
P10	22	1 1/2	Female	White British	Un-employed	9	Wychall	Letter	Home
P11	36	8	Female	South Asian	Part time	8	Greet	FTF	Home
P12	30	1	Female	South Asian	Un-employed	3	Greet	Letter	BCH
P13	34	6	Female	South Asian	Employed	4	Greet	Letter	Home

Table 11: Characteristics of young people participants

Young people							
Part No	Age	Gender	Ethnicity	Miles to BCH	Clinic	Recruit	Interview place
YP1	14	Female	White British	10	BCH	Letter	BCH
YP2	9	Female	White British	6	BCH	Letter	Home
YP3	8	Female	South Asian	1	BCH	FTF	Home
YP4	14	Female	White British	5	BCH	Letter	Home
YP5	14	Female	British Asian	3	BCH	FTF	Home
YP6	15	Male	South Asian	4	BCH	Letter	Home
YP7	12	Female	White British	7	BCH	FTF	Home
YP8	15	Female	British Asian	3	BCH	Letter	Home
YP9	11	Female	White British	11	Wychall	FTF	Home
YP10	10	Male	Black British	10	Wychall	Letter	Home
YP11	12	Female	White British	9	Wychall	FTF	Home
YP12	10	Female	Black British	4	Greet	FTF	Home
YP13	11	Male	South Asian	4	Greet	FTF	Home
YP14	15	Female	South Asian	4	Greet	Letter	Home

6.3 General structure

The general structure describes the invariant features of receiving General Paediatric outpatient care at the main Children’s Hospital, for participants in this study. Although parents and young people each provided their own distinct descriptions, all experiences of the phenomena were underpinned by invariant features or essential constituents. These are expressed in the general structure.

6.3.1 Receiving General Paediatric outpatient care at the Children's Hospital

Attending a hospital outpatient appointment requires considerable mental and physical preparation. The unpredictable nature of the appointment means that allocation of time is difficult to estimate. This causes disruption to the family routine, with activities of daily life having to be re-constructed around the child's appointment. Hospital outpatient care is experienced as *more* than just the appointment. It is an event which governs the family's life for that entire day and those leading up to it. When hospital outpatient appointments are impending, families feel torn between a desire to access specialist paediatric healthcare and the dread of enduring the whole procedure. After a hectic journey, hampered by heavy traffic and lack of time, families arrive at the hospital outpatient department. Leaving behind their sense of identity and autonomy, they step into an alternative social universe; a vast, self-governing and all-embracing space, bursting with people, noise and colour. Giving themselves over to a time and activity schedule not of their own making, families are guided through various administration checks and processes, before being instructed to find a seat amongst the chaos of people and toys. Waiting is briefly relieved by a nurse calling for routine measurements to be taken, before the family is escorted to another, calmer area to resume their waiting. When it eventually comes, the care provided by a Specialist Paediatrician is succinct, but does provide the kind of compassionate reassurance that families crave. After the appointment families seek out pleasurable activities to revive and restore equilibrium, always striving towards the point at which medical intervention is no longer required.

6.4 Constituents of the general structure

The essential meaning of the hospital outpatient appointment for families can be further understood by examining its eight constituents:

- Preparation
- Journey
- Arrival
- Waiting
- Height and Weight
- More waiting...
- Consultation and care
- Post appointment

The constituents reveal '*what*' participants experienced during their paediatric hospital outpatient appointments as invariant and sequential, mapping onto to the externally structured outpatient process. '*How*' participants experienced each constituent however did contain variation. Variations of the constituents included the age of the participant (whether they were a parent, adolescent or younger child) and whether the participant attended a Saturday rather than a weekday clinic. These constituents along with any variations will now be discussed in detail.

6.4.1 Preparation

This constituent encompasses all the happenings prior to the appointment, which allow the appointment to be attended. For parents and patients, an outpatient appointment at the Children's Hospital is *more* than just the appointment; it is a whole day out. As such, families are required to prepare for the event both mentally and physically, making plans for every eventuality. As parents 1 and 5 explain, attending appointments requires a careful balancing of work and home life commitments, and frequent rescheduling of appointments.

"I'd gone into work for about an hour and then popped out, collected (son) and took him and then again dropped him back at school and went back into work... my preference if I'm arranging medical appointments is always to try and arrange them on a Tuesday and Wednesday so I avoid interrupting my work pattern. But again... they only have certain clinics on certain days so then that does entail me sort of obviously having to take time off work... with working and the children's holidays you have to try and preserve your annual leave, because obviously you have to take the annual leave when they're on holidays and so forth which again is a struggle, you know it's juggling so actually when you get something like these appointments come up, to have to take half a day's leave is a bit of a nuisance really." (Parent 1)

"I don't work Mondays and Tuesdays so I try and schedule all (son's) appointments on Mondays and Tuesdays. I do tend to look after another little boy on a Tuesday afternoon, so it's either Monday or Tuesday morning, but I have managed to do that, I have managed to schedule all my appointments around my work and other commitments, so that has been fine. It's just a matter of ringing up and changing all the appointments." (Parent 5)

Being unable to predict the duration of the appointment means that parents cannot make plans for the rest of the day. This causes major disruption to their family and work routine. As Parent 6 describes, families with more than one child are also required to arrange for

siblings to be taken to or collected from school and cared for until the parent returns.

Saturday appointments however, contribute to less demanding preparations:

“I know it’s going to be hours and even if the others are at school I still need to organise child care because you just can’t guarantee what time you’re going to be back or what’s going on so I have to sort out what I will do with my other two kids. (Saturday appointments are) actually easier because it means I don’t have to worry about my other two kids because my husband can have them or my Mum can have them because she’s not at work. The Saturday’s are actually much much easier for me because I don’t have to worry about school runs or anything, I can just take him and just the two of us go together.” (Parent 6)

Families expect the outpatient department to be extremely busy with long waiting times during week-day appointments. Becoming aware that her child’s outpatient appointment is approaching fills parent 5 with a sense of dread: “You know your heart does sink when you think you’ve got to go in a week and the waiting.” (Parent 5)

To prepare for long waiting times parents try to equip themselves with enough food, drink and entertainment to keep their children satisfied. The aim is to complete the outpatient appointment as quickly and as smoothly as possible:

“I just want to get in and out and not have the whole drama of going to the hospital and then trying to find parking and paying umpteen pounds and waiting for hours...” (Parent 5)

“I just wish they would hurry up really so I can get in and get out... I don’t like hanging around, I like to just get in, get done and go home.” (Parent 6)

Preparation is less cumbersome for young people, who often view their appointment as an opportunity to miss school; relying on long waiting times to capitalise on the amount of school missed:

“I mean, like I am very keen at school, I do my work and all that, but it just feels good to be free and go home and I always want my appointments around 12 o’clock, 11 o’clock because if you go at 11 half past 11ish, then you don’t have to go in the morning and you don’t have to go after, otherwise you get sent afterwards. I don’t normally go in the morning though, I just normally say I’ve got too much busses to catch and it takes too long, I just say that and that’s why I never go.” (YP 6)

Nevertheless, as Young person 8 describes, multiple appointments during school time can severely disrupt learning:

“I had a lot of appointments with Dr (Consultant General Paediatrician), it wasn’t just a couple, it was hard because I had missed a lot of my school time because of that and in, because in school if you miss an hour, one lesson, you miss a lot of work so I had to catch up on that which made me feel bad because everyone else were ahead of me and I was behind, so because of that I felt really bad.” (YP 8)

6.4.2 Journey

The city-centre location of the main hospital means that it nestles between other buildings and blends into the cityscape. This can make it difficult to find:

“It is quite hidden because if you get off the bus, there are quite a few buildings and all that because town starts and you have to walk around a few buildings and I just, when you walk around buildings and all that, between buildings and all that. Like you walk through the streets, like some hospitals are just separate on their own place and some hospitals do it in between buildings and all that, so that’s what makes it a bit hidden.” (YP 6)

For parents travelling by private transport, the journey to a city-centre hospital is hectic and hampered by congested traffic. Car parking is also difficult as it is scarce and expensive.

The car park outside the hospital main entrance is cheaper, but rarely has available spaces:

“If you’re going in the week, you end up (parking) in the one (car park) across the road or somewhere else and then it gets very expensive, so if you’re going for repeated appointments... car parking, access is a problem.” (Parent 5)

“I think it was about £7 or something the once when I was there, it is very expensive because there is limited parking around there isn't there? They haven't actually got their own car park have they, so it's just on the streets.”
(Parent 4)

Access is improved by Saturday appointments as parking spaces near to the hospital entrance become available at a reasonable cost:

“From the house, well put my son in the car and drove there, I think we park usually, well that's an interesting point to make actually, we usually park in front of the hospital, but recently, I know the last couple of appointments I've had in the outpatients were on a Saturday and that for me was really helpful that they offered Saturday appointments and that then made parking really easy 'cause their front car park was free and 'cause it was only a short visit, like I was there for about an hour and a half or something that was really convenient. But yeah, we just parked easily.”
(Parent 2)

Most families avoid problems with parking by opting to travel by bus, train or taxi.

Travelling by public transport however is stressful and unreliable. As Parent 6 and Young person 6 explain, allowing extra time for delays, cancellations and non-direct routes contributes to an extended journey overall. Buses and trains can also be overcrowded and uncomfortable, depending on the time of day.

“I need to leave about an hour because you just never know because of the trains so I always have to allow an hour because I need to make sure I'm ok with parking and then if the train actually comes and then to allow for walking the other side... Yeah because parking is a nightmare there at the hospital and it's really expensive as well, we just don't bother, I'd rather just get the train.” (Parent 6)

“It's the time that gets you going there and coming back because you always have to leave a bit more earlier than the normal time you get there for waiting for the bus and all that. Like say if your appointment is at 3 o'clock and the bus takes 10 minutes, instead of going at 10 to 3, you might go at half past or much earlier than

the busses time in case they come late or something to make sure you're actually punctual." (YP 6)

For families travelling by taxi, the journey is shorter and less traumatic, but very expensive.

Parent 7 describes the cost of accompanying two daughters to separate outpatient appointments by taxi:

"It costs me a lot. £9 going in a taxi, £9 coming back, it costs me a lot, because I took (younger daughter) on the Friday to see Dr (Consultant General Paediatrician 1) and this one was on the Monday to see Dr (Consultant General Paediatrician 2), it was £9 going, £9 coming back and £9 her coming and going and I go this is stupid, yeah, I go, I'm not just paying all that and we know that every time they got appointments we got to keep going, because I don't drive and my husband doesn't drive and none of my kids don't drive, yeah and if we go on the bus, she vomits. She's travel sick. So we have to go, there is no other way to get to the appointment." (Parent 7)

6.4.3 Arrival

As they enter the hospital outpatient department, the world fades away behind double doors and families find themselves in a large, vibrant space, buzzing with swarms of people, desks, chairs and toys. The family's attention is quickly drawn to a small reception desk, guarded by hospital assistants who request to see their appointment letter before granting full access to the department. After being instructed to press a button on a machine to retrieve a numbered ticket, families are told to sit on particular colour seats and wait for their number to be called. Quickly they scan for pockets of free space. Once a seat is found, families sit and wait, clutching their numbered tickets:

"You walk through the double doors and there is a big, like massive hall, kind of a hall. In the middle when you walk in on the right hand side there is like a reception at the start and behind that there's more chairs and on the left hand side is all filled with chairs and there's like a shop where you can buy stuff and on the left hand side at the end there is a long line of reception thingies, what they called? Desks, where

people are sitting... you pick a number and you have to wait for the number and then there is a line of colourful chairs like in squares and there is a lot of toys and magazines to read... Then I had to, oh when my number was called then I had to go to the reception, I got my number from the door. When you get your number you have to go to the reception to show it, show your letter and all that and then you wait until you get called.” (YP 6)

After a short wait, the ticket number is called out and displayed on a screen. This indicates to parents and patients that they should approach the corresponding numbered reception desk. Details on the appointment letter are checked by a receptionist and information exchanged where necessary. Families are then instructed to sit on another set of colour seats to wait to be called by a nurse.

“When we walked in, we pulled a ticket, it’s quite an easy system, you understand the system, it’s not like you know there’s no problems there, pulled a ticket, wait then they call you up to the desk and the one experience I have had, but I think it’s to do with the GPs merging, every time I go to the Children’s Hospital, they say that my GP is (name) medical centre and that’s not my GP and I’ve told them this every time I go.” (Parent 4)

“When we go in first, you press the machine on the button and a ticket comes, yeah, then we sit down and the number comes up on the wall, and someone calls out ticket number whatever, then we just go and give the details and everything like that and they tell us to take a seat on the blue chairs or them chairs and we sit down, after we have sat for about half an hour, an hour sometimes, then the nurse comes and will call us.” (Parent 7)

At this point, parents feel torn between sitting where they have been instructed to sit and sitting where their child wants to be sat, either with the toys or in a quieter part of the room. Sitting in a different place to where they are supposed to be however, causes parents to worry about missing their name and the appointment. Although the process is

quick and easy to navigate, parents feel that they are forbidden to leave the waiting area until after the appointment. As Parent 2 describes:

“We were told to sit on the, as you walk in on the right hand side of chairs, I think they’re orange, before when I’ve been up, it’s always been the blue side and the thing is, is that, especially when it’s busy and there are toys on the orange side which are for older children and all the stuff he (son) wanted to be in was on the blue side and up the other end, so it was a little bit tricky because he was off and you know being a toddler, you can’t really contain him, he’d just get annoyed unless I strapped him in the buggy, so yeah, he wanted to go and play in the tunnel bit so I had to kind of keep going between there, and the orange area to listen out for my appointment otherwise we would have missed it” (Parent 2)

Young people are immediately sensitive to the interpersonal communication of reception staff. Many experience them as cold and unwelcoming, leading young people to feel self-conscious and reluctant to engage in further conversation. Young people 4 and 6 express the importance of being greeted by friendly, welcoming staff on arrival, and the effect this initial exchange has on setting the tone for the remainder of the appointment:

“The lady who’s there when you get the ticket, she’s like, not moody but yeah a bit moody like, ‘cause when, sometimes you’ll forget your ticket and sometimes she’ll just get a bit moody like, like ‘oh excuse me, you forgot your ticket’ like, but in a moody way which sometimes gets on my nerves.” (YP 4)

“The people like at the desk don’t actually speak to you like, I know that sounds... not like equals but like I know that they’re older than me and everything but like, they talk to me like I’m five and that was the last time I came and I didn’t really, I wasn’t rude enough to say ‘I am like 14’, but like ‘cause like you try not to be rude but then you disagree and then you feel embarrassed.” (YP 1)

6.4.4 Waiting...

Although unpredictable, the high volume of families in the main outpatient department means that appointments are rarely on time. Generally families experience waiting times as long and arduous. Time spent waiting is time wasted that could be used doing everyday activities. Participant's accounts of waiting are therefore saturated with negative feelings of impatience and frustration.

6.4.4.1 The main waiting area

The main waiting area is large, crowded, noisy and chaotic, with corridors leading off like spokes from a wheel. The central space is brimming with people, all different ages and cultures united by their need for specialist paediatric healthcare. The air is hot and the atmosphere animated, as individuals struggle to make themselves heard above other families chatting, children screaming, babies crying and nurses calling out information. Multiple layers of fresh vibrant colour emanate from the walls, desks, chairs and toys, with chairs deliberately set out in quadrangles, facing inwards and outwards to encourage a sense of informality and interaction.

“It was quite full and it was nice to see like loads of parents with little children and there were like little babies for the check-ups and they look really cute. And there's like little toddlers running around like enjoying themselves and exploring. There's like stuff on the walls like to play with and they were playing with that. There were loads of kids running about and they were all screaming.” (YP 5)

“It's very colourful, it's colourful and very like clean and it's very lively. All the people and all the colours and it's very clean and all the, it's like nursery and you've got the tables and all that everything, so organised and colourful... It is nursery; you've got toys there.” (YP 6)

6.4.4.2 The noise

When the department fills with people, the volume of noise becomes almost unbearable for some parents:

“It can be very busy, very busy to the point where it’s actually very noisy as well because I think it’s just the fact that it’s a big open sort of hallway... I do find at times when it is really busy is that it is incredibly noisy.” (Parent 1)

“Chaos, yeah it just seemed quite loud, a lot of talking, a lot of people.” (Parent 4)

“It’s noisy like hell in there, it’s very loud.” (Parent 7)

“It’s just very very loud, it’s really loud because of the passing things and the kids and things, it’s not really anything in particular it’s just like a loud buzzing noise what with all the kids in there.” (Parent 6)

Waiting on edge, families intensely concentrate on listening out for their name or number, but inevitably struggle to hear above the noise. Acute awareness of missing the appointment and enduring subsequent penalties is activated at the point of arrival and continues until departure.

“You’re like very alert to like hear your name and your number and all that, because you have to start when you come in. You’ve got to listen out for your number to check in, what desk it is and you have to go to the right desk.” (YP 6)

“It’s slightly more stressful I suppose especially with trying to not miss your appointment ‘cause I was aware of you know, if they’d called our name and, I mean I know you’ve been checked in so they know that you should be there somewhere but I was worried about missing the appointment and then having to wait a long time.” (Parent 2)

Trying desperately and unsuccessfully to block out the noise. Young people 1 and 4 describe just how uncomfortable the confined waiting conditions are for adolescents, often inducing feelings of anger and irritation.

“When I’m sitting down its loud... it’s the kids just screaming when they run around like when they’re playing tig around the hospital... we just move away from it all sometimes, away from all the toys and people, just so it’s a bit quieter, move to an area that’s quieter.” (YP 4)

“It was crowded. Even though I’m sure it was organised, it seemed like it wasn’t... I hate being crowed, it makes me feel all hot, I get quite moody, it feels like I’m isolated and I can’t move and so like, you stay there because there’s not any room to go, so you just stay in that spot and there’s people running across, kids running across obviously not adults and there’s parents shouting at the kids to stay like in one part and obviously most of the kids don’t listen, so the parents get angry, so they scream even more and then you end up getting a headache... (Little brother) hates noise, he was crying because it was so loud and there’s little kids crying because they don’t like it either, so like (little brother) cries because they’re crying which is quite annoying. It was noisy because like, all the noise is, just like with the tickets, calling out the tickets, people crying, moaning, people just having general conversations, just everything combined and that’s quite loud... I sat down and I just stared at the floor thinking please can you just hurry up and call my number?” (YP 1)

6.4.4.3 The staff

The doctors and nurses reside in small corridors off the main waiting area, only emerging to call patients’ names. Staff appear to be under extreme pressure with the amount of patients in the department, often causing them to be impersonal and impatient. Few nurses make the effort to interact with children and most struggle to make themselves heard over all the noise. Parent 4 gives an example of how this often results in names being called out repeatedly:

“It just seemed quite loud, a lot of talking, a lot of people and when they were calling the people through the healthcare, I don’t know if they were healthcare assistants or nurses they seemed to be getting quite sort of stroppy because people couldn’t actually hear what they were shouting. There’s obviously a lot of ethnic minorities that go there and their names are difficult to pronounce, so she kept coming out calling people and you know and unless your name is distinctive you

can't really, which my name was distinctive when I was actually in the hospital so you can't actually hear them calling you properly, I mean the one person she had to call three times and she didn't seem very happy about the fact that she had to call him and I didn't really like that attitude, I sort of said there and then like, you know I wouldn't have like it if she had called me like that so, but I think they were extremely pushed to the limits." (Parent 4)

6.4.4.4 Information

Little information is provided to families regarding waiting times. Speculating about the amount of time wasted causes frustration to build, culminating in the urge to demand to know how much longer the waiting will last. Parents maintain composure by rationalising that rage will not make time pass quicker. Being in possession of information on waiting times would however help parents to manage their waiting time and prevent staff from constantly having to explain to individual families how much longer they have to wait.

"I don't think they keep you very well informed but then I suppose because there is just so many different clinics going on from the main outpatients and a lot of the nurses aren't just allocated to the one clinic so they're kind of running around, I mean I think it would probably be very useful if they put those, you know those white boards saying which Drs are in clinic on that day and underneath they could just write on them, instead of having to say there's a 30 minute delay or an hour delay and then it's like at least then you know what to expect you can think, ok I've got an hour I can go to the toilet I don't have to sit here holding in case they come out and want me to go in, or I can quickly run and get something and if they did something like that just so that its up, they don't actually have to come out and see everyone individually because they are so busy, they can just write something where everybody can just clearly see on the outside of the door, you know put a white board on the door and they can just put the clinic, put the doctors on and then also it's useful then because sometimes we've gone and we've been expecting to see one doctor and she's not been in clinic and you think you've seen her, at least then you know, you don't just walk in and think I don't usually see you, we usually see her, it's there, you know, you can sort of prepare yourself... it would make patients a lot less tense if they can at least see who's in and what the delays are, otherwise you're hanging around thinking how much longer?" (Parent 6)

6.4.4.5 Parental Stress

Parents struggle to pacify their agitated and bored children. This rouses pressure and feelings of anxiety within them. Parental stress is further heightened as the waiting progresses and the child becomes tired and intolerant. Sensitive to the building tension, parents describe how families become increasingly distressed by the lengthy waiting times.

“You’re stressed, yeah, because obviously, I suppose when the doctors look at your child they want them sat on your knee say for example and like for him they needed to measure his head circumference so he’s needing to sit reasonably still and you know if he was very tired or hungry or something he would probably not want to sit still, yeah so it makes the actual doing of the appointment more difficult.” (Parent 2)

“I just get on edge mostly... I just find it really stressful with the kids, I mean it’s not a hospital thing; it’s not that, it’s just... I don’t like taking the kids to the hospital, all that waiting and all those things and they get on edge and they get bored, so you know, its fine but it’s stressful. Its only when it’s really busy as well, it gets really busy sometimes.” (Parent 6)

“The last time... we had to wait quite a long time, and that is my experience of the outpatients, I have had to wait a long time, the clinics are usually running late... It was very very hot, very impatient I think because there were so many people around me and my son kept on saying how much longer, can I have something to eat, can I have something to drink you know, so it was very very stressful really, I think stressful is the wrong word actually, a bit sort of frustrating, you feel restless, I felt restless, I felt like I just wanted to go up and say how much longer am I going to have to wait but you know, there’s no point because they don’t know how much longer you’re going to have to wait, so, we just had to bear with it really.” (Parent 4)

Parental anxiety intensifies in large, chaotic spaces due to the potential for losing sight of a child. This means that parents are bound to watching their young children and chasing after them when they wonder off. The cafe provides some entertainment, but closes early, prohibiting families from purchasing food and drink.

“They always seem to be closing as we arrive and it’s really frustrating because you’re like ahhh I’ve booked in now, I can’t go up to the shop and get something and when you’re there for a long time it is frustrating, even if the cafe didn’t stop open, even if they just had a machine or something in there so that you don’t have to walk out because if you walk out then you’re going to miss your thing... it’s a reality of the hospital, you hang around, clinics go on forever sometimes especially if they have to go for tests and that’s fine but it’s just the thing of you know, it’s children, they get hungry and they get thirsty and there’s only so much you can take with you, especially going on the train, so, I mean he throws the biggest strop when he’s hungry.” (Parent 6)

6.4.4.6 Young children

Younger children take pleasure in being amongst other children and playing with toys and books whilst waiting. For them, the hospital is an exciting adventure set in a new environment and filled with new people. Bright, vibrant colours feed the child-friendly ambiance, creating a sense of comfort, as well as being stimulating and lively. Younger children are kept entertained with toys, a plastic caterpillar tunnel, books, a big fish tank and table football.

“(My son) loves the fish, so he usually has a look at that, or there’s like a tunnel, a play tunnel and stuff, so it’s nice that there’s a few toys and stuff, that’s good for keeping him entertained.” (Parent 2)

“(My son) had a little boy, same age as (him) sitting opposite, they both at different times got up to play on this I think it was a billiard table or something, no I think it was a football table, football and they just started chatting, you know, so there was something there for them both to head towards and he just started talking and they would have just carried on playing and chatting away to each other which would have fully occupied them, both of them then.” (Parent 1)

6.4.4.7 Adolescents

Adolescents feel their needs are neglected, as age-appropriate entertainment is noticeably absent. Subsequently waiting times are experienced as long, tedious and monotonous. Rapidly becoming bored and irritable, they fidget about before repeatedly asking how much longer they will have to wait. They either play with mobile phones or sit doing nothing. Boredom often leads to requests for refreshments from the shop as a mechanism to pass the time more quickly.

“For her age (14) there is nothing to do... there is nothing to do there, so she’s bored out of it... it’s boring to be there, I’ll be really honest with you, I’m not going to say ‘yes it’s really good’ because you do get fed up because you got nothing to do.” (Parent 7)

“There’s only stuff there for toddlers, there’s nothing there for my age or people older than me, there’s nothing there for people like us, there’s only toddlers and children’s areas, that’s it, there’s nothing much else there to be honest.” (YP 8)

“I was sitting there thinking how bored and what a waste of time it was just sitting there for ages but, like, I didn’t really have anything to do so I just sat there and waited.” (YP 1)

Parents suspect that their children are also unsettled whilst waiting, as they are worrying about their consultation.

“You can see in his little face that he is a little bit worried and a little bit nervous but I think overall he’s quite laid back really.” (Parent 4)

Adolescents feel infuriated at the injustice of other people jumping the queue by arriving after them, but being seen before them. They also become annoyed with double standards set by the hospital, such that if they are late they are reprimanded, but if the

consultation is late, there are no repercussions. Young people feel that the effort put in by families to be on time should be matched by the hospital.

“Sometimes you get angry. You start asking, you start noticing all the people coming in after you and they’re getting in before you and that makes you feel a bit odd. Like, you’re like, you start thinking how come they come after me and they got served so quick and our doctor is taking so long and then you get frustrated because if you come late, the hospital gets angry and whenever you get there on time, you never get called in on time. You always get called in late.” (YP 6)

6.4.4.8 Cleanliness

The waiting area is described as clean and hygienic with clean floors and air that always smells fresh. Cleanliness and hygiene are important aspects of hospital care for families due to the vast throughput of individuals. The feeling of being clean helps families to feel calmer about waiting in a potentially infectious environment.

“I noticed in between every visit they were wiping everywhere even the seats parents had sat on and everywhere I noticed as people were coming out, they had got healthcare assistants going in and wiping the seats which I think is a very important aspect when you’ve got so many people in an environment like that.” (Parent 4)

“It just like looked clean. There was hardly anything like on the floor or on the walls and everything and it kind of smelt a little bit clean.” (YP 7)

6.4.4.9 Sick children

Waiting in the same area as children with serious conditions or disabilities is distressing for some parents and young people and serves as a reminder that they are in a Children’s Hospital. Parents worry that being around children with an observable medical condition is an emotional burden on their own children.

“You do see some very poorly children and you know, for my child, for his like minor thing that he’s got and he’ll sit there sometimes and you can see him looking at the other children and I have to explain to him what’s wrong with them, you know, some of them have got limbs missing or bigger heads than they should have and it’s hard really because you sort of like, he’s probably scared by them and which I don’t want him to be, so I have to explain to him what is wrong with those children and you know, get him to understand that you know there are some very poorly children.” (Parent 4)

“There’s lots of children there with really big problems and it’s kind of like, my children, well most children are inquisitive and you’re always like don’t stare, don’t do this you know, it’s like, I think that’s probably why I get myself much more worked up is because I feel sorry for all the other parents if my children are sitting there staring or asking questions which they do being young and not old enough to realise you really shouldn’t be asking those kinds of questions sort of thing... mostly because I don’t want to make their parents feel like awkward or like, have, you know it’s not nice when people are asking questions or staring.” (Parent 6)

Young person 4 describes managing her feelings of being around other sick children by mentally detaching herself from her surroundings and physically moving to a different area.

“When I’m sitting down it’s loud and like it’s not nice seeing all the ill people and all that... Well if you can’t tell they’re ill it’s alright, but when you can tell they’re ill, you just want to move away from it all ‘cause it’s upsetting to see all those little kids especially as I’ve got a little sister that is roughly the same age.” (YP 4)

Young people also discussed feeling uneasy about being in close proximity to other sick children for fear of contamination. This often causes tension with young people as, on one hand they feel that it is immoral to discriminate against families with sick children, but on the other hand they do not want to get close for fear of infection. Many families feel reassured by the availability of anti-bacterial hand gel.

“I don’t really like being around ill children. I don’t really have anything against them, but I just don’t like it and so... but there was those hand things which was reassuring to have those. The bacteria spray things that you put on your hands... the

hand gel, I used that at least three times when I was there. Every time I went into a different thing I used it and my brother used it quite a lot too...You don't really know what it is that they have and it's rude to ask, so like you don't really, you'd rather be safe than... That's probably the most main reason why I don't like going because you don't know what you're going to come out with. I'm not rude, I don't have anything... you don't feel like that people have to be separated because of the illness, because that would make them feel like there shouldn't be other people and you don't want to make them feel like awkward, but at the same time you don't really want to be around them. But that's just the way life goes I suppose." (YP 1)

6.4.5 Height and weight

It is customary at the hospital for patients to have their weight and height measured separately from the clinical consultation. When called, patients and parents follow the nurse to a room where they are asked to remove coats and shoes before blood pressure, weight and height measurements are taken. Young people like to be involved in the measuring of their weight and height, taking a keen interest in any changes and seeing growth and weight as an indicator of health and wellbeing. This process only takes a few minutes.

"It's a bit scary at first because it's like 'have I grown or have I put on weight' and then, like normally like I go down the other end but we went in to a different room this time and normally I have to stand on the weighing thingy scale but this time I had to sit down in this chair to be weighed and it was kind of weird but yeah and then when she checked my height, the nurse was a little short so it was funny because she had to reach up to pull it down and then she escorted me to the other seats around the corner." (YP 5)

The room is an adequate size, small but not too small, with pictures painted on the wall.

During weighing and measuring healthcare professionals are generally patient and friendly which helps families to feel more comfortable.

“We went into the room and she and then I had to take my shoes off and I had to converse on and I had to take all the laces out, it was really annoying and then she weighed me and that was it... It was kind of small but not that small; it was still spacious like, a little room. There was like a little Mickey Mouse or something painted on the wall.” (YP 5)

6.4.6 More Waiting...

The nurse escorts young people and their parents along painted footsteps, from the weighing room to a separate waiting area where there is a different set of seats. The space is narrow and corridor-like with doors leading off to various consultation rooms. Coloured chairs line the walls together with sensory toys which keep young children occupied. Being transferred from the main waiting room is a relief for parents. Although still waiting, the calmer and quieter area helps make waiting more tolerable:

“Once they’ve called you, then they call you again through to another waiting area... it’s much more relaxed in that little corridor then ‘cause you’re out of the waiting room, you’re just in the little corridor, you can still wait for 20 minutes in there, but it is much more relaxed.” (Parent 4)

Yet again little is provided to keep adolescents entertained. They just sit and wait, dwelling on the dragging time, observing other people and playing on their mobile phones.

“It’s just small and thin, like a small thin. It’s just a little area with three doors and a dead end and there’s a row of 8 chairs. There’s just chairs, there are some magazines and on the wall there is a little like play area and some magnetic toys on the floor and when you put your foot on them the colours move... The others are just sitting or on their phone or doing something else or they are looking at you and you are looking back and then you are like staring at each other and then he’s like ‘what you looking at?’ and then you’re thinking ‘what’s he looking at?’” (YP 6)

“You got to wait again which is sometimes annoying especially if you’ve waited a long time before. I mean it’s not that long, it’s just like, if you got to wait for a long time before, you don’t want to have to be going in there and having to wait again.” (YP 4)

6.4.7 Consultation and care

After a second period of waiting, patients and their parents are called into the consultation by their doctor. During the consultation, the Consultant discusses the child's condition and general wellbeing with both parent and patient, depending on the child's age. The consultation room is small, warm and cosy, but also formal and organised. It contains a desk with a computer, chairs, a bed and a few toys and books for young children to play with. The room smells fresh and feels clean. Indicators of cleanliness include uncluttered floors and walls and detergent smells. The doctor sits at the desk and invites families to sit on chairs opposite. The consultation is calm and compassionate with the Consultant facilitating discussion about the families concerns, listening attentively and respecting the families understanding of the patient's condition.

"It was like, there was a bed, there was two chairs where like me and my Mum sat and there's the Dr's desk with the computer and the chair and then there was another chair with folders on there and there was light coming in through the window and the window was open and I don't know, it smelt of like flowers for some reason and then there was like a clown or something painted on the window and then there was a bed behind me yeah and there was cupboards on the side and there was a little sink with tissues and gloves there as well. On the window there was a curtain that she closed when I had to, when she checked my eczema." (YP 5)

Parents feel that their concerns are validated when; instead of just talking, medical activities are carried out such as a test or examination. Even negative test results provide parents with the evidence they need to accept what the doctor has verbally diagnosed. Active investigation satisfies parental need to be heard by the doctors and provides reassurance which makes the whole appointment worthwhile. Parent 3 describes:

“Very worthwhile, very mind reassuring, I was reassured and I was happy when the doctor saw him. I mean when he saw him and the doctor says this and this and that is getting better, this is all fine, the constipation, this and that, I kind of feel happy in myself and I know there is someone there, you know that reassuring me, that he’s ok, that everything is fine, so very worthwhile, the appointment is worthwhile.”
(Parent 3)

For young people consultations are about making progress with the management of their condition. Consultants are attentive to their needs by explaining medical terminology in an age-appropriate and personal way which encourages children to ask questions and demonstrate their comprehension. Children feel empowered to talk about their condition when the doctor demonstrates empathic understanding of their concerns. As Young person 7 describes, doctors who take an interest in the young person’s life more generally, result in them feeling that the appointment is more than just a medical review; it is about them as real, individual people:

“Just talking about all the different stuff and I think he just asked how I was and like, not just about the appointment so that made it a bit nicer... It makes you feel more important, so like instead of just going for an appointment, it makes you feel a little bit nicer.” (YP 7)

Parents feel content when their children open up to the doctor to express how they feel about their condition, but witnessing the volume of patients waiting outside can lead to parents feeling they need to rush through their appointment so that others can get in. This can lead to parents feeling their child’s healthcare needs are unfulfilled.

“Dr (Consultant General Paediatrician) has got that magic touch, to kids, yeah... the first time she seen Dr (Consultant General Paediatrician), she just opened to him and he was like open to her because when he asked her some private questions, she was like replying to him in a decent way, yeah, she wasn’t stubborn to him, she wasn’t like really tough to him, yeah, she was open to him... when she started

talking to him, yeah because I knew there were people waiting outside, but when she started talking to him yeah, she opened up and I was so happy I wish she took longer, do you know what I mean, because first time I seen her really opened with any doctor, 14 years she never opened with any doctor... I was happy that my child is open for the first time in her life talking to a doctor about inside her what her feelings were. If I could sit there for hours, I would have that day if her appointment was longer, I'll be honest with you, I would sit there, because that made me happy." (Parent 7)

"When you've waited a long time and you are aware of all the other people waiting, it's very difficult because you then try and rush everything through because you're aware there's everybody else sitting outside waiting. So it does put you slightly ill at ease I think in terms of having a relaxed conversation with somebody about your child and so you're trying to make sure you haven't missed anything and that the person has understood what you're saying fully, because obviously some of the cases I'm sure like (son) are quite complex and there is a lot of detail that you want to get across and sometimes when you've been waiting a long time and you're aware that other people have been waiting a long time, you don't do it justice if you know what I mean, you don't feel that you can spend the time you want to. That's not to say that I felt rushed by the Consultant but you, it's something that you put upon yourself a little bit." (Parent 5)

The consultation concludes with the doctor inviting the family back for an appointment before the standard follow-up if needed. Consultations are brief in comparison to waiting times, but valued and appreciated by parents when they feel reassured by the specialist Paediatrician's clinical opinion. Although parents want to reach a stage where their child no longer requires medical intervention, they also want to feel supported in the process. Knowing they are not alone and can return if needed provides parents with a sense of security, as Parent 4 demonstrates:

"But the last outpatient's appointment it was just basically I did say he has improved. They do give me the option which I'm really happy about as well. They do give me the option, they don't discharge me, they say to me, do you want to be discharged or do you want to come back in six months, twelve months? And I think

the last time I said I'd go back in, I think it was getting on for about 9 or 10 months, my follow up appointment is in November, so I don't want, I didn't want to be discharged at that point. I still wanted the security that I could go back if there was an issue... and they were very understandable about that, they never once questioned the fact that I wanted a follow up appointment, so I was very satisfied with that, you know they're not pushing me out of the system." (Parent 4)

6.4.8 Post appointment

After seeing the doctor, families take their letter to the reception desk to make further appointments. They exit through the main doors to either go straight back home or to the shops. The city-centre location of the main hospital means that young people and their parents can combine the appointment with a treat, such as purchasing a new toy, clothing or food. This contributes to hospital outpatient appointments being conceived as a 'special day out' by young people.

"I didn't have school and it was around about 12 o'clock. So me and my mum, we went to get something to eat and then we went shopping... I like the way that hospital is in town because there's lots of nice shops and we go shopping." (YP 5)

"What I do every time we go to the Children's Hospital, we go a bit early, yeah so we doss around, I take them to the rag market because it's a bit cheaper there, I'll be honest with you, then I make them have something to eat, tummies full for when they give blood, she goes 'every time I have to give blood, I don't like it', I go 'don't worry darling it's free of charge' yeah, I take them out, I have to take about 60 to 70 quid with me, get them something from town and everything like that, then come home." (Parent 7)

The second general structure describes the invariant features of receiving General Paediatric outpatient care in one of the two community-based clinics, for the participants in this study.

6.5 General structure: Receiving General Paediatric outpatient care in a community-based clinic

Attending a community-based outpatient clinic is a fairly insignificant activity within the family's hectic life. As time allocated for the appointment is contained to a manageable amount, families feel able to balance attending their child's appointment alongside other activities of daily living. An existing, trusted relationship with the Consultant Paediatrician helps to alleviate anxieties about the quality of care provided at an alternative location. Comfortable and convenient travel and parking help to ease the burden of attending appointments and, as clinics are embedded within the community; they are experienced as a familiar part of the family's everyday surroundings. On arrival, the process is relaxed, but efficient. A pleasant, uncluttered and informal environment contributes to a calm and caring atmosphere in which families feel 'at home' and 'at ease'. Waiting areas are small and intimate, but adequately sized for the amount of people. Being seen promptly at their allotted time leads to families feeling that they are respected and their time is valued. Unhurried and unpressured by time and space, the clinician and family are able to engage in meaningful dialogue, working towards a shared understanding of the child's health condition, within the context of their unique and subjective world. Such an empathic approach supports families on their journey towards wellbeing. After the consultation, families return to their everyday activities with minimal disruption to their overall routine.

6.6 Constituents of the general structure

The essential meaning of the satellite clinic outpatient experience for families can be understood from its constituents:

- Preceding the appointment
- Journey
- Arrival
- Waiting
- Consultation and care
- After the appointment

Variations of these constituents include the age of participant (whether they are a parent, adolescent or younger child), whether the family attended the family centre or health centre clinic and whether the patient is symptomatic of illness or not. These will now be discussed with illustrative verbatim quotations from participant data.

6.6.1 Preceding the appointment

Community-based clinic appointments *fit* into to families' lives. As such, they require few preparations. As Parent 8 describes, this means that families feel calm and relaxed about attending the appointment.

“I always look forward to going down to that, the clinic down there, it's just easier to get to and as I say, we're not so pushed for time and it's just easier and it's nice when you just get in there because you can just relax, just chill out. When you walk in, you know I find it really nice and pleasant in there. It's quiet and nicely decorated out and it's really, you know it makes you feel at home and just relaxed.” (Parent 8)

Like any other weekday, young people attend school before and after their appointment at a local clinic. This means little disruption to the family's normal routine and less time away from school.

"From here Greet is only about 5 to 10 minutes' walk, so it's not far, I'm a slow walker but you know I managed to get her back into school. I think (daughter) was only out of school for just about an hour I think, can't remember exactly, but I think about an hour." (Parent 13)

"It's really handy, it means my husband can get out of work because he only works in (name) and it's, we don't have to take (daughter) out of school all day because if we go actually to the main hospital it is a journey there, the journey back, it takes up most of the day. So it's nice and handy with the other children, with nursery it means we can fit it all round, so it's really handy." (Parent 9)

"I was at school before I went to the doctor. I go to Wychall primary school it is attached to the children's centre so we didn't have far to walk." (YP 10)

"I was at school and then my dad picked me up at half 10 to go to Wychall to have my appointment, it only takes about 7 minutes, (name) the school's in, so it's not that far... They took me out at break and I was back before lunch." (YP 9)

Families were surprised that hospital Consultants delivered clinics within community-based settings. They did not expect such highly trained healthcare professionals to provide services in such informal settings and found the concept to be unusual.

"When the letter came and it said that it was linked to a school I wasn't expecting it to be linked to a school and to be so close and I don't know, I thought it would just be a bit more like a medical place, like just aimed at medical purposes so I was quite surprised when I went in there, I was like oh it's not like a GPs in a sense of all medical stuff, there's a little nursery here and I saw NVQ training going on there so quite a lot of different things and very different to the doctors." (Parent 9)

Most families were invited to attend follow-up appointments in a community-based clinic by the Consultant in a prior hospital-based encounter. As such, an existing and trusted

relationship with the Consultant helped to minimize parental concern about the place in which they were seen for the child's appointment.

"It was like 'whoa' where's Wychall lane like and I thought family centre, is that a nursery? I'm sure it's a nursery and I thought oh that's a bit strange going there like, sort of thing. It didn't really bother me because I knew Dr (Consultant General Paediatrician) would check him over and stuff like; obviously he'd always given me the best advice in hospital, so why is it going to be any different elsewhere?" (Parent 10)

"If they said to us 'oh there's a satellite here that's local to where you are, but it's a different doctor, would you come', I think our answer would be no. It could be really local to us but our answer would have been no because (Consultant General Paediatrician) knows her, she knows her patient, obviously because there are so many patients they have, but to us it feels like she knows her case and you can talk to her. I don't think I would be happy with a new Consultant." (Parent 11)

As Parent 13 describes however, those parents invited to a community clinic for their child's first outpatient appointment, thought that the hospital had made an error which led them to challenge the change in clinic location.

"We had a letter to say that it was going to be at Greet. I think I rang them back then because I thought have they made a mistake, you know because I have never had an appointment there before so they just confirmed everything. It's like if you don't know about something and then something suddenly changes." (Parent 13)

Some parents chose to attend community-based clinics as an appointment could be offered sooner at that location than at the main hospital. In this case, as Parent 11 expresses, rapid access to care also informed parental decision making about which clinic they attended:

"We got a choice as to whether we wanted to go to Children's or Greet and they said if we wait for Children's it's a longer wait and if we go to Greet, we can get to see somebody sooner, so obviously, but do we mind travelling and we said no not really, I think you know, we said as long as she, you know gets to see somebody and

it's probably less hectic because you get more one-to-one and you get a bit more time with the doctor probably and we said we'd rather go to one of those satellite clinics." (Parent 11)

Prior to their appointment, young people felt that they were not involved in decisions about where their outpatient care was provided. The first they hear about the change in location is when they receive a letter stating that they have been allocated an appointment to see a Consultant General Paediatrician at a community-based clinic.

"It's alright us going to Greet, but obviously we've never spoken to (daughter) about it really and I wouldn't even say what her point of view is because I'm sure she'd have a lot to say." (Parent 11)

Although apprehensive about seeing a new doctor, young people can be comforted by going to a place that is known to them and considered a part of their community.

"I know the place really well because like I've only ever been there twice but like I know it really well, like where you go in and everything and what rooms are there so it was just the new doctor that I kind of got a bit scared about." (YP 9)

"It's part of my community. It's just around the corner and like when you go to school or something you go past it, you see it and I'm used to it being there." (YP 14)

However, as community-based clinics were seen to blend in with other everyday activities, so attending a community-based clinic is experienced as a relatively unexciting event.

6.6.2 Journey

Travelling to community-based appointments is convenient and undemanding in terms of time and effort for families. Short journey times provide many options for travel. As well as public and private transport, many families are able to walk, cycle, or be taken by family and friends.

“Either bus or I get family members to drop me off or we’ve gone on our push bikes before now so. It’s much more easier to get to that one than going to town because of parking and everything else in town.” (Parent 8)

“We walked it, I walked it with my mum and then my father came to pick us up in the car afterwards. By walking it takes about 5 minutes and by car it only takes about 2 minutes.” (YP 13)

“It’s near so we walked it, left the house about 10 minutes earlier and we got there in time. It only takes a maximum of 10 minutes to walk there, it’s really close. It’s just round there by the school.” (YP 14)

Time saved on travelling allows more time for parents to work and children to be at school. Short travelling distances also mean a less hectic journey. Even families who have either subsequently moved further away from a community clinic or attended it due to a quicker appointment rather than physical distance continue to use community clinics as the out of town journey is much less stressful. As the routes to community clinics are familiar, so time is also experienced as passing more quickly.

“I work at the Greet children’s centre as well which is just down the road, I know the way and stuff it just seems, because sometimes when you’re travelling somewhere and you’re going for the first time, it’s a bit, but because I work just there it doesn’t seem like much of a travel.” (Parent 11)

For families who travel by car, free parking is always available at the community-based clinics, either on onsite car parks or on the road nearby. This is convenient for families and relieves parental stress each time they attend an appointment.

“We always park on the side road to the school, you can always get a space round there, it’s never a problem parking and it’s all free, it’s just on the road.” (Parent 9)

“We parked outside, it was right next to it, we didn’t have to walk far from the car.” (YP 12)

6.6.3 Arrival

The temperate surroundings of community-based clinics are experienced as homely, relaxing and pleasant by parents. However, they can leave young people feeling somewhat underwhelmed. Booking-in processes are equally relaxed and unceremonious, simply consisting of informing a member of reception staff of their arrival.

6.6.3.1 Family centre

At the family centre, families walk up the driveway, past children's play equipment to a set of double doors. They go through a cloakroom into a reception area made up of a few chairs and a small reception desk where staff members sit and chat. Parent 10 and Young person 9 describe:

“You walk up through the driveway, past the little cabin things that the children play on, and it's entrance to the nursery schools and stuff in one entrance and you walk into another reception area where you've got like a few chairs, a reception desk.”(Parent 10)

“Like, you go in and like you have to go through two doors and then there's like clothes wracks and like where the buggies go and then you walk in the other door and then you sign in at the little desk.” (YP 9)

The family centre delivers a friendly and personal service from reception staff, with efficient and straight forward processes. On arrival, families are invited to sign a register before being updated on the doctor's timing. Once introduced, they are encouraged to take a seat whilst waiting to be called into their appointment. Parent 9 expresses how the reception staff contribute to the creation of a warm and welcoming atmosphere, by being cheerful on arrival.

“It was friendly, really bright, well it wasn’t scary. The hospital I find can be quite daunting especially for (daughter); it’s very noisy and echoey, lots going on. It’s quite calm at the children’s centre, even though there are people doing different things, you know everyone smiles and says hello and it’s just a welcoming atmosphere, which I think puts (daughter) at ease definitely. You just go to the reception and sign in and then they tell us whether we are running on time or if the doctor is running a bit late and then we just go and take a seat and wait for the doctor to call us.” (Parent 9)

6.6.3.2 Health Centre

When they arrive at the health centre, families are presented with an open reception area consisting rows of chairs and a reception desk. This constitutes the GP surgery part of the centre. There are few signs instructing families where to go or what to do if they are attending a paediatric outpatient appointment. This can create some confusion for families.

“When you go in at the first bit, you know the first bit, there is one thing, when we went in the first time, and they said Greet, it was a case of we went in with the paper and they said, there was no kind of signs at the front for Dr (Consultant General Paediatrician)’s surgery saying follow this or go to reception to let them know you are here... when you get into the back, I think there is something there that says the clinic, but there is nothing from the start when you’re going in there to say, directing you to say that’s where her clinic is, or you need to report, Dr (Consultant General Paediatrician)’s clinic, report at reception, there’s nothing like that you kind of did it all on your own head.” (Parent 11)

In absence of any other instruction, families present themselves and their appointment letters to the receptionists. They are let through two security doors and instructed to walk down a corridor to wait for their appointment. At the end of the corridor, families come to a smaller waiting area. A lack of any formal booking-in processes can be unsettling for parents who feel unsure about what they should do once they reach the smaller waiting

area. They sit down and worry about whether they have followed the correct procedures and whether they are waiting in the right place:

“Over there (Greet) to go to your appointment, you just tell them and they just go, they just give you directions, they just go, go straight down the corridor and just sit there, someone will come. The only thing about that, you don’t know if your doctor knows you are here or not. I mean they probably do, they’ve probably got some kind of system, but you just think, oh you know, am I just waiting or shall I just go and tell the reception again or something. There’s not, you just tell them I’m here and they just tell you to go in. You know, you say ‘I’ve got an appointment with Dr (Consultant General Paediatrician)’ and they just tell you to go in, they say ‘oh there’s a clinic down there, just sit there’. So there’s not someone saying you know, like check your letter or something to say I’ll tell the doctor you’re here... nothing like that, I don’t know if they do, but I’ve never been told that, they just say go and sit down and they’ll call you. It doesn’t feel like the doctor knows you’re there.”
(Parent 13)

As the health centre does not provide care exclusively for children, it is experienced as somewhat ordinary in appearance and feel.

“There’s hardly any children there, there’s more adults and then people are going in there for different things whereas when you’re in the Children’s you know it’s more for the child and it’s more child orientated the problems but with the satellite clinics you don’t know whose there for what.” (Parent 11)

“I think it was more appropriate for adults because I was just thinking you know is it only my child that has got an appointment here? I think that that day there must have been a lot of other adult appointments. It felt a bit strange really.”
(Parent 13)

“With Greet clinic it’s everyone, it’s all ages, all races, everyone. With children’s hospital it’s just children, you don’t see any adults there like getting treatment or something.” (YP 14)

6.6.4 Waiting...

Waiting areas in community clinics are generally small with few distinguishing features.

Time is saved as waiting times are short, if families are made to wait at all.

6.6.4.1 Family centre

The surroundings at the family centre satisfy families by conveying a warm and welcoming feel. Although physically small, the hallway waiting area feels spacious as it has ample capacity to accommodate those inside, without feeling too large or over-crowded. This contributes towards families feeling at ease:

“It’s a medium place you know, it’s not massive where you’ve got plenty of room, but it’s not crowded where you feel enclosed. There’s plenty of room to sit and you’re not standing up waiting to see the Drs and stuff, you can just relax.”
(Parent 8)

“Even though Wychall is small it’s big in a way because there’s loads of room to move around in like, so I feel more comfortable and less claustrophobic there.”
(YP 9)

Filled with familiar objects and soft furnishings, the centre looks and feels homely. Whilst waiting in the hallway, outside the consultation room, families observe a kitchen, play room and a bathroom. There are also doors leading off the hallway to the main nursery and to a room for community classes. Families can see toys on one side for young children to play with, computers, a sofa, a bookcase and notice boards containing information on various family matters and community groups. Five or six chairs are provided for waiting, which is adequate for the number of people present. Security doors also prevent access to the clinic by people without valid reason. This makes the place feel safe and secure.

“You’ve got the staff room with like a plain area near there and then you walk up and there’s some seats and then you’ve got Dr (Consultant General Paediatrician)’s room and then you’ve got the kitchen, and then you’ve got the play room and then you’ve got the hall way and then you’ve got the bathroom and I think and different staff rooms get food and everything from.” (YP 9)

There is a gentle coming and going of people carrying out their activities. Background noise is temperate and unobtrusive, consisting mainly of muffled voices from children in the adjacent infant school and nursery, as well as staff talking amongst themselves or on the phone.

“There are generally people coming in and out, people enquiring about things, you can hear staff talking, sometimes you can hear the nursery children, which is quite nice, but generally you can just hear people going about their business. It’s never noisy, it’s moderate, nothing that would annoy you, you know, there’s nothing that you could complain about, it’s just general background noise.” (Parent 9)

The atmosphere is calm, comfortable and homely with friendly and bright staff who try to make families feel at ease. Although there are few activities appropriate for adolescents, some toys and games are available for younger children. Waiting times to see the doctor however, are almost guaranteed to be short. This means that parents and young people are happy to just sit whilst they wait.

“It’s got toys obviously in the waiting room, it’s like got pictures and stuff of what children have drawn on the walls and stuff like that, so that’s nice to see, it’s good for the children to look at pictures and stuff like that, numbers, lettering on the walls, so it is child friendly.” (Parent 10)

“There was some games that I could have played but I didn’t want to, I just wanted to sit down.” (YP 10)

“They’ve got a book shelf there and they’ve got some computers, I’m not sure if you can use them, I’ve never been on them so. Usually I would just wait and go on my phone.” (YP 9)

6.6.4.2 Health centre

After informing the receptionist of their arrival at the health centre, families walk down a corridor into a small but adequately sized, square waiting area. Chairs are arranged around the outside of the space with a few in the middle. The space is quiet and calm, with a few patients chatting and walking around and healthcare professionals carrying out their normal activities. Health information posters plaster the white walls and natural light floods in from the windows. There is another long corridor leading off the waiting area, with doors leading to various consultation rooms and toilet facilities.

“You go down a corridor into a waiting area, it’s just like a little square area with some seats and you just sit there waiting and there’s another long corridor and that’s where the doctors rooms are and obviously different doctors there, I don’t know but, there’s a toilet there, you know staff toilet and patient toilet there, I mean there’s no magazines there or nothing for the children to play with, I mean, I know she was sleepy anyway but she was just really bored so, you know if they had some little toys or something. It’s a small area that’s probably why they haven’t got anything. There’s some posters on the walls about the NHS and that with general information. Because like, because there are lots of different people there, you like obviously don’t know what appointments people are here for.” (Parent 13)

“When I went there, there were two doors I went through down there and I sit there for a while in a waiting area, really nice, peaceful because it was three or four patients there. One was my age and two was old people and I was sitting there and I feel like comfortable there because it was a waiting area to go to her (Consultant General Paediatrician), it was really, there were chairs, three or four piles of chairs and it was boards everywhere you know, if you’re going to wait, you can look up at things do you know, information this one, it was really nice.” (Parent 12)

The environment is clean and uncluttered with a fresh smell. Noise is kept to minimal levels with only a gentle murmur of people quietly chatting amongst themselves and staff carrying out their duties.

“I just waited until they called my name. I just sat there... It was really quiet; I couldn't really hear anything, just some people talking, like the adults. The other children, the babies they were just messing with some toys that were there.”
(YP 12)

“I could see other people; it was a bit quiet and nice. There was like posters and stuff on the walls that tell you about your health and stuff. There wasn't anything to do in there; we were just sitting, not doing anything. We couldn't hear much stuff, some people were talking... I felt happy because like it was like nice and quiet.”
(YP 13)

As the health centre provides health services for adults well as children, it has a generic, clinical feel reminding most of a doctor's surgery or mini-hospital. Whilst waiting, some parents chat with other waiting patients, whilst others read health promotion leaflets and information posted on the walls. Some toys are provided for very young children, but there is little consideration for the needs of adolescents.

“We are Asian yeah; we can make way to speak to somebody about anything! Because my son was playing and she started talking to my son and I feel ok she is from my community and I can talk to her. It wasn't long I think, 10 minutes it was, I think in 15 minutes the doctor came to see if I was comfortable because she was busy with another patient and then I feel happy, I said I'm alright, don't worry... there was some toys and there was a leaflet as well, a very good leaflet about the flu, and one more thing it was there and it was really helpful, it was a leaflet about the bladder. It was valuable information that I was reading.” (Parent 12)

Waiting for the Consultant out of sight of the reception staff, at the back of the health centre, can also lead to feelings of abandonment with families unsure about whether they are in the right place and doing the right thing. The area feels physically and psychologically

detached from the main surgery with only a small sign indicating the presence of a Children's Hospital clinic.

"It just seems like go over to that area and they haven't got anything to do with it, but they have. When you go in there is a reception there but then there is a long corridor that you walk down and there's the little clinic there but there's no reception there." (Parent 13)

"Because we are a room at the back type thing, we are on the side, not in the main bit and they're, what it is is they're dealing with those reception girls that haven't really got anything for us, is because they are dealing with their own patients which are probably causing havoc there because their waiting area is just there isn't it and then we get pushed to the side... Even when we went there this time, we had that, shall we let them know we're here or do we just walk straight in, you have that little confusion, lucky I did let them know because this time she actually had a tick list which she did tick to say that we've come, she said who and I said (daughter) and she said oh yeah, but last time we went they just said go straight through because then we thought, how does she know we're here?" (Parent 11)

Typically families are seen on time at community-based clinics. After a short wait, they are called into their appointment by the Consultant.

"By the time (daughter's) getting bored she's called in; it's not a long wait. 'cause if you've got a 10 o'clock, you know you're going to be guaranteed to see her by 10 past ten, you're not going to have to wait any kind of longer than that." (Parent 11)

6.6.5 Consultation and care

The relational aspects of care are just as important as the physical space and equipment for families attending community-based clinics. The community-based centres provide adequate accommodation for patients requiring discussion-based appointments.

6.6.5.1 Family centre

The generously sized consultation room at the family centre provides a quiet, airy and relaxed environment. In the room, families can see a desk with a computer, a bed, weighing scales and a measuring tape, filing cabinets and a window letting in natural light. Health promotion posters cover the walls and toys are scattered casually on the floor. The welcoming environment puts families at ease and encourages the exchange of information within the consultation. As Parent 8 describes, this can make the consultation feel more productive:

“It’s just nice and relaxing when you go in there, you know it doesn’t feel like you’re going in to see a Consultant, you’re, it’s just like you’re going in to see your own GP. Its less pressure, it makes you feel more relaxed... If you’re up tight then you don’t get to the problems and sorting things out because you feel nervous and everything. If you feel relaxed you’re like, you’re more prone to open up about things and relax in a situation and say what you feel.” (Parent 8)

“It wasn’t very clinical, it was just like going into an office a bit, apart from it just had the bed there on the side, so yeah and it was light and airy, that had a good vibe as well. When you walked in, the way the room was set out with the desk; it was just like you were going into someone’s office. The bed wasn’t you know, a big piece in the room that you know that you were drawn to at first, you know it had filing cabinets you know, the window, the way you walked in, the window being right in front of you, it just seemed to flow, you looked straight there rather than at the side and yeah, it was more like just generally going to your doctors, your GPs, rather than going to the actual hospital.” (Parent 9)

However, for some patients and parents this relaxed and informal space is not conducive to receiving specialist healthcare. Parent 10, for example expresses how the non-medical setting initiates doubts about the quality of care provided, undermining her confidence in the competence of the clinician.

“It’s ok, don’t get me wrong but like it’s not, it’s not a place where I would say I would see a Consultant if you know what I mean. It’s not like a very doctorly environment sort of thing... Like, it’s not like a proper like, whereas like obviously at the hospital they can do like a full MOT basically, like check your ears, nose, throat, all that sort of thing, whereas that one you can’t. I mean obviously they’ve probably got the equipment put away somewhere, but it’s not like, it’s just a room basically with a doctors bed, like thing in and then a computer and chairs and toys and that is about it and it’s not like a hospital or a doctor’s place.” (Parent 10)

When patients feel symptomatic of illness, they can also find the non-medical setting inappropriate and at times, uncomfortable. Young Person 11 describes how feeling unwell in the family centre, led to feelings of dis-ease and disillusion.

“I hadn’t been very well so I was still, like my hair was quite messy and things and I wasn’t looking the best... I was still feeling quite dizzy and things so it was all a bit you know, a bit of a blur and then, I felt ok but because it was so big and as my mum and the doctor were talking, like the posters, I didn’t feel exactly, you know like when you walk into a room and sometimes you can just sit and chat, it wasn’t very, I didn’t feel like I could, it was quite cold as in the atmosphere was quite cold in it. It was a bit uncomfortable and a bit, it was too big... and then it was like plastered in posters so it was all a bit daunting because it kind of like, you had all of these like photos and everything kind of looking at you and it had things like, about smoking and things but it was quite, you know like dark posters.” (YP 11)

During the consultation, the doctor discusses the child’s clinical condition and treatment options. The clinician is patient with families, taking time to listen and talk through their understanding of the child’s symptoms. Feeling free from the constraints of time allows families to have a comprehensive and meaningful discussion with the Consultant regarding their child’s overall wellbeing. Parents are also free from the pressures of knowing that other patients are waiting to see the doctor or having to get back to the car.

“At Wychall you get like a longer period of time to talk to the doctor and get everything out like that you need to get out like. At the hospital you don’t get everything out like and then you go home and you think why didn’t I tell him that, why didn’t I tell him that? but obviously there (at Wychall) you can have like a full blown conversation sort of thing whereas there (at the hospital) you have to try and get as much out and let the doctor then examine or say what she’s got to say or say what he’s got to say and then that’s it then, the conclusion’s there and you’re going home, whereas there (at Wychall) you’ve got like a lot more time span... you get a lot more like in depth conversation sort of thing, you can talk a lot more about the medical side of things in Wychall than you can in the hospital so that’s the difference.” (Parent 10)

“The doctor greeted us with a very nice friendly welcome and she spoke to (daughter), talked to (daughter), she didn’t just talk about (daughter) the doctor actually spoke to (daughter). And yeah we was quite at ease, you know, we felt like we weren’t rushed and we felt like we could sit and chat. Sometimes when you’re at the hospital, you are conscious that there’s lots of people waiting and you know, but yeah it was a very relaxed atmosphere.” (Parent 9)

Whilst in the consultation, people can be heard walking up and down the hallway outside.

This can undermine confidence in the confidentiality of the interaction. As Young person 11 explains, walking out of the consultation room and into an enclosed hallway can cause a patient to feel conspicuous and self-conscious, as though everyone has been listening to their conversation.

“You’re kind of coming straight out into a group of people who are all looking up at you as if kind of they’ve heard what was going on... it felt like everyone knew what was going on. Yeah and it kind of felt that everyone, you know as if, like if you were in school and something you’d done, something really silly and everyone knew about it, and then as you walk down the corridor everyone kind of stopped what they were doing and kind of turned to look at you.” (YP 11)

6.6.5.2 Health centre

The consultation room at the health centre is small with a blue floor and a window with a curtain. There is a desk where the doctor sits and two extra chairs, a computer, equipment

for measuring height and weight and a bed. Such instruments help to convey the room as legitimately medical.

“It was alright, it was a bit small. The floor was blue and there was windows and there was a curtain and there was chairs, two chairs as well and I think there was that thing what you lie on, yeah, I don’t know what’s it’s called. It’s like a bed.”
(YP 12)

“There was a books there, there was stuff this side, yeah there was a tap. Many doctory things and there was a board like this to lie down. Like there was boxes and there was bandages and there was measuring stuff for weight and there was files as well on the left hand side, no it was on the top and it was a proper room, proper doctor room. That made me feel comfortable.” (Parent 12)

During the consultation, the doctor takes time to discuss the young person’s progress and condition with them and their parents. Young people are measured and weighed before discussing any test results and medication management. The Consultant is extremely personable, companionate and empathic. This approach encourages open discussion without families feeling rushed or judged in any way.

“I was being like this (hunched over) and she made me relax back and she like went step by step do you know, not rushing all at once, it was like, how do you say it, it was done bit by bit so I was comfortable with it... She was kind, it was like a, do you know it was like a one to one, you like, like when you have a conversation with your friends, it’s nice, it was good, I felt like I could talk to her openly, so that’s how I felt...” (YP 13)

“Because she behaving nicely, she talk nicely and she explained in the very better way not like a doctor, like a friend. If you don’t understand anything she will explain again and again and again and carry on and do you know sometime doctor annoyed, you can just tell yeah, she won’t, she always explain to you, ok you understand, I could tell you again.” (Parent 12)

6.6.6 After the appointment

On leaving the community-based clinic, young people walk out of the consultation room and 'sign out' at reception. Following their appointment, families return to their normal daily business either at school and work or by going home if it is the holidays. Parent 9 describes:

"It just feels like we've just popped in somewhere you know. We go back to our normality then, but when we come back from the Children's, I always feel a bit drained, a bit like 'uh', you know it almost feels like it's been a bigger occasion with perhaps, you know, it's nice really to have a normal appointment." (Parent 9)

By attending appointments at the family centre, many families feel more connected to their community, having learned about other community-based services that are available to them.

"There was some information about the health for life fitness, there was some good stuff, I got the number and I phoned there and then I called the lady... it was because of the fitness thing and I wanted to go and there was Mehndi, do you know Mehndi, Henna, there was something about this as well, good stuff it was." (Parent 12)

6.7 The experience of receiving paediatric outpatient care in hospital and community settings: Similarities and differences

Data analysis revealed two general structures; one for receiving outpatient care within a hospital setting and one for receiving care in the new, closer to home, community settings. These two structures will now be compared in order to draw out some of their similarities and differences.

6.7.1 Time wasted, time saved

The most significant difference between receiving general paediatric outpatient care at the hospital and at one of the two community-based clinics is the amount of time families are required to allocate for the appointment. The highly unpredictable nature of hospital-based outpatient care usually means that a whole day is lost as families feel unable to plan for or do anything else that day. Community-based clinics allow families to carry on their lives as normal, without causing significant disruption to their daily routine. In this way, community-based clinics provide paediatric outpatient care that is more convenient and less obtrusive. They facilitate the careful balancing act of managing work, school and other child-care commitments alongside attending the child's outpatient appointment.

Fitting appointments into families' already hectic lives, together with the hassle of difficult to find parking spaces, unreliable public transport and long waiting times in a noisy and frenzied 'holding' area, contributes to feelings of stress and anxiety for families attending hospital outpatients. Time spent waiting for hospital appointments is clearly articulated as unproductive and wasted time, leading parents and older children to become consumed by negative feelings of irritation and boredom. Little indication of how long the waiting will last further contributes to time passing slowly. In contrast, time and stress are reduced at community-based clinics, as they provide easy access to specialist care during the allocated time slot. Families attending community-based clinics are therefore altogether more relaxed before, during and after their appointment.

6.7.2 Space and place

Familiarity with the surroundings and procedures at follow-up appointments helps to restore coherence at a time when uncertainty surrounds the child's health status. At community-based clinics families are often struck by the absence of a large, chaotic waiting area which epitomises the hospital as a specialist centre for children's healthcare. Nevertheless, the informal surroundings and straightforward processes of community-clinics contribute to the creation of a calm and welcoming environment. This assists families to feel more at home and therefore more comfortable and relaxed, particularly during the clinical interaction. Not only then are the mechanical processes of care improved by holding clinics in community settings, but the relational aspects are too.

For some families with small children however, community clinics fail to deliver the excitement and exclusivity that the Children's Hospital provides. For parents with much younger children, this can mean a trade-off between convenience and experience. The absence of medical technologies can also serve to undermine community-based clinics as legitimate places for paediatric outpatient appointments; leading to decreased confidence in the quality of care provided. This is exacerbated when patients are acutely unwell, meaning that patients who are symptomatic take comfort and reassurance from being in a medical environment, with immediate access to investigations. Asymptomatic patients (for example, those with long-term conditions who generally feel well), are less concerned about their consultation being carried out in community setting. Continuity of healthcare professional however is important to all families and significantly contributes to decisions

about where outpatient appointments are accessed. The person who delivers the care therefore can help to overcome barriers regarding the place of care delivery.

6.7.3 Consultation and care

As time with the Consultant is less restricted in community clinics, families feel able to discuss the child's condition in a less hurried and more meaningful way. Delivery of healthcare is experienced as positive and satisfactory by families when the Consultant presents as friendly and respectful of the families' views and opinions. Some excellent practitioners also have intrinsic qualities that make them special, including the ability to intuitively understand families' needs and concerns. Parents and patients experience dissatisfaction with healthcare when there is dissonance between the clinicians' and parents' beliefs about the child's condition. If the healthcare professional's medical understanding does not resonate with the parent's intuitive understanding, the parent is left feeling unsettled, discontented and likely to want to seek a second opinion. This can also impact on parent's evaluations of the quality of care provided. Interactions with other staff members are considered just as important by families to the overall healthcare encounter and are experienced as positive when reception and support staff are polite, welcoming and cheerful.

6.7.4 Adolescent needs - all is forgotten

Adolescents' accounts of their experiences of receiving outpatient care were saturated with feelings of neglect and exclusion, regardless of setting. Although community-based clinics were better as they provided shorter waiting times, adolescents felt that their needs were

unaccounted for in the Children's Hospital which focused on very young children and in community-clinics that were more appropriate for adults. Young people suggested that they would like to attend adolescent-focused outpatient clinics that did not interfere with their education and that provided the opportunity to be with people who were similar in age and illness experience.

6.7.5 My community, not the community

Finally, participants expressed the importance of local clinics being in their own community and not just in *the* community. This was not only because of convenience of travel and time, but for those who experienced them, community-based clinics offered more than just medical care; they reunited families with the fabric of their community. Moreover the physical repositioning of the Consultant outside of a medical institution was regarded as an effort to connect with families in their world. Extending into the clinic consultation room, this meant that consultations which took place in community-based clinics were experienced by families as more compassionate and responsive.

6.8 Summary of findings

Through explication of the lived experiences of those families attending paediatric outpatient services in one of three research settings, this phenomenological study showed that the place of care delivery has an effect on the spatial and temporal aspects of outpatient care, such that community clinics help families to 'save' time as well as providing a calmer and more comfortable environment. This has an impact on emotion and social relationships, such that the feelings of uncertainty, frustration and stress associated with

hospital appointments are reduced in community-based clinics. The place of healthcare also has an impact on the clinical consultation, with families experiencing more empathic and meaningful interactions with healthcare professionals outside of the main hospital. These findings underscore the need for paediatric outpatient services that focus not only on the technical aspects of care, but on the very essence of what it 'feels' like to be a parent or patient receiving care.

In the next chapter, findings from the NHS Staff and Stakeholder interview study are presented. This is followed by a discussion of the overall study findings set within the context of the broader literature base.

CHAPTER SEVEN

7 NHS STAFF AND STAKEHOLDER STUDY FINDINGS

7.0 Introduction

In this chapter, findings from interviews with healthcare professionals and other NHS stakeholders are presented. The aim was to explore the views and experiences of a range of primary and secondary healthcare providers on delivering general paediatric outpatient services in the hospital and in new, closer to home settings. Data analysis generated 3 main themes: Organisational factors, Policy implementation and Service design. Following a description of the participants, each theme will be discussed in detail using verbatim quotations to illustrate points made in the analysis.

7.1 Research question

In this chapter the following research question is addressed:

- What are the views and experiences of healthcare professionals and other NHS stakeholders on providing paediatric outpatient care in different settings?

7.2 Description of participants

A total of 37 NHS staff and stakeholders from primary and secondary care took part in individual, semi-structured interviews. The sample included a variety of healthcare professionals, executive team members, service managers and commissioners from the Children's Hospital and from local primary care trusts. As can be seen in table 12, participants comprised: nine Consultant Paediatricians; three Specialist Paediatric

Registrars (SpRs); six other healthcare professionals (HCPs) including Clinical Nurse Specialists, a Phlebotomist, an Occupational Therapist and a Health Visitor; six General Practitioners (GPs); seven executive team members; four service managers and two commissioners.

Table 12: Characteristics of staff and stakeholder participants

	Secondary Care	Primary Care
Healthcare Professionals (HCPs)	<p>9 Consultant Paediatricians 6 x General Paediatrics Emergency Medicine Dermatology Respiratory Medicine</p> <p>3 Paediatric Registrars Metabolic disease Paediatric Intensive Care Neurology</p> <p>5 Other Healthcare Professionals Head of Nursing: Medical Directorate Head of Phlebotomy Nurse Practitioner: General Paediatric Clinical Lead Specialist Nurse Practitioner: Diabetes Homecare Occupational Therapist (CAMHS)</p>	<p>6 General Practitioners</p> <p>1 Health Visitor</p>
Other NHS Stakeholders	<p>5 Executive team members Chief Executive Officer Chief Financial Officer Chief Medical Officer Chief Operating Officer Deputy Operating Officer</p> <p>3 Service Managers Associate Service Director for Medical Directorate Service Manager for General Paediatrics / ED Service Manager for Main Outpatients</p>	<p>2 Executive team members Chief Executive Officer Director of Public Health</p> <p>1 Service Manager Director of 'Right Care, Right Here' Programme</p> <p>2 Commissioners Strategic Lead for Paediatric Acute Commissioning Associate Director of Clinical Commissioning and Transformation</p>
	Total 25	Total 12
	Total 37	

7.3 Organisational factors

This theme incorporates participant's views on providing community-based specialist paediatric services within the context of the Children's Hospital structure and service configuration, organisational objectives, pressures and hierarchies. The theme comprises three sub-themes in which organisational characteristics are perceived to have an enabling or disabling influence on the successful implementation of new policy initiatives such as Care Closer to Home (CCTH). The three sub-themes included in this theme are: Space and place; The Ivory Tower; Impact on healthcare professionals.

7.3.1 Space and place

Participants talked about the Children's Hospital in terms of location and access, as well as the interior processes and environment of the outpatient department. Existing and potential settings for community-based clinics were also discussed.

7.3.1.1 Access

The city-centre location of the main Children's Hospital was considered to make access to outpatient appointments difficult for families, particularly for those who choose to travel by car. This could be because of "all the trauma of getting into town" (HCP 3) and parents feeling "it's a big fight to get into the city centre" (Executive 1) due to heavy traffic and difficulties with transport and travel in a busy city-centre. Parking at the hospital was also perceived to be a significant barrier to access for families, contributing to increased stress and potentially influencing families' decisions to attend.

“If you’re driving it can be a real nightmare, getting into town at critical parts, points of the day... So I think travel into the city is difficult, parking is unquestionably difficult. We have a very limited number of parking spaces on site.” (Executive 2)

“I’d rather see twice as much car parking so that people can actually get here without being stressed and can arrive and not feel that coming to the hospital is a huge traumatic experience... actually trying to get here or park here is probably the biggest problem.” (SpR 3)

A small number of positive aspects of the hospital’s location were also noted. For example, “people know where it is... and it’s sign posted” (Commissioner 2), and families can make a day out of coming to the city-centre to “do some shopping” (Consultant 4). Public transport links into the city were further highlighted as a positive aspect of the hospital’s location, leading some hospital-based participants to question how difficult access to the hospital really was for families. For those participants, the hospital location was more a matter of convenience than access:

“Parking in the city is fabulous. But people seem to think that they need to park within three metres of my consulting room, which is a bit odd... I’m astounded by the number of people who assume that they can drive into the Children’s Hospital and park here. When a moment’s thought or checking would tell them that they can’t... we’ve got such brilliant public transport links... I don’t get it.” (Consultant 2)

“There’s a lot of families that probably think they should just be able to drive up in a car, park and go in for their appointments and with the best will in the world, in the middle of a city that’s not going to, and is there anything wrong in catching a bus or a train and walking five minutes up the road?” (HCP 1)

Community-based participants, including those running the specialist satellite clinics were more understanding of families’ experiences of accessing hospital outpatient appointments, acknowledging that travel by public transport can be expensive and difficult

for those families travelling with small children or children who have complex needs and disabilities:

“It is true in terms of our communities that travelling about the city is expensive and people will talk about the costs of getting to a hospital and there are real issues I think in terms of what we have as a, as a population, a lot of income-poor people having to travel.” (Executive 7)

“To get from this area to Birmingham Children’s Hospital with a child and a toddler in tow and a pushchair is absolutely horrendous, even if you drive and have a car, to get there for a 9 o’clock appointment in the morning, you can’t park, it’s expensive, it’s time consuming.” (GP 2)

Although attendance at appointments was considered to be a complex phenomenon, participants perceived that moving clinics into community settings would make it easier for families to attend their appointments, by reducing financial costs and journey times:

“So many patients are, are on sort of low income and some haven’t got jobs at all and sort, based in King’s Norton, it’s a long journey into town to the Children’s Hospital. Costs money, sometimes they have other children they have to take along with them, so if they have something more locally based it’s more of an incentive, one to turn up and it makes it easier on them.” (HCP 6)

“The advantages are access. Where I do the clinic, there’s loads of parking, a lot of families can actually walk to the clinic... It is convenient in terms of the money they spend and the time they spend.” (Consultant 5)

Locating clinics in the community was also thought to encourage attendance by those families who might not otherwise access paediatric care in traditional ways:

“It might allow you to access individuals who don’t access professional services and certainly I do get a few walk-in patients who normally wouldn’t go to the doctor at all.” (Consultant 7)

“And the real gain in that is that for the immediate vicinity where people live, they see and can access a clinic that they can walk to or that they believe is part of their neighbourhood.” (Executive 7)

7.3.1.2 Environment

Generally participants felt that the hospital outpatient department provided a pleasant environment for children and that the decor and facilities rendered it particularly child-friendly:

“I’ve always thought actually this is quite a nice place to come if you’ve got to have an outpatient’s appointment, you know it’s not all everybody sitting there, classic British, not talking to each other, you know it’s mayhem in there, but nice, controlled mayhem, so I think it’s actually a lovely part of the hospital, I think it’s one of the nicest parts of the hospital.” (Consultant 8)

Nevertheless, a few participants did recognize hospital outpatients as a large, impersonal and sometimes overwhelming space that could become crowded and noisy. Because of these features, it was likened to a “cattle market” (Consultant 4, Consultant 9) “airport” (HCP 5) and “train station” (HCP 3):

“Some mornings by 11 o’clock, it’s absolutely totally full, there’s virtually no seats, the noise is awful, you know the children are running around, you can see these stressed families and I just sometimes feel actually some of them look a bit appalled.” (HCP 4)

Participants further noted that little consideration had been given to the needs of adolescents visiting the hospital for outpatient appointments. Justification for this disregard was given on the basis that accommodating “such a diverse and varied age mix” (Executive 2) presented challenges for designing an outpatient space that was appropriate for all:

“It’s very children orientated when you go in there and it’s more like a, it’s more like an infants, lower junior type environment and if you think that we’re treating kids going up to sixteen and that’s children in secondary school... we really push a lot in terms of children and young people, but I think the way we market things and the way we decorate things is very children and babies based.” (Manager 1)

“Outpatients is, isn’t perfect. I think particularly the waiting area because it’s very difficult I think to meet the needs of the breadth of children that we see.”
(Manager 2)

In addition to issues with the environment, participants felt that the current set-up of the outpatient clinic was inefficient in terms of operational processes. This was perceived to impact on the effectiveness of patient flow through the space available. For example:

“You are sitting in the room waiting for the patient, the patient is actually outside and, but it takes another twenty minutes for him to go through the process to actually get to you. So I think that’s a waste of both the clinician’s time and the patient’s time really.” (Consultant 1)

Improvements to the process and flow of patients however were thought to be constrained by the physical structure of the building and the “limited rooms” available (Consultant 1):

“In terms of an outpatients department and the way the patients flow through systems and things, my view is that we’ve done the best that we can with the space that we’ve got, but you probably wouldn’t design it that way.” (Executive 2)

7.3.1.3 Settings outside of the hospital

Participants considered that the significance of the setting and clinic environment may be more or less important depending on the service being provided. As a speciality which often entails more discussion rather than investigations, it was felt that General Paediatric outpatient services could be delivered in a variety of settings.

“Hospital based specialists can exaggerate what they need to provide services, especially on an outpatient basis, because basically you need a consulting room, that’s appropriately equipped and that’s about it really.” (Manager 4)

Participants promoted community-based clinics as quieter and “friendlier” than the “intimidating” and crowded hospital (Executive 5). Sure Start children’s centres were

thought to be particularly appropriate for paediatric outpatient clinics as they were already embedded within the community and well used by families:

“The children’s centre in our patch is very accessible and I didn’t realise quite how much patients do use it. I am a trustee there, so I went in to see and saw lots and lots of families and patients that we knew, so I didn’t realise quite how accessible it was, so yeah, certainly children’s centres.” (GP 6)

Community-based clinics were also thought to assist clinicians in re-connecting with the local population, enabling them to better understand the specific health needs of different communities and to tailor the provision of care accordingly:

“If we were to use care closer to home as a concept, you would think we should be looking at things like the deprivation, socio-economics of that area, accessibility in terms of networks, roads whatever else, bus routes.” (Commissioner 2)

“Attempts that have been made in the past to relocate specialists in the community, if you don’t do it with a real cultural understanding of what those communities need... you’ll get exactly the same problems of DNA that you get in the secondary care sector.” (Executive 7)

Places where clinicians could interact with other agencies were also thought to be good for providing CCTH, as they presented opportunities for sharing knowledge between professionals and delivering care that is coordinated around the needs of individual families.

“If you’re intending to be a link between primary and secondary care and have a sort of two way process going on, then yes a GP surgery where if the health visitor was co-located, I could ask the health visitor what do you think about the family, so I think ideally I think that sort of, multi-professional site really would be good, you know even a Sure Start centre especially if mothers feel like dropping in.” (Consultant 6)

Overall participants expressed a belief that delivering paediatric outpatient care in community settings would improve the quality of healthcare experience by providing more convenient access and a more relaxed environment. These advantages were further anticipated to facilitate a more effective clinical encounter:

“In terms of patient experience standards, one would hope that it might be improved because they can either walk up the road or get the bus rather than getting two buses and a train or they can park the car and the environment is much more sort of conducive to waiting around so, I hope it’s a better patient experience.” (Executive 4)

“If you are in a setting you’re comfortable in, you’re going to be more relaxed; you might be more honest and open and give better quality answers particularly if there are social issues.” (GP 5)

There were contrasting views about whether clinics should be limited to traditional healthcare settings, with some questioning how far community clinics could stray from a traditional model of healthcare delivery, before they became ineffective and unacceptable. For some participants, retaining the essence of a traditional service model was essential:

“It does have to look like a clinic. Either a GP clinic or a well-baby clinic, you know it has to look like a clinic, it has to have a certain persona but lots of family centres do look a bit clinical, so I don’t think there’s an issue in terms of that. I think it is important.” (HCP 5)

“There is an inherent sort of trust of established centres, of you know, what’s the norm, what’s known about, what society considers to be the ‘well that’s where you get your healthcare’, you know, you go to the dentist to get your teeth done, you go to the hospital to get, you go to ASDA to get your shopping. And I think there is that kind of, safety and familiarity but those culture thoughts are not unchangeable, but more difficult the further away you get from the traditional medical model you go.” (Consultant 8)

For others, CCTH was about pushing outside of the normative rules and expectations of where secondary care has traditionally been delivered:

“I do wonder if there’s more we can do to think about alternatives you know places like Sure Starts, schools, leisure centres you know all that sort stuff. Does it need to be, especially for General Paediatrics, does it need to be in a health labelled environment full stop, question mark.” (Executive 1)

Most participants suggested that the setting should be fit for purpose, meaning that it should be appropriate for the type of service being provided.

“I don’t think we should be narrow-minded in where we think about delivering them from just as long as it’s appropriate to the care... It does need to be some sort of controlled environment I think, making sure that actually all of the right boxes can be ticked, like infection control and all of that sort of stuff.” (Manager 3)

7.3.2 The Ivory Tower

The Children’s Hospital was discussed by participants in terms of its status as a leading provider of healthcare for children and young people with respondents often referring to it as an “Ivory Tower” (GP2; HCP4; Consultant 8). This phrase served to convey the hospitals’ monumental presence within the city, locating it at the top of the healthcare hierarchy.

“The Children’s Hospital is an Ivory Tower you see... Well it is, let’s be honest, it’s an Ivory Tower, stuck in the middle of Birmingham.” (GP 2)

A lot of emphasis was put on the importance of retaining ownership of any hospital services being delivered in community settings, as participants were keen to distinguish themselves from other healthcare providers, partly for reasons of accountability and partly due to feelings of superiority.

“We own it, everything about it, you know they get BCH notes, they get a BCH Consultant, we’re doing BCH tests, we just happen to see them out there rather than in here.” (Manager 2)

“I would entirely support the need for us to have the brand out there and for people to know that it was us and to know we were doing a good job and the reputation does two things doesn’t it; it tells people that they’re going to get a good, high quality service and it sells the organisation, so for me, that’s a two way street. But I also think it’s clear that if we’re offering services out in the community, that people know that’s what’s happening, so if people have a problem, they know who to raise it with.” (Executive 2)

In doing so, hospital clinicians often constructed paediatric services provided by primary care clinicians as below the standards that they would provide:

“We’re in the Ivory Tower down at the Children’s Hospital and we don’t, we know everything and we look at GPs and think ‘oh they can’t even do this right and they can’t even manage asthma properly’.” (HCP 4)

“There is a bit of me that says, they [families] should come to us and we’ll do everything for them, we’ll make them better and then we can send them home and they’ll feel great, but that’s not necessarily being as patient focused as perhaps you know objectively you could be.” (Consultant 8)

This point was further evidenced by Executive 3 who highlighted the Children’s Hospitals’ extraordinarily high ‘first to follow-up’ appointment ratio. This practice was considered to indicate the organisation’s paternalistic nature and lack of trust in primary care clinicians to provide adequate paediatric care:

“Our first to follow-up ratios, that’s the number of times we call children back, is the highest of all the specialist paediatric centres in the UK. And that would say that we’ve got a more paternalistic attitude, or that we don’t trust primary care clinicians to take those children back on.” (Executive 3)

Others questioned whether community-based paediatric services should be conceptualised as the same as hospital healthcare or whether preserving the hospital model within a community setting simply served to maintain the fragmentation of care between sectors:

“If it’s going to be outside the hospital then you badge it in a slightly different way... Not to pretend that it’s the same as, exactly the same, but we’re doing slightly different things than we would do in the hospital.” (Consultant 4)

7.3.2.1 A ‘branded’ identity

For participants in this study, the Children’s Hospital ‘brand’ symbolised the hospital as a “centre of excellence” (HCP 4), replete with medical expertise and state-of-the-art technologies. Thus, many of the clinicians suggested that the ‘place’ of care delivery itself may hold “therapeutic value” for families (Consultant 2).

“Having the identity that you are being seen by Birmingham Children’s Hospital doctor, but in this setting, would be, could influence patients’ choice when they chose where to be seen, so definitely if you are being seen by BCH doctor, making that clear from choose and book time, should be, is important.” (SpR 2)

“We’re seen as the centre of excellence and one of my colleagues actually calls it ‘the pilgrimage’ and I think that’s quite right. I see children with simple things like childhood constipation, they come from everywhere, an allergy, you know, Wales, Shropshire, because they have to come to the Children’s Hospital.” (HCP 4)

“There’s something about coming to the hospital that creates confidence because you know, we are what we are and we have a reputation which people see as being about doing the right thing for children, which they may not associate with their GP practice.” (Executive 2)

As consumers of a branded service, participants suggested that families gained reassurance from the presence of the Children’s Hospital identity, perceiving that it would influence their decisions about where to access care. For many of the participants however, this

'brand' of the organisation was bound up the physical hospital building and thus may have difficulties transferring into smaller, community-based clinics.

"We've come to one of the big famous Children's Hospitals in the country and we're seeing the Consultant'. It has this sort of mystical, magical element about it, which potentially seeing the same Consultant but within a shed at the back of the GP surgery... you kind of lose that." (SpR 1)

"If you have it in Birmingham Children's Hospital, it might be a perception change that you're coming to the Children's Hospital which has its own reputation. And the fact that you're not actually coming to a tertiary hospital and just meeting some bloke in GP surgery might be perceived as slightly being different." (Consultant 1)

7.3.2.2 What is BCH? What is General Paediatrics?

There was some divergence in participants' views about what BCH is or should become, that is, whether it was there to provide a secondary care service to people within the local community or whether it should concern itself with becoming a national, tertiary-care centre which only provides "super-specialist" (Consultant 8) services.

"There's some real debates that they [the Children's Hospital] need to have about their overall strategic direction, you know. And how much of a tertiary service as opposed to a district general hospital they're going to provide... That then translates into the argument about, you know, if care closer to home, if they are very much more of a tertiary provider then, you know, that's going to be more difficult. If they have more, more of a balance of district general hospital services, then those outpatient services *can* be more community-based." (Executive 5)

"We should be interested in the health of the children who actually live in the community. I don't see a great deal of evidence of that in the Children's Hospital, I think they're more interested in providing additional peens to put on the turrets to build the cairn higher." (Consultant 7)

Many clinicians felt that people within the organisation were trying to push secondary care services (including General Paediatrics) out of the hospital in favour of turning BCH into a tertiary-care centre. Thus, by encouraging CCTH, participants felt that they were consenting to resources being diverted away from their specialities, leaving them vulnerable to being downsized.

“There’s already enough people in this Trust who would like there to be no General Paediatrics here and they just want it to be Great Ormond Street, the super-specialists and I don’t think that’s what Birmingham needs. You know, I think Birmingham needs to have a secondary paediatric centre here, as well as a tertiary.” (Consultant 8)

“Other, non-General Paediatricians would be delighted for us to clear out of, stopping messing up their lovely clean outpatients so that they can do some ‘proper work’.” (Consultant 2)

Executive team members acknowledged this concern, but opted to minimise it by focusing on the clinical justification for moving services into the community, rather than any perceived micro-political reasons:

“Sometimes there’s a degree of cynicism amongst clinicians that managers might try to force clinics into the community in order to deal with some of the capacity issues that I’ve just described and I don’t think that’s the right reason to do that, but as long as there are good clinical reasons for taking care out into the community, the closer to home argument, then I think the vast majority of people will support that and actually I don’t think that it matters whether it’s General Paediatrics or any other service.” (Executive 2)

Nevertheless, Executives did highlight the wider economic impact of hospitals providing care that could be provided, in their view, just as clinically effectively and more cost-effectively by primary care clinicians.

“Children’s paediatric services should only be seeing the more complex and serious case-mix of children and everything else should be being dealt with out in primary care and in community sort of services... if we’re going to achieve the QIPP savings which next year is meant to be £150 million coming out of the acute sector in Birmingham, you know, some of that’s got to come from children’s, you know making those services more efficient and only dealing with the things that really do need to be dealt with.” (Executive 7)

“There’s a lot of things that GPs should do that we’re, that we are currently doing and shouldn’t be paid for, and it’s costing the NHS millions.” (Executive 3)

In a similar vein, questions were raised about what the specialism of General Paediatrics is and whether it constitutes primary or secondary care. Thus it was thought that clarification of the parameters of the service would give some direction as to where it should be delivered.

“There’s a lot of people within that [General Paediatric] case mix that are essentially just really primary healthcare that should be done by a GP.” (Executive 1)

“We are doing things that we don’t need to do, that could be done in the community by other clinicians. And I think that that is, that would be the first sensible starting point. That would then free access up here for us to look at more specialised cases.” (Executive 3)

One clinician pointed out that the status of the Children’s Hospital General Paediatric service came from the access clinicians have to other specialties and technologies, rather than from the service itself:

“The General Paediatric service here if it has any status which it doesn’t really, but its status is actually not because of the service itself, but because of the other services to which we have access. Services like radiology, intensive care, biochemistry services; these are really excellent support services which make an enormous difference to what we offer. It’s not us I don’t think that allows it to in any way be special.” (Consultant 7)

7.3.2.3 Strategic direction

Many participants felt that if the Children's Hospital was going to implement CCTH, then it would need strong leadership with clear strategic aims, so as to ensure adequate infrastructure could be emplaced. The present set-up was conveyed as "tokenistic" (Manager 4), "haphazard" (Manager 1) and "a halfway house" (Executive 1). This was seen to reflect a lack of commitment and direction from the Children's Hospital regarding CCTH, and in turn indicated a lack of belief in the policy as a realistic approach for the long term.

"We need Trust wide direction and a proper strategy which I don't feel we have in terms of what we're doing with satellite clinics or community services and if that's where we want to go as an organisation and actually have proper drive behind it so we can get the infrastructure and protocols in place 'cause at the moment it feels a bit haphazard." (Manager 1)

"I provide all the resources, there is no cost for my Sure Start clinic, they don't charge any rent, I take everything with me, notes, equipment, toys and I take it away again afterwards. I've bought all that equipment myself. The Trust was not able to or interested in funding blood pressure equipment or anything... the cost to the Trust is simply my salary, but they would have been paying my salary anyway. So, the actual cost to the Trust is very little." (Consultant 7)

There was also uncertainty between participants about whether the hospital was or should be expanding or whether it should be planning to make reductions in service provision.

Certainly the feeling was that increasing demand should lead to expansion, however sustainability of health services within the context of the wider health economy suggested that efficiency-savings should take priority.

"There's a not a clear message in terms of whether we should be expanding, whether we should be cutting back and then the hospital looking to expand services but then we have to cut back on others, so it's kind of, I think a lot people, there's a bit of a mixed message around that at the moment." (Manager 1)

Related to this were questions about what would happen to any extra space if community clinics did help to free capacity within in the hospital. If General Paediatrics as a department for example, were able to create space by moving their clinics into the community, they felt reluctant to relinquish that capacity, as losing physical space within the hospital was equated with decreasing power and potential destabilisation of the department. This reinforced concerns that delivering services outside of the hospital would initiate a slippery slope towards being driven out of the hospital completely.

“If we move (Consultant General Paediatrician at Greet) out from outpatients, then that’s our initiative, you can’t go and give it to a new plastic surgeon it’s ours, otherwise why the hell are we going to do it? Given that you’ve told us there’s no space, so if we’re going to do something to create space, the space is ours not... We’re not doing it for the general good for everybody; we’re doing to help ourselves.” (Manager 2)

7.3.2.4 Managing families’ expectations

Participants felt that it was important that GPs described any new models of care (e.g. Consultant-led paediatric outpatient clinics in the community) to families at the point of referral, so as to manage their expectations of the appointment.

“It depends on possibly who’s referred them and what they’ve been told by the person that’s referred them because if they’re coming expecting all sorts of tests and things done and actually they’re not going to get those because they’re not on the site.” (HCP1)

“In the traditional model, when a GP says that he’s going to make a referral into a hospital Consultant, then people expect to be seen in a hospital.” (Executive 2)

“They all expect... their perception with a lot of those families is that they have to go to a medical place, for example they all expect to have a blood test and the perception of ill health has got to be, you know it’s a medical model that is going to get us better.” (HCP4)

Some participants also discussed the importance to some families of attending a physical hospital setting for their child's healthcare appointment, particularly for specific population groups.

"Some South Asian populations prefer to come to hospital isn't it, for asthma care and other things and I think that is slightly different thing in that it isn't actually an acute setting. They are unwell; they prefer to come to hospital and not to their GP." (Consultant 6)

"For our BME [Black Minority Ethnic] community there is certainly a perception that the hospital doctors are definitely superior to what you get in primary care and kind of the white coat mystique." (Executive 7)

7.3.3 Impact on healthcare professionals

Participants acknowledged that the development of community-based outreach clinics would involve a change in traditional ways of working and that the physical setting of the clinic would influence aspects of professional practice. The current 'drag and drop' model or replication of the hospital model in different settings, entails a lone Consultant travelling between sites and carrying out routine tasks such as weighing and measuring children which, in a hospital clinic environment, would be carried out by a healthcare assistant. This was considered to be an inefficient use of Consultant time and hospital resources.

"Spending your week going from one clinic in the community to another, where you don't feel you can achieve anything 'cause you don't know the local setup, is just not satisfying and the not the right way to be working." (Consultant 4)

"In the community you tend to fend for yourself, because you often do it on GP's premises, so you've got to weigh and measure the kids. You call them in, you do everything basically. Whereas in the hospital it's all done." (Consultant 3)

The physical hospital was also perceived by participants as bestowing medical authority and forming part of their professional identity. As a consequence of moving services into

community settings, some clinicians felt they were being “stripped” (Consultant 2) of a fundamental part of what it meant to be a Consultant, and of the “prestige” (SpR 1) that comes from working within the “Ivory Tower” (GP 2; HCP 4; Consultant 8) that is the Children’s Hospital.

“I felt a little bit exposed... Part of my authority comes from the fact that I have the edifice behind me. So you know people come to see ‘the doctor at the Children’s Hospital’ and that has a therapeutic value in itself.” (Consultant 2)

In the same way that outpatient services were perceived as “a little bit second class in terms of [having] no beds and no real clout” (Other HCP 5), moving away from the hospital and into community settings was associated in some cases with a decreased clinical status.

“There is a bit of prestige of going to the hospital to see the Consultant, the specialist carries a kind of weight with it.” (SpR 1)

However, others viewed the distance from the hospital as potentially liberating, allowing them to take control of a clinic, released from the constraints of working within a large and busy organisation. In this case, closer to home services were perceived to provide a calmer and “more peaceful” (Consultant 5) working environment with a smoother patient journey.

“In a funny sort of way it provides a sort of freedom to practice... I find it quite refreshing and certainly you don’t get any of the mantraps that you do working in the [hospital] outpatient department.” (Consultant 7)

7.3.3.1 Primary - secondary care interface

Closer to home services were further seen as an opportunity for developing working relationships across the primary-secondary care interface, allowing healthcare

professionals from different disciplines such as “health visitors, midwives [and primary care] link workers” (GP 2) to work together. Thus contributing to greater integration of primary and secondary care services for the benefit of patients and providers:

“We would like to think that we can work collaboratively with our secondary care colleagues and use joint facilities and share our knowledge and share our expertise, you know as a learning tool for general practice and for secondary care clinicians.” (GP 6)

Participants had differing perspectives however on the potential for CCTH services to facilitate education and training. Although potentially advantageous, the personal experience of some participants indicated that the transfer of knowledge and skills between clinicians rarely happens in practice and that simply placing different healthcare professionals together would not in itself facilitate integrated care. Evidence from existing paediatric satellite clinics and from former GP fund-holding initiatives were given as evidence for this claim, and restrictions from time or inclination were given as explanation for the lack of clinical dialogue.

“It used to be thought that doing peripheral outpatient clinics, the hospital’s expertise would transfer in some miraculous way to the General Practice or vice versa, bonkers! It just doesn’t happen.” (Consultant 7)

“[GP fund holding] was a complete waste of time because, you know it was, it was proposed as exactly that sort of teaching thing, that the GP would be there, but of course the GP wasn’t there; they haven’t got time to sit in a clinic.” (Consultant 4)

Nevertheless, there were suggestions that CCTH services could positively influence referral practices by Consultants providing feedback on the quality of referrals and encouraging primary care clinicians to manage less complex cases.

“Doing them in GP premises, that would be good. And then you could hopefully influence GP referral practices and stuff like that by actually talking to them.”(Consultant 3)

However, wholesale reorganisation of existing referral practices was thought to be a challenge.

“It’s then getting 270 independently minded GPs to use the same pathway. So we have had a problem with community clinics, even though we set them up and they exist, colleagues will still refer centrally so these are things that would need to be thought about.” (GP 5)

Recently proposed reforms to the NHS (DH, 2010) which advocated a shift in power to primary care were also discussed in relation to collaborative working. Specifically, GP consortia were seen as a potential facilitator of ‘joined up working’ as commissioners look to providers for “better pathways... better education or a better set up generally” (GP 5). The introduction of competition between ‘any willing provider’ however, was perceived as a barrier to collaboration, as competition to drive-up standards was conceived as incompatible with joint working:

“People will become much more insulated and want to protect their own organisations more than wanting to collaborate with other clinicians which would potentially mean that they lose business.” (Commissioner 1)

7.4 Policy implementation

The ‘closer to home’ policy was generally supported by participants as a sound principle for guiding the provision of paediatric outpatient care and underpinning children’s health service re-design. The idea of keeping children out of hospital was viewed as intrinsically desirable, particularly for those not requiring specific investigations:

“I think [CCTH] is a good recommendation. I personally feel that as far as outpatient work is concerned, only the patients who need specific investigations they can only get in the hospital really need to attend the hospital for their outpatient appointments.” (Consultant 7)

In contrast to the traditional service design which was perceived to reflect the needs of the organisation rather than those of patients and families, participants were keen to support a user-led agenda in which new, closer to home services were not only convenient, but also responsive to the healthcare needs of children. Imperative to this was the view that new services should be responsive to the needs of individual communities and that families should be involved in service re-design.

“We need to be very different in how we deliver services based around what the patients and their families need and I think at the moment we’re not, we’re still focused on what’s easier for us.” (Manager 1)

“The preservation of the institution, rather than the needs of the population they actually serve, seems to me to be the predominant interest.” (Consultant 7)

The principle of providing care that is both closer to patient’s homes and tailored to their needs was compared with the practicalities of delivering traditionally hospital based services within community settings. So, although closer to home policies were presented as unproblematic in principle, the process of actually setting up and maintaining clinics, finances and infrastructure outside of the hospital were perceived as presenting practical and financial challenges.

“Behind it in theory but the practice is often more complex than the theory.” (Executive 1)

“It sounds good, makes the public happy, but I’m a clinician and from a clinical point of view I’d worry it was making life more difficult.” (SpR 1)

“What we’re talking about is logistics and possibilities and that’s not necessarily the same as kind of philosophical approach is it?” (Consultant 8)

The CCTH policy was also contested on ethical grounds. Many participants for example, saw the moral imperative of needing to provide outpatient services in community settings which were, at minimum, an equivalent standard to hospital outpatient care.

“You would never want to take something out into the community that’s any different than you’d be happy providing here.” (Manager 3)

However, hospital based participants believed that community services would be of inferior quality due to a lack of specialist equipment and facilities. Anchored to this perception was the assumption that hospitals provide the ‘ideal standard’ of care and that access to investigations constitutes improvements in care quality. GPs on the other hand were critical of this supposition, arguing that certain types of Consultant would be better suited to the community, such as those who rely more on clinical judgment than technology.

“When I was doing General Paediatrics, the Paediatricians varied. Some investigated a lot; others were much more based on their assessment and clinical judgment, so maybe it depends on the nature of the Consultant... there might be a certain type of Consultant, this is what I’m saying, that is better suited to the community.” (GP 5)

There was some suggestion that waiting times for appointments might be shorter for community-based clinics, depending on clinic frequency. However this was seen as a negative, given the aim to reduce variation and ensure equivalence between hospital and community-based services:

“It creates difficulties for us in managing different queues because if you’re only allowing patients who live in this postcode to go to that clinic it creates separate queues and you might then get variance in waiting times.” (Executive 4)

Regarding location, participants emphasised the need to deliver clinics in areas of high referrals and places with good public transport links. It was suggested that clinics should be provided in areas of high deprivation or high levels of non-attendance at outpatient appointments to address inequalities in access to healthcare. This highlighted a tension between the need for a wide geographical coverage of services on the one hand, and the economies of scale needed for cost-effectiveness on the other. Given that it would not be economically feasible to provide outreach clinics in multiple areas with a low volume of patients, many participants proposed that decentralisation of services may have the perverse outcome of reducing access for some families.

“If you just transfer a clinic from a, from a hospital setting into a community-based setting you’ll improve the access for some people and reduce it for other people.” (Executive 5)

“There isn’t enough of a local population to sustain an outpatients clinic and therefore you have to draw in from wider areas, and if you draw in from wider areas many of them aren’t on bus routes, or accessible by public transport as much as this place is [the hospital]. And therefore you have to ask both financially and in terms of access, do they [CCTH services] really work?” (Executive 3)

Although not “insurmountable” (Consultant 8), perceived difficulties in ensuring equivalence in standards of care provision and equality in access to services challenged the philosophy underpinning CCTH.

“We’ve got to strike the balance between improving access and improving choice... And what’s actually affordable.” (Executive 5)

7.4.1 Bringing about change

Many participants felt that full and effective implementation of the CCTH policy would require a 'whole system' approach, rather than the few individual, but enthusiastic 'CCTH champions' who were currently driving innovations in service delivery.

"There will be individual clinicians absolutely who want to do things individually and small scale stuff but that's not going to happen, that's not going to work and that's not going to be sufficient. You need the whole system to change; you need the whole system change processes in place to support that policy shift."

(Commissioner 1)

However, it was recognised that such changes in practice would require courage from individual practitioners and support from the wider organisation:

"It would be a fundamental change in the way we do things. The reason I haven't done it is that I'm a bit scared really because it is slightly revolutionary and I just think that is something I would really love to do but I'll think about it another day."

(Executive 6)

7.5 Service design

7.5.1 'Drag and Drop' model

Participants discussed different service models for the delivery of outreach clinics. The model utilised by the specialist Children's Hospital was described as "drag and drop", meaning a direct replication of hospital services in an alternative location.

Hospital managers expressed the belief that outreach clinics whether delivered in hospital or community settings "shouldn't look any different" (Manager 2), meaning that they should be identical in terms of service model and quality. Commissioners and community-

based executives, however, questioned the cost-effectiveness and sustainability of this approach, suggesting the necessity of service re-design as well as relocation:

“That’s not the way forward, it’s not sustainable, it doesn’t really deliver what people need, it’s trying to take a model that is designed and is developed in a hospital for a hospital into a setting that doesn’t have those design features.”
(Commissioner 2)

Consultants were also in favour of outreach services that provided added value rather than simple relocation in the community, for example a more substantial “ambulatory care” or “boundary-less hospital” approach (Consultant 6), or a model incorporating education and joint working with community-based staff.

7.5.2 ‘Drop-in’ clinics

The potential for ‘drop-in’ access to outreach clinics was also discussed, together with the possibility that this benefit might encourage a sense of community ownership of the service for families and “an atmosphere of availability, approachability” (Consultant 7) by the hospital. However, it was recognised that the walk-in option available at the current family centre outreach clinic had not been greatly utilised and Consultants expressed concern that it might result in inappropriate cases being seen.

“I would be nervous about doing that because you’d end up with the walking well or the people who want a sort of a covert second opinion about you know, ‘Doctor X is managing this this way, what do you think?’” (Consultant 2)

Open GP access to community clinics through the ‘Choose and Book’ appointment system was also not endorsed. This was to prevent “trivial” (Consultant 4) cases being seen merely because families like the idea of attending a Children’s Hospital appointment:

“And choose and book is a nonsense really because stupid things happen, you know a child with something you know, that is trivial... May like sound of the Children’s Hospital so they decide they want to come here... So that element of patient choice, although it’s important, actually makes it very difficult to organise services sensibly.”
(Consultant 4)

7.5.3 ‘One-stop-shop’ model

Many participants were strongly in favour of a ‘one-stop-shop’ model of service delivery for paediatric outpatient care, whereby patients could receive assessment and care from different specialties on the same day. This was seen to be impractical in community settings, given the difficulty of organising multiple teams to be present at one time and the lack of diagnostic equipment available outside of acute care services. Participants therefore expressed concern that families attending community clinics would be disadvantaged by having to attend multiple appointments. However, this potential negative was counteracted by the fact that same-day appointments were often also not possible for patients attending hospital clinics due to scheduling difficulties.

“The only downside is if they might need a blood test, further investigation, they’ve got to come here, but having said that, all the other investigations normally except just a blood test have to get booked in anyway, so they have to come back.”
(Other HCP 4)

“Even when they are complex, we don’t necessarily offer sadly, multiple consultations on the same day. So I cannot really justify that. I have a lot of complex patients who see the dieticians and the physios and a lot of people however, the system doesn’t really lend itself to you know, having them come on a single day, seeing all these people, which I don’t do, I must be honest, not me personally. Somehow the appointments don’t seem to fit together.” (Consultant 6)

In the case of specialist phlebotomy services for children, a walk-in service is provided at the hospital, meaning that blood tests would normally occur within the same visit (a service is also used by GPs to obtain blood tests for children). Given the difficulties of providing a cost-effective phlebotomy service in the community for a small number of patients, and the governance regarding transport of samples back to the hospital, it was suggested that patients likely to require any tests should be seen at the hospital rather than in the community.

“You need to have a system whereby the appropriate cases are selected. So there’s no point kind of seeing somebody who clearly you know is going to need to have bloods and x-rays in peripheral clinics and then sending them into hospital the next day or third day or whatever, to have those tests done.” (Consultant 1)

A range of participants suggested that this case selection might be achieved by adopting a ‘follow-up only’ model, with all initial appointments taking place in hospital, as follow-up appointments were thought to be less likely to generate investigations. Alternatively, patients potentially requiring tests could be screened out of the outreach clinic caseload at the point of referral. Clinicians, however, reported that selection of patients would be difficult as insufficient information was provided in GP referral letters. A solution, suggested by one GP was a “pro forma” to provide more detailed clinical information (GP 5).

A further perceived difficulty in providing outreach clinics was the management of patient records. Consultants had encountered significant difficulties regarding the transfer of patient notes from the hospital to outreach clinics. It was made clear by several

interviewees that remote access to electronic records would facilitate the smooth running of outreach clinics.

“I know [Consultant delivering a satellite clinic] has to carry all his notes with him, but again, if you had a good IT system, he could dial up via a secure access point with appropriate passwords and be actually using IT for his benefit in the community. You wouldn’t have to carry lots of notes.” (GP 2)

Integrated Information Technology systems were therefore perceived as integral to the implementation of CCTH policies:

“I don’t know what the IT set up would be like, that would, you know obviously if the Consultant can access notes remotely whatever you’re planning, that would be very very important.” (GP 5)

“In terms of the clinics that we’ve run to date... I don’t think we’ve used technology over and above the base line, so you know again, there may be solutions to that, that we’ve not explored as part of the pilot work.” (Executive 2)

7.5.4 Telemedicine

Alternative ways of providing CCTH, other than Consultant-led outreach clinics, were also identified. Telemedicine, where advice is provided electronically or by telephone to families or to GPs, was highlighted by several participants.

“Technology is increasing, developing as well... so you can use health and telemedicine as an example of developing something, not just close to people’s homes but actually in people’s homes.” (Commissioner 1)

Respondents however reported both negative and positive experiences of such initiatives.

A telephone line for families had proven to be effective in reducing hospital admissions

within one paediatric specialty, but a second specialty had found their staff “constantly struggling” (Consultant 4) to provide this additional service.

7.5.5 GPs with Special Interests

An alternative model for providing CCTH might be to develop the role of GPs with special interest in paediatrics (GPwSIs). This was seen to be of interest to commissioners because they would allow Consultants to remain in the hospital and might have advantages in terms of shorter waiting times for patients. However, it was also recognised that GPwSI would not be able to manage all cases, therefore requiring a “differentiated system” (Executive 7) and in some instances requiring families to return for a second appointment with a Consultant. Moreover, one GP did not see this model as desirable to either families or GPs.

“As a patient, if I was wanting to see a specialist, I would want to see a, someone in a Consultant team. And I don’t think GPs working outside have that... I think GPs are better to be GPs. I mean take an interest in whatever, is fine, but don’t try and do the hospital’s job for them.” (GP 1)

7.5.6 ‘Out-of-hours’ clinics

Finally, participants highlighted that there may be models other than CCTH by which to improve access and attendance rates at outpatient clinics. ‘Out-of-hours’ clinics provided in the evenings, early mornings or at weekends had previously resulted in very low non-attendance rates and were perceived to be well-received by families.

“So evening clinics, and I’ve done a few, and I think that the response is good from the patients. Where they find it easy, they don’t have to maybe miss a day off work, kids don’t have to miss a day off school, parking is easier, those kind of things really.” (Consultant 1)

7.6 Summary of findings

The benefits of CCTH that were anticipated by staff and stakeholders, such as easier access for families, a friendlier environment and more effective clinical encounters, were consistent with families' concrete experiences, as were their contrasting views regarding how far community clinics could stray from a traditional model of healthcare delivery before becoming unacceptable. Nevertheless, for hospital-based clinicians in particular, places were constructed as sites of interaction and identity, signifying that medical authority was enmeshed within the physical setting of healthcare delivery and thus may not transfer out into smaller, community-based clinics. Many hospital participants were further concerned by an alternative agenda of CCTH policy, speculating that its real purpose served to scale back particular specialities, leaving them vulnerable to cut-backs. Moving out into the community was therefore perceived as a threat to the clinical speciality as well as a threat to personal and professional identity. Although many participants could see the potential benefit of 'joined-up' working for patients, barriers were identified in terms of time; incompatible systems and general desire of practitioners to share their knowledge. In practice then, implementing CCTH policies held significant challenges. Maintaining traditional ways of working were further defended in terms of the risks of delivering poorer quality of care to patients, creating differentiated systems and the potential for reduced access for some families. Finally, participants indicated that to be successful, CCTH would require re-design as well as relocation of services, describing a range of alternative models for delivering care closer to patient's homes.

The aim of the next and final chapter is to draw some conclusions about the role of place and space in paediatric healthcare experience. It provides further discussion of these findings, together with findings from the family study, within the context of existing theoretical and empirical literature, as well as highlighting implications for policy and practice.

CHAPTER EIGHT

8 DISCUSSION

8.0 Introduction

This chapter synthesises findings from the three studies presented in this thesis, integrating the views and experiences of young people, their families, and NHS staff and stakeholders to develop broader and deeper understandings of paediatric Care Closer to Home (CCTH). The chapter opens with an overview of the original aims of the study and how these have been achieved. This is followed by a discussion of main findings in relation to existing empirical and theoretical literature, and a consideration of methodological issues including credibility and transferability of findings to other settings and populations. Attention is then given to the implications of the findings for policy, practice and research, explaining how the findings have already contributed to service re-design at the Children's Hospital and how they may influence future health service provision. A discussion of the research thesis's strengths and limitations and suggestions for future research concludes the chapter.

8.1 Revisiting the aims

The aim for this project was to explore the experiences, views and meanings of paediatric healthcare provided in different settings. Impetus for the research came from (i) policy recommendations that young people who are ill should receive care as close to home as possible (DH, 2004); (ii) a lack of evidence regarding the provision of specialist paediatric outpatient care in community settings; and (iii) a request from Birmingham Children's

Hospital for an evaluation of their two community-based satellite clinics. Although a review of the CCTH literature suggested that the initiative led to improvements in patient satisfaction (see chapter 2), little was known about families' experiences of receiving care in specific settings, or how changes to the location of care impacted on those experiences. As healthcare professionals are instrumental in the implementation and running of new services, their views and experiences were also considered important for service re-design and evaluation. The aims of this study were:

1. To describe the experiences of families receiving specialist paediatric healthcare in traditional and alternative settings.
2. To explore the views and experiences of healthcare professionals and other NHS stakeholders on providing paediatric outpatient care in different settings.
3. To better understand the role of place and space in the experience of providing and receiving care closer to home.

The first aim was addressed through a meta-synthesis of qualitative literature, and phenomenological interviews with service-user parents and young people. Taking a descriptive phenomenological approach to an applied health research study was novel, and offered a richer and more nuanced account of the place-care experience than other experience-based approaches such as Experience-based Design (Bate and Robert, 2006) or Discovery Interviews (Wilcock et al., 2003), which are limited in terms of their philosophical underpinning and analytic procedures. A descriptive phenomenological approach had the added benefit of describing the essential structure of the phenomenon, while retaining individual variations. In doing so, findings illuminated aspects of healthcare that have previously gone unnoticed in health policy and practice; that is, the relevance and meaning

of 'place' within families' healthcare experiences. CCTH services were shown to transform the lived experience of receiving specialist paediatric care by minimising disruption to family life temporally, spatially and emotionally. These dimensions of place were particularly empowering for families, enabling them to engage with paediatric healthcare in a more relaxed, present and meaningful way. In contrast to hospital care, CCTH *'fitted'* into the families' lifeworld, thus extending its value to other family members.

The second aim was achieved through semi-structured interviews with healthcare professionals and other NHS stakeholders about CCTH policy and practice. This approach offered empirical insight into how healthcare professionals perceive CCTH policy initiatives, which in turn is likely to influence their attitudes towards organisational reform and the extent to which the policy is implemented. The findings of this study indicated that the place of service delivery is not only an issue of physical location and supportive infrastructure, but also involves professional and organisational identities. It is likely then, that policy initiatives which ignore assumptions about place, power and identity, or which challenge them too strongly, will have limited success. Findings further indicated that for CCTH to be implemented effectively, services will need to be re-designed in a way that actively supports integration across care sectors. Such integration will require traditional professional and service boundaries to be dismantled and NHS stakeholders to be provided with convincing evidence regarding the benefits of working in new ways.

The third aim was to contribute to theoretical literature about the meaning of place within paediatric healthcare. Although pre-existing theories, findings and meaning structures relating to the phenomenon were set aside during data analysis (Ahern, 1999), existential

concepts of time ('lived time'), space ('lived space') and human relationships ('lived other') became increasingly evident. Interpreting these findings in light of the philosophical notion of the lifeworld (in particular, constituents of temporality, spatiality and inter-subjectivity) was therefore productive for facilitating understanding of the phenomenon as it emerged (Dowling, 2007), and illuminated aspects of the lifeworld in a way that deepened and clarified understanding of the human experience of CCTH. As highlighted in the literature review (chapter 2), the human experience of place is a significant dimension of the lifeworld (Seamon, 2000b), core concepts of which include the experience of 'rootedness', 'insideness' (Relph, 1976) and 'at-homeness' (Seamon, 1979). These concepts will be explored further in the discussion of main findings.

In summary, this thesis offers new empirical insight into paediatric CCTH, grounded in participants' lived experiences. As the experience of healthcare has been shown to change with space, place and time, so using a 'lifeworld' framework has the advantage of illuminating those aspects that are often taken-for-granted in policy initiatives, but may hold serious implications for policy implementation. The main findings will now be discussed in relation to theoretical concepts of 'place and space' and other empirical literature.

8.2 Discussion of main findings

Using the principles of reciprocal translation analysis, taken from meta-ethnography (see chapter 3 for more detail), concepts from data analysis of the three studies in this thesis (supported by participant data) were compared within a matrix to determine how the studies were related, and to identify any common, recurring or refutational ideas (Britten

et al., 2002). This synthesis of findings across the three studies resulted in the development of three main organising concepts: temporality, spatiality and inter-subjectivity (see table 13). Although these concepts are interlinked, for ease of reading they are presented and discussed sequentially.

Table 13: Synthesis of concepts from each study

	Temporality	Spatiality	Inter-subjectivity
Meta-synthesis	Maintaining normality	Transformation of home; Transformation of parent	Support and Coping; Working in partnership
Family study	Time wasted, time saved	Space and place; Adolescent needs; My community-not the community	Consultation and Care
Staff study	Policy implementation	Organisational factors (Space and place; Ivory Tower; Impact on healthcare professionals)	Service design

8.2.1 Temporality

As a significant aspect of daily life, time was an important feature for families attending paediatric outpatient appointments. As conveyed in the findings, time was something that all families had a constant awareness of. Time was discussed in terms of appointment scheduling, journey, waiting, consultation and time spent away from family, work or school. Essentially, community-based clinics allowed time to be ‘*saved*’, whereas long journey and waiting times at the hospital meant that time was often ‘*wasted*’. For clinicians, time spent traveling from their hospital-base to community clinics was also perceived as time wasted. However, feeling able to give patients and families more time during the consultation was considered valuable and constructive.

It is clear from the findings that participants' awareness of time altered according to the place in which healthcare was provided. It is possible to develop and explain this phenomenon of '*time wasted, time saved*' by looking more closely at time perception. Husserl (1917/1991) for instance, distinguished between objective, shared time as measured by clocks and calendars, and subjective time as a personal or inner experience. Although objective and subjective time are both lived by human beings, the two are encountered in different ways. Objective time is experienced in relation to the structure of activities in daily life (e.g. managing appointments) whereas subjective time relates to how time is experienced while carrying out those activities (e.g. feeling bored / time pressured). Husserl's understanding of time will now be considered in more depth, with regard to families' experiential accounts of receiving paediatric outpatient care in different settings.

8.2.1.1 Objective experience of time

One of the most significant differences between receiving outpatient care at the hospital and at one of the two community-based clinics was the amount of clock time families allocated for an appointment. Within the context of families' busy and hectic lives, where the planning and allocation of time for activities was seen as crucial for managing lifeworld commitments, hospital-based appointments were experienced as difficult and disruptive, due to irregular and unpredictable waiting times. This often meant that families felt unable to plan for, or do anything else on the day of a hospital-based appointment, usually resulting in the whole day being given up for lost. Such disruption to families' lives is consistent with previous empirical studies of adult outpatient care, from a patient perspective (Mitchell, 2011, Moran et al., 2009).

Community-based clinics, however, provided care that was more convenient and created less disruption to the family routine. Moreover, by requiring less mental and physical preparation, CCTH enabled parents to balance commitments such as work, school and childcare, alongside attending their child's outpatient appointment. This was particularly important when families felt time-pressured in their lives more generally and meant that families could manage their child's healthcare needs alongside the needs of other family members. In line with research investigating specialist paediatric care *in the home* (Hansson et al., 2012), the value of CCTH was thus shown to extend beyond just the child receiving care, to improved wellbeing for the whole family.

8.2.1.2 Subjective experience of time

In addition to the amount of clock time allocated for appointments, *how* participants experienced their 'appointment time' was related to the setting that they were in. Time spent waiting for appointments in the hospital for instance, was clearly articulated as wasted, unproductive time that could be used to do something more useful. This finding reflects other studies (Moran et al., 2009), including those reporting adolescent experiences of outpatient care (Tivorsak et al., 2004, van Staa et al., 2011). Part of the waiting experience was the phenomenon that participants' perceptions of time appeared to slow down or speed up depending on how that time was spent (e.g. being bored or occupied), the waiting environment, the emotional state of the person waiting, and their feelings of control. These factors will now be discussed.

Being bored

Consistent with other empirical research on waiting in healthcare settings (Moran et al., 2009, Bournes and Mitchell, 2002), parents' and adolescents' experiences of waiting for hospital outpatient appointments were described as long and arduous. Clinic waiting times have previously been associated with reduced satisfaction with health services (Rondeau, 1998), as well as feelings of irritation and frustration (Dube et al., 1991). In this study, families' accounts of time as 'dragging' or 'standing still' while waiting for hospital appointments could be understood as a form of existential boredom.

According to Heidegger (1930/1995), boredom is a fundamental, existential mood in which we become aware of our own being, through a direct experience of time. In describing boredom, Heidegger identified three forms: (i) becoming bored by, (ii) being bored with, and (iii) profound boredom. Each exist in relation to the passing of time and contain "two essential structural moments, being held in limbo and being left empty" (Stafford and Todres Gregory, 2006, p.159):

"We straight away take 'boring' as meaning wearisome, tedious, which is not to say indifferent... Wearisome means: it does not rivet us; we are given over to it, yet not taken by it, but merely held in limbo [hingehalten] by it. Tedious means: it does not engross us, we are left empty [leer gelassen]... [That] which bores us, which is boring, is that which holds us in limbo and yet leaves us empty." (Heidegger, 1930/1995, p. 86-87)

When parents and adolescents in this study became bored whilst waiting, they experienced 'becoming bored by'. They described being held in limbo as time dragged, and feeling empty by unfulfilled expectations to be entertained. According to Heidegger, people

endeavour to shake off boredom and make time pass more quickly by driving it on through engaging in distracting activities. The lack of interesting diversions in this case meant that waiting was experienced as long and tedious. This finding is consistent with previous research of adolescent views of paediatric clinic settings (Tivorsak et al., 2004). Families tried to speed up waiting times by engaging in their own distracting activities, such as playing with mobile phones or chatting with others, but this was often unsuccessful.

In addition to time dragging, waiting for long periods of time before an appointment also prevented families from pursuing other, more productive activities. Time was thus also experienced as standing still, as in Heidegger's second form of boredom, 'being bored with'. Similar to other studies of boredom (Martin et al., 2006), this was evidenced through parents' accounts of feeling guilty and constrained whilst waiting. Although parents demonstrated that they were better rehearsed than adolescents at battling the dull and mundane experience of boredom, they still had to fight to keep their frustration hidden, which often led to feelings of irritation.

Being occupied

Not all participants in this study described such feelings of boredom whilst waiting for their appointment. Smaller children for example, enjoyed playing with the toys provided in the hospital setting and so tended not to notice the time passing. This may suggest that the more absorbed a person is in a task, the less attention they pay to time itself (Eastwood et al., 2012). As is made clear by the adolescents in this study however, distraction may not eliminate the boredom of waiting or alter the perception of time if it is unappealing to the individual. As younger children were interested in a new and exciting environment and

were attracted to the toys provided in the hospital, they were able to keep occupied by engaging in enjoyable activities which distracted them from the burden of waiting. This meant that the time waiting prior to the consultation formed part of the whole appointment experience in a positive way. Such enjoyable activities however, were less prominent in community settings, thus leading younger children to feel less satisfied.

The waiting environment

Findings of this study also demonstrated that differences in the clinic environment (e.g. quieter, calmer and more relaxed) led to time waiting in community settings being perceived by parents and adolescents as more worthwhile and pleasant, thus having an overall positive effect on the experience of care. That parents and older children preferred CCTH despite the lack of distraction may suggest that the setting or environment in which people wait also plays a part in their perception of time, and satisfaction with the duration of time spent waiting. Evidence that time passes more quickly in a pleasant environment is documented in other studies of waiting in healthcare settings (Mitchell, 2011, Pruyn and Smidts, 1998, Moran et al., 2009). The present study supports these findings, demonstrating that when the environment is pleasant and relaxed, waiting is experienced as more agreeable, irrespective of time duration. Research also shows that the subjective (waiting) experience of time is a good predictor of consumer satisfaction (Pruyn and Smidts, 1998, Van Hagen, 2011). By improving the physical outpatient environment and providing appealing diversions, the hospital waiting experience could also be improved (Dijkstra et al., 2006), leading to waiting times being experienced as more tolerable and potentially leading to increased satisfaction.

Emotion

Fitting appointments into families' already hectic lives, together with difficulties of hospital access, long waiting times in crowded and noisy conditions, and the worry about missing school, work or incurring car parking fines, were all shown by parent and adolescent participants in this study to contribute to feelings of stress when attending hospital appointments. As a person's emotional state can influence their perception of time (Hammond, 2012), so feeling anxious or irritable about the wait, may lead to families experiencing time as slowing down, thus perceiving the waiting time to last longer. As Hornik (1992) suggests, "people in a positive mood, enjoying themselves and their current state may pay less attention to time, and when asked to estimate recent events, will respond that time seems to be passing more quickly" (p.212). This was made clear at community-based clinics, where providing more convenient access, shorter waiting times and longer consultation slots led to families feeling more relaxed before, during and after their appointment, contributing to their sense of *'time saved'*.

Control

Finally, the absence of any defined end to the waiting at the hospital contributed to feelings of powerlessness for parents and adolescents. Such uncertainty affected families' sense of control over the wait and reduced the likelihood of them engaging in activities to fill the time. Providing information on estimated waiting times and the reasons for clinic delay would dispel uncertainty over waiting duration, and affect the experience of time waiting, as shown in a previous study exploring ways to improve patient satisfaction in an outpatient department (Pothier and Frosh, 2006). Families in this study also suggested that

real-time, reliable information would increase their acceptance of the extra wait, by increasing their sense of control over the waiting experience.

In summary, less clock time is allocated by families for a community clinic appointment as the journey and waiting times are almost guaranteed to be shorter. This reduces anxiety which affects the subjective experience of *'time saved'*. Time spent waiting at the hospital is generally perceived as *'wasted'*, unproductive time which can be stressful and frustrating, particularly when the waiting environment is experienced as uncomfortable or unpleasant (e.g. noisy and crowded with little or unattractive distraction activities).

8.2.2 Spatiality

Spatiality concerns the appearance and meanings of the enviroing world and how those meanings are altered according to a person's circumstances (Todres et al., 2007). The place of healthcare delivery held relevance and meaning for all participants in this study, demonstrating that experiences are not solely derived from the human subject, but co-constituted by the world in which the subject lives (Giorgi and Giorgi, 2003).

The meaning of CCTH was understood by families as healthcare which *'fitted'* into their daily life, with minimal disruption. Where hospital care was seen as a dis-located and demanding activity, CCTH tended to blend into family life, with little conscious awareness (Seamon, 2000b). In addition to the perceived physical closeness of clinics, part of this integration was shown to come from the spatial setting and straightforward processes of CCTH, contributing to the creation of a calmer, more informal and relaxed environment. In contrast, shifting hospital services out into the community was perceived as disruptive to

hospital-based healthcare professionals' traditional working practices and their sense of attachment to the hospital. For staff then, CCTH initiatives were seen as threatening to their professional identity and medical authority. In the following section, CCTH is discussed in terms of spatiality from a service-user and then service-provider perspective.

8.2.2.1 Place as a sense of 'being-at-ease' for families

For most families, CCTH provided a familiar, informal and more relaxed environment in which they felt comfortable and secure. The domestic-like rooms (e.g. kitchen, playroom and bathroom) and soft furnishings (e.g. carpet, bookcase and sofa) at the family centre clinic helped to create an atmosphere of warmth and calm, and was described by parents and young people as having a feel of homeliness, leading to a sense of 'being-at-ease' in the surroundings. According to Seamon (1979), feelings of 'at-easeness' constitute one of the five essential aspects of the experience of 'at-homeness' (see figure 9). Homeness in this sense is not necessarily a house or a shelter, but a distinct sense of being in the world. As Seamon (1979) explains:

"...the experience of *at-homeness* (is) the taken-for-granted situation of being comfortable and familiar with the world in which one lives his or her day-to-day life. Observations on home point to five underlying themes which mark out the experiential character of *at-homeness* - *rootedness*, *appropriation*, *regeneration*, *at-easeness* and *warmth*." (p.78)

Being '*at-home*' means being relaxed and comfortable within the self as well as within the physical, social and symbolic landscape (Moore et al., 2013). Retaining a closeness to families' homes both in terms of proximity and through the provision of familiar, warm and welcoming surroundings, CCTH enabled families to experience a sense of comfort, security

and unreflective ease (Todres et al., 2009). This was in stark contrast to the sense of alienation and ‘dis-ease’ many parents and older patients felt within the main hospital setting, and sometimes within their own homes when hospital healthcare was provided at home.

Being ‘at-ease’ however, also refers to the freedom to be oneself without fear of repercussion and without having to display a particular public image (Seamon, 1979). While many parents found this freedom in CCTH clinics, and younger children in the hospital, adolescents often felt out of place and un-easy about being themselves, regardless of which setting they were in. Nevertheless, consistent with other studies of young people’s clinic preferences (Miller, 1995, Jacobson et al., 2001, Tivorsak et al., 2004, van Staa et al., 2011), adolescents generally favoured the more home-like, relaxed and comfortable surroundings that CCTH provided.

Figure 9: Seamon’s notion of ‘At homeness’

Essential features for a sense of <i>at-homeness</i> (Seamon, 1979)
<i>Rootedness</i> : a sense of familiarity and belonging
<i>Regeneration</i> : the restorative function of place
<i>At-easeness</i> : the freedom to be oneself
<i>Warmth</i> : a friendly and supportive atmosphere
<i>Appropriation</i> : a sense of possession and control

In this study the meaning of the enviroing world was also shown to change according to health status (Todres et al., 2007). Just as health and wellbeing were equated with a sense of ‘homelikeness’ and ‘at-homeness’, illness was shown to be related to a sense of ‘unhomelikeness’ and ‘homelessness’ (Svenaesus, 2001, Moore et al., 2013). Enabling

patients to feel 'at ease' is particularly important during times of sickness, when they may feel weaker and more vulnerable than in times of health. This was made clear by one of the adolescent participants who attended a new community-based clinic while feeling unwell. For her, a new and unfamiliar place led to a deep sense of vulnerability and 'unhomelikeness' (Svenaeus, 2001) both within the place and within herself (Moore et al., 2013). Such 'un-ease' was shown to lead to feelings of stress and anxiety, particularly as the girl felt incapable of putting on a public face. Similarly, families of children receiving long-term healthcare in the home were shown in the meta-synthesis findings to experience a "loss of the familiar world" (Toombs, 1993, p.96) as their home became appropriated by medical technologies and healthcare professionals, eventually transforming from a family home into "a landscape of care" (Moore et al., 2010, p.4). Feeling 'at-ease' within a place was therefore shown to vary according to changes in health status (such as feeling symptomatic or not), and also in relation to changes in physical surroundings.

According to Seamon (1979), appropriation also involves a sense of emotional attachment, possession and control over places. In this study, families receiving care in the home relinquished custody of their homes to medical technology and equipment that was necessary for their child's health, but which did not necessarily '*belong*' in the home. In terms of outpatient CCTH however, families demonstrated an appropriation of community-based clinics by emphasising the importance of clinics being in their own community and not just in *the* community. This was not only due to ease of accessibility, but for those who experienced them, community-based clinics offered more than just medical care; they presented families with the opportunity to re-form relationships with the people and places of their communities. CCTH clinics thus also had a social function for people to meet in

ways that enhanced their sense of community (Curtis, 2004). Moreover, the physical repositioning of the Consultant outside of a medical institution was seen as a welcome awareness and responsiveness to the lifeworld of individual families. Extending into the consultation room, this led to a blurring of boundaries in community-based clinics between the families' world and the medical world, thus bridging the gap between hospital and home. This finding is re-visited in the later section on inter-subjectivity.

8.2.2.2 Appropriateness

The idea of an 'appropriate' place for healthcare alludes to unspoken rules and place-based norms (Cresswell, 2009) which the CCTH policy initiative was seen to challenge within the context of healthcare. Appropriateness for families in this study was often linked to the purpose of the outpatient appointment and beliefs about the child's health condition. For example, where a parent felt that the child's condition required only a discussion-based consultation, then a community clinic was felt to be appropriate. However, where a parent felt that their child required more intensive medical treatment or assessment, then the hospital was where they wanted to be because of the facilities available. Similarly where a patient was symptomatic of illness they took comfort and reassurance from being in a medical setting. In this way, the service environment may need to suit the function or purpose of the appointment (Pine and Gilmore, 1999). In cases where the perceived purpose was to carry out 'medical' tests as opposed to 'relational' care, absences of medical technologies served to undermine community-based clinics as legitimate places for paediatric appointments, leading in some cases to doubts about the quality of care provided.

8.2.2.3 Function vs. experience

Policy states that not only should health outcomes be good, but the experience of treatment and care should be good too. Thus the meaning and process of value creation in healthcare has shifted from a product-centric view to that of a more personalised consumer experience (Pine and Gilmore, 1999). In terms of medical spaces, research and policy advocates a balance between clinical function and a warm and welcoming environment, particularly in paediatric healthcare settings (Kearns and Barnett, 1999). By including amenities such as cafes and shops, vibrant décor and stimulating activities, the Children's Hospital has attempted to minimize the medical nature of its spatial environment in favour of designing a place which provides an 'experience' more like those created at leisure centres or theme parks (Curtis, 2004).

Different families may also have different aims when it comes to their children's healthcare, which could lead to them experiencing environments in different ways according to their goals or expectations (Van Hagen, 2011). Whereas task-oriented service-users might prefer the simplicity, punctuality and efficiency of community-based services (e.g. "get in, get done and go home", parent 6), more experience-focused service-users might prefer to embrace the 'genius loci' or spirit of a place (Seamon, 2000a), taking the opportunity to embrace the "medical theme park" (Kearns et al., 2003, p.2313) experience of the Children's Hospital as an experiential activity in itself. For those families and perhaps those with smaller children, CCTH may fail to deliver the excitement and exclusivity that the Children's Hospital provides.

8.2.2.4 Summary of spatiality from a service-user perspective

The environment in which the appointment takes place may hold different meanings depending on the needs, wishes and goals of the family. These may also be related to the child's health condition or age, the frequency of appointments, intensity of treatment and constraints on time. When the child is asymptomatic, CCTH can provide a sense of being 'at-ease' and 'at-home'. In times of acute illness however, appropriation of the self and home can lead to feelings of 'unhomelikeness' which may lead to a desire for more 'medical' hospital-based care. Perhaps reflecting their transitional status in life, adolescents also felt out of place regardless of setting. With this information it is possible to better understand families' preferences for particular settings and to generate ideas for service improvement. The spatial impact of CCTH policy and practice on healthcare professionals will now be explored.

8.2.3 Professional Identity

The individual's incorporation of place into the larger concept of self (Proshansky et al., 1983) is demonstrated in the findings of the service-provider study, revealing place as an integral part of professional identity (Hauge, 2007). While all NHS staff and stakeholders accepted the principles of CCTH in theory, hospital-based clinicians were particularly apprehensive about putting the theory into practice on a large scale. This was mainly because of concerns regarding the requirement to change traditional roles and existing working practices, which were also perceived as challenging to professional identity. As Dixon and Durrheim (2004) explain:

“At moments of change or transition, when the bond between person and place is threatened the significance of place identity becomes apparent; loss of place tends to provoke strong social and psychological responses precisely because it entails a loss of self.” (p.458)

Previous research on place and identity has similarly highlighted how people use places to communicate qualities of the self and to form a sense of affiliation (Williams, 2002). In this study, service-provider participants attributed different meanings and values to healthcare settings, positioning the hospital at the top of the healthcare hierarchy and suggesting that the authority and expertise embedded within the physical hospital building (and thus attributed to hospital-based professionals) would be diminished in a community setting.

The resistance that hospital-based healthcare professionals displayed regarding moving hospital care into the community can thus be understood as a disruption to what Relph (1976) terms ‘insideness’. Relph (1976) suggested that the more profoundly inside a place a person feels, the stronger his or her identity with that place will be, and the stronger sense of belonging they will feel (Seamon and Sowers, 2008). Intrinsic to the idea of ‘*insideness*’ is the notion of ‘*rootedness*’; rootedness is felt when a deep sense of attachment and familiarity is formed with a particular place, such that people respect, care for and feel responsibility for the places in which they find themselves rooted (Seamon and Sowers, 2008). By resisting CCTH initiatives, healthcare staff in this study displayed their sense of ‘insideness’ as a kind of attachment to the main hospital and disinclination to be physically separated from it.

Appropriation also involves a sense of possession and control over places (Seamon, 1979), the loss of which can lead to feelings of anxiety, infringement and discomfort (Seamon, 1979). In this case, re-moving General Paediatric services to the community was

interpreted as a step towards transforming BCH into a super-specialist, tertiary care centre, no longer providing General Paediatric secondary care. Local opposition to the implementation of CCTH could then be conceived as a form of place-protective action, such that when a new policy initiative disrupts existing emotional attachments and threatens place-related identity processes (Devine-Wright, 2009), there is resistance to change.

Rather than opting to re-design CCTH outpatient services to promote integrative working with primary care clinicians, hospital-based professionals in this study appeared keen to retain their professional culture and organisational practices regardless of place, presenting their ways of working as the ideal standard of care by taking a 'mini-hospital' 'drag and drop' approach. This finding supports those of a Canadian study on satellite dialysis units (Lehoux et al., 2007) in which hospital services were seen to extend their expert reach into community healthcare sector, rather than collaborating with it in new ways. Nevertheless, specialist outpatient services that are developed and delivered in partnership with primary care were perceived as advantageous for children and young people as they were thought to have the potential to provide enhanced continuity through bringing together elements of health, education and social care.

Moreover, hospital-based service providers expressed only minor concerns over the existing outpatient set-up which may suggest that they felt little pressing need to change and saw few apparent gains from doing so. This could explain why, in this case and more generally as Munton et al (2011) suggest, CCTH has been implemented on a small scale and has largely been driven by the enthusiasm and motivation of a few individual clinicians.

In sum, findings from this study indicate that there are implicit assumptions about where quality and expertise are located which lead to hierarchies about legitimate health places. In representing conceptions of medical expertise and technology, the hospital was placed at the top of the hierarchy of healthcare, presenting their ways of working as the 'ideal standard' of care (Lehoux et al., 2007). These complex barriers regarding place and professional identity have significant implications for full CCTH policy implementation, despite expressed desires to provide more accessible and family-centred care.

8.2.4 Inter-subjectivity

By improving the clinic environment, both service-users and providers expressed a belief that delivering paediatric outpatient care in community settings would improve the relational aspects of care as well as the technical processes. The medical consultation was thus constructed as an extension of place experience, such that the 'front stage' (Millie, 2012) waiting area set the tone for the 'back stage' consultation. In linking healthcare settings (as well as the characteristics of services and staff) to patients' experiences of feeling '*enabled*' within consultations, this finding supports and extends recent research examining the range of healthcare experiences that matter to patients (Entwistle et al., 2012).

Drawing on previous studies of communication within medical encounters (Mishler, 1984, Barry et al., 2001, Greenhalgh et al., 2006) the effect of place on the inter-subjective experiences of service-users and service-providers will now be discussed in more detail.

8.2.4.1 Place as a sense of 'relationality'

As time with the Consultant was less restricted in community clinics and the environment was calmer and more comfortable, families felt '*enabled*' to discuss their child's condition in a more relaxed, present and meaningful way. This meant that the relational aspects of care were also improved by CCTH, offering consultations which were more in tune with families' narratives of their own lifeworld experiences.

Applying Habermas's theory of communicative action to the patient-practitioner interaction, Mishler (1984) distinguishes between the voice of the lifeworld and the voice of medicine. He explains:

"The voice of the lifeworld refers to the patient's contextually-grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a "natural attitude". The timing of events and their significance are dependent on the patient's biographical situation and position in the social world. In contrast, the voice of medicine reflects a technical interest and expresses a "scientific attitude". The meaning of events is provided through abstract rules that serve to decontextualise events, to remove them from particular personal and social contexts." (Mishler, 1984, p.104)

This indicates that clinicians and families may approach consultations in different ways because their knowledge is derived through different means (Shaw, 2012a).

According to Todres et al (2007, 2009) a Lifeworld-led care approach requires health systems and practitioners to value human beings both as subjects and objects, simultaneously attending to what is unique to the individual patient (their life context and meanings) as well as what the patient has in common with others (their medical symptoms

/ diagnosis). Paying attention to the seven dimensions of the lifeworld: selfhood, sociality, embodiment, temporality, spatiality, project and discourse (Ashworth, 2003) is argued to endorse such a humanising framework, which focuses on establishing a sense of 'at homeness' with the patient. Mishler (1984) suggests that the distorted, impersonal voice of medicine is incompatible with the more natural, experiential narrative of the lifeworld, thus resulting in fragmentation of the 'whole' on which understanding of a patient's condition depends (Dahlberg et al., 2008).

However, the binary opposition of the voice of lifeworld and the voice of medicine may be too simplistic (Coyle, 1999). Through their analysis of medical consultations, Barry et al (2001) developed Mishler's concept, identifying four communication patterns within medical encounters: strictly medicine; lifeworld ignored; lifeworld blocked; and mutual lifeworld. They concluded that the best outcomes resulted from consultations where both doctor and patient talked through the voice of medicine (strictly medicine) or where they both talked through the voice of the lifeworld (mutual lifeworld).

Consistent with these findings and other qualitative explorations of healthcare satisfaction (Coyle, 1999, Berglund et al., 2012), families in this study experienced the ignoring or blocking of their lifeworld voice as dehumanising and disempowering. This was shown to produce dysfunctional and unsatisfactory consultations (Barry et al., 2001), particularly if a clinician failed to validate the parent's or patient's concerns about symptoms. In cases where the voice of the lifeworld was used by both doctors and families, consultations were shown to be more relaxed and grounded in everyday events, with a clear emphasis on working together to reach a common understanding. This sense of equality within the

consultation was also found to facilitate more empathic and holistic care. This is a finding that supports and extends those of Shields et al (2006) who suggest that negotiation is key to successful interactions between families and paediatric healthcare practitioners.

Some practitioners in this study were also described by service-user participants as having intrinsic qualities that made them special, including an ability to intuitively understand families' needs and concerns. It may be that these individuals had the capacity to operate in both the voice of medicine and the voice of the lifeworld, demonstrating an ability to oscillate between the two voices according to patient preference, or perception of functional or experience-orientated service-users. Further explanation might come from the freedom or limitations placed on healthcare professionals operating within different organisational systems. Competing demands, time pressures and more rigid systems within the hospital for example, may constrain a lifeworld approach, whereas healthcare professionals operating outside of the hospital system may feel freer to experiment with different ways of working, or feel more relaxed generally, making them more sensitive to the type of consultation that a family requires. Either way, the findings of this thesis show that CCTH facilitated a model of care in which clinicians could be "open to the lifeworlds of their patients" (Dahlberg et al., 2009, p.269).

8.2.4.2 Interactions with support staff

Interactions with other staff members were considered just as important by families to the overall healthcare encounter and were experienced as positive when reception and support staff were welcoming and cheerful. When communicating with support staff,

adolescents were particularly sensitive to the interpersonal dynamics, which, when experienced as cold, led to them feeling uncomfortable and reluctant to speak altogether.

8.2.4.3 Involving young people

In line with healthcare policy (DH, 2004, 2011d) and previous research (e.g. Darbyshire, 2003), parents in this study were appreciative when clinicians attempted to involve their child directly in the consultation, so that the child was able to participate in decisions about their health and care. Young people also confirmed a desire for healthcare professionals to be informed and competent, avoid difficult words, ensure confidentiality, and demonstrate acceptance and empathy. These findings echo those of other studies on patient involvement in healthcare consultations (Robinson, 2010, van Staa et al., 2011).

In contrast to existing literature (e.g. Coyne, 2008, Byczkowski et al., 2010), young people in this study generally had positive experiences with clinicians, often feeling enabled and encouraged to take part in their consultation. In the few instances where young people did feel excluded, feelings of frustration and distress were described. Some young people in this study also told of instances where they felt uncomfortable about participating in their healthcare for fear of being disbelieved, not listened to, having difficulties understanding medical terminology or due to a perceived lack of time. These factors are also reported in the literature (Cavet and Sloper, 2004). It may be then, that although young people often felt consulted within their medical encounters, they did not always feel heard (Curtis et al., 2004). Effective communication with young people within medical consultations clearly warrants further investigation, as Coyne (2008) points out, “children’s participation in

consultations and decision-making remains an under-researched area, complicated by conflicting opinions” (p.1687).

8.2.4.4 Working across boundaries

For NHS staff and stakeholders, CCTH services were seen as an opportunity for developing working relationships across the primary-secondary care interface, allowing healthcare professionals from different disciplines and sectors to work together for the benefit of children and young people (Heath, 2008, Protheroe et al., 2013). Places where clinicians could interact with professionals from other agencies (such as health centres and children’s centres) were therefore thought to be appropriate for providing CCTH, as they presented opportunities for delivering more coordinated and integrated health and social care.

However, staff and NHS stakeholders had differing perspectives on the potential for CCTH services to facilitate education and training. Although potentially advantageous, the personal experience of some participants indicated that knowledge and skills transfer between clinicians rarely happens in practice and that simply placing different healthcare professionals together in one location would not in itself lead to a sharing of knowledge. Evidence from existing paediatric satellite clinics and from former GP fund holding initiatives were given as evidence for this claim, and restrictions of time, interest or inclination proposed as an explanation.

8.2.4.5 Service design

Findings indicated that confusion about the primary purpose of relocating outpatient services for children into community settings had led to challenges in implementing the

CCTH policy. Since the original aim set out by the Platt report (1959) outlining the broad philosophical position that child-focused CCTH is a fundamental good, in and of itself, there appeared to be a number of goals for paediatric CCTH. One goal was to reduce disruption to families' lives and keep children out of hospital. A second was to reduce health inequalities by improving access to specialist paediatric healthcare regardless of demographic, socio-economic or geographical status (DH, 2007). A third goal related to health service reforms and attempts to relieve demand on acute services by reducing the number of hospital contacts and re-designing services (e.g. outreach clinics or telemedicine). There is also an implicit assumption that improving access to outpatient care would lead to a decrease in levels of non-attendance at clinic appointments. Such lack of clarity regarding the purpose of CCTH however contributed to difficulties for participants in making judgments about a suitable model for community-based clinics. This finding, which is echoed by Parker et al (2011b), suggests that clearer objectives may facilitate CCTH policy implementation by providing a set of desired outcomes from which models can be developed, implemented and evaluated. This should include a number of factors, including the mix of patients, professional skills, equipment and training required for each service and each population, as well as ensuring that the physical environments of service delivery are sufficient, appropriate and child-friendly (DH, 2003).

As this research has shown, the process of clarifying CCTH policy objectives and designing models of care that are acceptable to families should also involve the service-user perspective in a collaborative way. As Darbyshire suggests, "we need the humility to listen to [families] before we plan services for them... For only from a basis of such shared understanding can a system of genuinely shared and humane care evolve" (1994, p.185).

8.3 Contributions to knowledge

As the first qualitative study to explore families' and NHS staff and stakeholders' views and experiences of moving paediatric outpatient clinics into community settings, this research makes a number of contributions to knowledge in the area of health services research and practice. In the next section, contributions to knowledge in terms of providing a deeper understanding of CCTH will be discussed, followed by a summary of implications and recommendations for policy, practice and future research.

8.3.1 Understanding Paediatric Care Closer to Home

Through its explicit theoretical focus on place and space, the research presented in this thesis makes a substantial and original contribution to our understanding of Care Closer to Home, by illuminating aspects of healthcare that have not previously been explored; specifically, that the place of healthcare delivery holds relevance and meaning for service-users and providers, in ways that are likely to affect patient experience, policy implementation and service design and utilisation.

The empirical findings contribute to the under-developed evidence-base for paediatric CCTH. They demonstrate that from a patient and family perspective, the rationale underlying the policy is well-founded in its assumptions that families prefer CCTH, for reasons of improved access, convenience and overall experience. The studies presented in this thesis thus support the findings of other research on paediatric CCTH (Spiers et al., 2011, Carter et al., 2012), but also extends them to include a specialist outreach model of care, and adds theoretical depth through the lens of 'place' as a way of 'being-in-the-

world'. This has enabled previously taken-for-granted nuances of place, time and space to be highlighted in the experience of receiving paediatric healthcare. Such an understanding may facilitate patient-led service improvements such as providing 'therapeutic environments' (Gelser, 1991) which value the place of service delivery as a social, psychological and symbolic landscape, capable of contributing to families experiences of being 'enabled' to "feel, be and do what they value feeling, being and doing - during healthcare contacts" (Entwistle et al., 2012, p.8).

The findings suggest that the place of healthcare delivery also holds significant and diverse meanings for service-providers, demonstrating that even small changes can affect how a place or profession is perceived or experienced, how it feels and what it means, serving both to nurture and challenge professional identity (Speller et al., 2002). This finding highlights potential barriers to CCTH policy implementation, as it may be difficult to change the location of care services, without considering the impact on personal, professional and organisational attachments (Andrews, 2006). These are rarely acknowledged in policy initiatives, and may contribute to explaining why CCTH has not been consistently adopted, despite a push from policy objectives (Parker et al., 2011a, Heath et al., 2012).

In addition to their spatial dimension, places were also found to be temporal, with time being a significant factor in families' preferences regarding where to access care and how services were experienced. This study thus further contributes to the literature by demonstrating that patient experience is shaped by perceptions and experiences of time, which in turn can be influenced by the spatial surroundings. Findings also revealed that different families may seek different outcomes when it comes to their child's healthcare,

leading them to experience environments differently depending on how they use the service. Finally this study has begun to address the gap in evidence regarding CCTH as a model of care for children and young people, supporting the recommendation that young people's views and experiences of healthcare settings should be valued as much as those of their parents (Coyne, 2008). This work has implications for improvements in health service design, patient experience, provider satisfaction and potentially, non-attendance at appointments (Freed et al., 1998). This is particularly important because missed appointments have significant implications for service-providers and can pose serious consequences for the health of the child.

Methodologically, the use of a qualitative approach was original and provided several benefits. Firstly, being grounded in real, concrete experiences, the findings provided the kinds of credibility that only human stories can give (Todres et al., 2007). Secondly, by enabling children and families' to share their experiences for the purposes of informing and improving health service design, service-users were encouraged to participate and take ownership of healthcare reforms that affect them (Todres et al., 2007). This also goes some way towards implementing the kinds of "patient-centeredness" and service-user involvement that are pervasive in UK policy (Bate and Robert, 2007). Finally, the particular phenomenological method used in the family study was valuable for moving towards a shared meaning of CCTH as a phenomenon, while retaining the unique variations of individual accounts (Seamon, 2000b). The depth of data in this work thus enabled the phenomenon to be understood from rich, experience-close descriptions of the service-user perspective.

Finally, the two different methods for the empirical studies with families and staff in this thesis were selected on the basis of their suitability for answering the research questions. Descriptive phenomenology provided a strong theoretical underpinning for the service-user perspective, and the thematic Framework method provided a pragmatic tool for managing a large data-set from a diverse sample of stakeholders, as well as enabling within and between case comparisons. The pluralist methodology used in this project thus demonstrates the possibility and potential of using multiple qualitative methods to approach a similar topic or phenomenon from different perspectives, in a meaningful way.

8.4 Implications for policy, practice and research

This study has immediate implications for improvements to service design and delivery at Birmingham Children's Hospital. Initial findings have already been fed back to NHS stakeholders as part of the hospital's 'Commissioning for Quality Improvement Initiative' (see appendix 8) contributing to re-design and refurbishment of the main hospital outpatient department, including more adequate provision for adolescents. As greater provision of community-based outpatient clinics features in the hospital's plans for managing outpatient capacity, these findings will also feed into the development of new, family-centred, closer to home outpatient services. Staff study findings have been disseminated to the General Paediatric hospital team, and plans are in place to circulate findings to a wider range of families and stakeholders in the near future. Furthermore, findings from this study have been presented at National Health Service Research Network conferences and published in academic journals (see appendix 9), demonstrating a contribution to the evidence-base for CCTH.

8.4.1 Recommendations for policy and practice

Findings of this study show that serious consideration should be given to aspects of place, space and time as lived constructs within policy initiatives concerning health service design and delivery. Healthcare providers should also take into account how time, space and place are experienced when evaluating existing service models and developing new ones. For example, this study has shown that improving the physical waiting environment could lead to improvements in overall service experience, including shorter perceived waiting times, increased patient satisfaction and potentially, lower rates of non-attendance. Providing families with real-time information on clinic delays would also enhance perceptions of control and feelings of tolerance. Finally it was clear from this study that families value clinical interactions which are empathic and inclusive of their lifeworld voice, and that community-based services facilitate such consultations.

To be effective, CCTH services are likely to require re-design as well as relocation. To ensure that new services deliver high-quality, integrated care that meets the needs of individual patients and their families, investment in service-planning will be required. This should include an assessment of the community population needs in which the satellite clinic will be located, consideration of infrastructure requirements, economic assessment, appropriate marketing and changes to traditional working practices. Such investment in the implementation of CCTH on a larger and more meaningful scale would increase the presence of paediatric outpatient care in the community, and potentially increase the status of clinics with families and staff in terms of their perceptions of quality and trust.

As service innovations such as CCTH can be interpreted as a threat to professional identity and attachments, which may result in resistance to change, it is recommended that staff, as well as families, are consulted before, during and after service re-design. This is also likely to require 'innovation champions' to support change by challenging traditional professional and service boundaries (Singh, 2006).

Figure 10: Recommendations for policy and practice

- Consider 'place' and 'time' as lived constructs in the development and implementation of policies concerning health service design and delivery.
- Include families' experiences of place and time in healthcare evaluations.
- Provide families with adequate information regarding waiting times.
- Consider the unique needs of adolescents.
- Re-design as well as relocate CCTH services.
- Include NHS healthcare professionals on policy initiatives which require a change in working location / practices.
- Identify CCTH champions to lead service innovation and support change.
- Facilitate consultations which pay attention to the lifeworld of patients and their families.

8.4.2 Recommendations for future research

Although this study has started to fill the evidence-gap in relation to paediatric CCTH, there are questions that remain unanswered which could be explored in future research (see figure 11). First, findings of this study suggested an inter-dependency of place and medical expertise and healthcare experience from service-user and provider perspectives. Further research is therefore required on the role of place and space in other health services and settings to broaden theoretical insights. Second, the idea that there may be different kinds of service-users who seek different outcomes from healthcare may hold implications for

service design and utilisation. This finding also calls for further investigation. Third, it is clear from the findings that there is a need for research into more effective methods of involving children and young people in the planning, designing and delivery of new healthcare services, ensuring that their views and experiences are heard and incorporated into the plans for and implementation of service change. Finally, research should be conducted into scaling-up current community-based clinic provision, with a specific focus on how hospital services translate between physical settings and the effect this has on patient perceptions of quality.

Figure 11: Recommendations for future research

- Explore the role of 'place' in other health services and settings.
- Explore the implications of different types of service-users on service design, satisfaction and utilization.
- Explore the most effective methods for involving children and young people in the planning, designing and delivery of new healthcare services.
- Explore how place perception impacts on decision making (e.g. preference for place / attendance)
- Explore how the brand of the hospital translates between settings.

8.5 Methodological considerations

As discussed within the methods section, trustworthiness and rigour were maintained through a number of different strategies. These included; keeping an audit trail, a reflexive diary, memo-writing, deviant case analysis, discussing the analysis process with peers, and demonstrating a clear logic of enquiry with a convincing rationale for choice of methodology and methods (Horsburg, 2003). In addition, a conscious decision was made

not to engage deeply with previous research until after data analysis, with a view to remaining open to unexpected discoveries, and not to contaminate the analysis with preconceptions (Charmaz, 2006, Van Manen, 1997). To demonstrate interpretive trustworthiness (Spencer and Ritchie, 2012), extracts of raw data were presented, illustrating that although data were transformed during analysis process, descriptions and interpretations were clearly rooted in participants' accounts. Adding to the debate on quality in qualitative research, Yardley (2000) also highlights the importance of utility and application of findings in terms of theoretical and practical impact and in particular for health research, pushing beyond explanation to the creation of "new solutions" (p.224). As demonstrated in the section above, this study makes a number of recommendations for research, policy and practice, clearly demonstrating the use and application of findings for a 'real-world' setting.

Polkinghorne (1989) outlines a number of guidelines for validity in phenomenological studies, emphasising that findings should draw the reader in and enable them to: recognise a phenomenon from their own experience; enter the account emotionally; and move towards a new path of understanding (Seamon, 2000a). In drawing out the complexity and ambiguity in participants' accounts, this study attempted to illuminate the essential lived structure of paediatric CCTH, while being open to individual variations and being "careful not to make definite what is indefinite" (Dahlberg et al., 2008, p.94). As only elements of the experienced phenomenon that were present in all accounts were included in the essential structures, findings can also be seen to have a kind of internal validity. Moreover, by embracing a phenomenological attitude throughout the research process,

preconceptions of the 'natural attitude' were consciously and reflexively set aside so as to remain open and present to the data.

Finally, Morse (1999) argues that for qualitative research to be of use, findings have to be generalisable. In contrast to the generalisability criteria of quantitative research however, generalisability in qualitative research can be conceived of as the extent to which the broader theoretical concepts developed within one study may be exported to provide explanation for the "experiences of other individuals who are in comparable situations" (Horsburg, 2003, p.311). In this way, it is the topic or phenomenon under study rather than the demographics to which findings can be generalised (Popay et al., 1998, Morse, 1999). The findings of this study may therefore be applied to similar settings or contexts (Lincoln and Guba, 1985) such as CCTH provided by other healthcare organisations. Findings may also be transferable from the study population, to the parent population from which it was selected (Lewis and Ritchie, 2003), in this case, to parents and young people accessing specialist health services other than General Paediatric outpatient care.

8.6 Limitations

Since the development of the study, there have been many changes in government, the economic climate and health and social care services. Nevertheless, recent reforms aim to achieve patient and family-centred care by reconceptualising the long-established boundaries between NHS and social care and redistributing the balance of healthcare from hospitals to community settings (DH, 2012). Thus, despite recent changes to the commissioning landscape, CCTH remains a key objective for the future of the NHS (Abdelhamid et al., 2012), demonstrating that findings of this project remain relevant.

Even though the family study had a diverse sample of parents, children and young people from a range of social and ethnic backgrounds, a second limitation might come from the fact that all parents in the sample were female. Explanation for this may relate to mothers as the principal care giver within many families (Darbyshire, 2003), suggesting that mothers had greater experience of accompanying their child to outpatient appointments and were more likely to be approached to participate. As data collection was mainly carried out during school holidays, many of the mothers were also at home looking after their children, which may have meant they had more time to participate. Nevertheless, fathers are likely to have different understandings and experiences that would be important to purposively sample in subsequent studies. Moreover, although socio-demographic information was collected from participants to ensure maximum variation within the sample, the impact of socio-cultural variables on families' experiences was not a focus for the study and as such, conclusions regarding their influence cannot be drawn from the findings.

The qualitative approaches taken in this project meant that the researcher was unavoidably present throughout data-collection and analysis and intimately involved in generating the study findings. As explained in chapter 5 (section on reflexivity), critical self-evaluation and diligent self-monitoring were an important means of responding to this complexity (Doyle, 2013). Such reflexivity enabled personal values, beliefs and experiences to be recognised and set aside (Ahern, 1999) with the aim of attending to participants' accounts with an open mind (Starks and Brown-Trinidad, 2007). Nevertheless, the position of the researcher can impact on the research by affecting access to the field, the information shared by participants, and the analysis and interpretation of data (Berger, 2013). It is possible therefore that as the instrument for recruitment and analysis, I, a white, middle-class,

female researcher, positioned primarily as a hospital 'insider', may have inadvertently influenced who decided to take part in the study, and what participants chose to disclose during interviews. Moreover, although strategies for maintaining reflexivity were adopted and deliberate efforts made to separate participant and personal experiences of paediatric health services (see reflexivity in chapter 5 and the above section on methodological considerations), it is possible that a different researcher may have transformed, coded, interpreted or elicited meanings from the data differently, resulting in subtle differences to study findings. To counter-act this limitation, feedback was sought from peers who were familiar with the topic under investigation; however a second researcher may also have been beneficial during stages of data analysis to enhance credibility and dependability of the findings.

8.6.1 Reflections on the research process

Taking a descriptive phenomenological approach to health services research was a novel and consequently challenging prospect. Although key texts such as those by Giorgi (2009), Langdrige (2007) and Dahlberg et al (2008) were invaluable for guiding each stage of the analytic process, their focus on the experience of psychological phenomena meant that the method had to be adapted for a health services research project. In addition, with the exception of a recently published paper by Englander (2012) little guidance was available in the literature on the process of phenomenological interviewing. Subsequently lessons learnt throughout the project in terms of carrying out research interviews included: the importance of allowing participants time to recount their experiences, active listening and paying close attention to participant narratives in order to be able to effectively prompt for

the kinds of detail which are essential for producing rich and nuanced data. Moreover, although the large sample sizes and diversity of participants are arguably advantages of this study, such a large volume of data was difficult to manage, particularly in terms of retaining a sense of the 'whole'. As data were only collected at one time point, potential changes to the experience over time could not be captured. An alternative approach would therefore have been to adopt a longitudinal design, with fewer participants.

8.7 Concluding remarks

Through an exploration of the lived experiences of those attending and working in paediatric health services, the findings of this research provide a deeper understanding of paediatric care closer to home and in the home, and greater theoretical insight into the development of new health services for children and young people. Bringing together issues of health service design with concepts from phenomenological philosophy and existential geography (Malone, 2003), this study reinforces the relevance of 'space and place' in healthcare experience, establishing 'place' as a meaningful concept that should not be ignored by service providers. Policy initiatives which overlook the concepts of place, time and inter-subjectivity, or which challenge them too strongly are also likely to meet with limited success.

Collectively, the findings presented in this thesis make an important contribution to paediatric health services research, demonstrating that future CCTH services will need to be designed both pragmatically and ideologically, taking into account the views and experiences of service-users as well as those of service-providers.

APPENDIX 1

1 Meta-synthesis documents

1.1 **Electronic Search Strategy (Ovid Medline 11/03/2013)**

1. Outreach.mp.
2. paediatric nursing.mp.
3. Secondary Care/
4. Pediatric Nursing/
5. Home Nursing/
6. Home Care Services/
7. Ambulatory Care/
8. Child Health Services/
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. care closer to home.mp.
11. alternative setting\$.mp.
12. hospital at home.mp.
13. home-based.mp.
14. Ambulatory Care Facilities/
15. Community Health Centers/
16. Hospitals, Community/
17. 10 or 11 or 12 or 13 or 14 or 15 or 16
18. paediatric\$.mp.
19. young people.mp.
20. exp Child/
21. Pediatrics/
22. Adolescent/
23. Infant/
24. Parents/
25. 18 or 19 or 20 or 21 or 22 or 23 or 24
26. 9 and 17 and 25
27. exp Qualitative Research/
28. Interview/
29. experienc\$.mp.
30. 27 or 28 or 29
31. 26 and 30
32. limit 31 to (english language and yr="2003 - 2013")

1.2 Data Extraction Form

Study ID	Study 1	
Authors & Year	SPIERS, G., PARKER, G., GRIDLEY, K. & ATKIN, K. (2011)	
Journal/Source	Health & Social Care in the Community	
Volume/page numbers	Vol 19 p. 653-60	
Title	The psychosocial experience of parents receiving care closer to home for their ill child	
Reviewer & date of entry	Gemma Heath 13/03/2013	
Study details	Location and setting	Four PCTs in the English NHS; Five CCTH service models (2 CCNS, 2 specialist outreach nursing, 1 children's assessment unit) providing specialist, long-term and acute care in home and outpatient settings.
	Research Question	To explore the implications of CCTH through understanding the experiences of those who use such care.
	Theoretical Framework	-
Participants	Population	27 parents and one extended family member providing care for children who use CCTH services
	Age	Children of parent participants ranged from 0-16 years old
	Gender	Mothers and fathers
	Ethnicity	-
	Recruitment / Sampling method	Maximum variation sampling; potential participants approached by CCTH service staff. Staff encouraged approaching parents from a wide range of backgrounds regarding participation.
Data Collection	Method (interviews, focus groups)	22 in-depth, semi-structured interviews conducted face-to-face with parents.
	Who collected the data?	Researchers
	Was study (including data) translated / interpreted?	Some interviews were translated. No other details given.

	How were data prepared for analysis (e.g. transcribed)	Transcription
Analysis	Method (e.g. thematic analysis, IPA)	Framework approach (Ritchie and Lewis, 2003a)
Validity	What validation methods were used? (e.g. member check, audit trail)	Double coding of transcripts / two independent pilots of framework for refinement.
Reflexivity	Did the study report engaging with reflexivity?	"A reflexive approach was taken and collected data were reviewed continually to inform subsequent data collection."
Theme 1	Title: Parents' responsibilities during care closer to home	
	<p><i>Responsibility status: having responsibility for nursing tasks</i></p> <p>For those who had responsibilities for nursing aspects of their child's care, the tasks in question included flushing a peripherally inserted central catheter (PICC) line, gastrostomy feeds and administering complex regimens of medicine to their child at home. The degree to which these parents felt supported with this responsibility, however, differed somewhat. For example, one parent was trained to flush her child's PICC line and felt the community nurses had supported her in this:</p> <p>"I never felt under any pressure whatsoever to, to go for this sort of training ... I mean it just, they, you know, they were great in that respect they really were. They instilled some confidence into me" (Int 16, Mother)</p> <p>Another family described feeling 'daunted' initially at having to do gastrostomy feeds at home, but had support from the community nurse, which had helped: "It is ... a bit nerve wracking ... but they were ringing and they were actually coming in out of their own weekend off time as well just to check we were coping" (Int 1, Father)</p> <p>In contrast, two separate parents of children with cancer responded less positively to the responsibility they had for their child's care at home. Both described feeling they had a lot responsibility for administering a complex regimen of medicines to their child at home, some of which included oral chemotherapy:</p> <p>"I do think it does put a lot of responsibility on the parents, you know, to have to give a lot of the medication, you know, at home" (Int 9, Mother)</p> <p>Whilst both of these parents valued the input from the community nurses, one stated a need for more support and monitoring from them, and described using a cognitive coping strategy to help deal with the responsibility of the care: "...when you're giving something every day, you know, it's like you have to mentally [ask yourself], I did give it to him today, didn't I, I did, and so we feel that is quite a lot of responsibility" (Int 10, Mother)</p> <p>Both of these parents observed that giving the drugs at home was an alternative</p>	

	<p>to having it carried out in hospital. Both, however, emphasised their preference to stay at home, despite the increased level of responsibility that accompanied this choice.</p> <p><i>Responsibility status: having no responsibility for nursing tasks</i></p> <p>Of those who had no or little responsibility for nursing tasks in their child’s care, some parents had declined an increased role, whilst others felt they would like to do more. For the latter, this may have been about being able to have more care at home rather than in hospital, as one father, for example, said: “...if there was a way that we could do more at home, even like you say with the temperatures, checking through the night and stuff like that, then we’d be happy to take on that responsibility” (Int 7, Father)</p> <p>However, some felt they did not want to play a role in their child’s nursing care. Two separate parents did not want to take on the responsibility of passing their children’s naso-gastric tubes, and these decisions appeared to be supported by the CCTH team. For one mother, the decision appeared related to her perceptions of how it would affect her child: “...it is so distressing to him and I’d, I’d end up giving up and not being able to do it. Cos it’d upset me to distress him.” (Int 20, Mother)</p> <p>This mother later said that she might be open to taking on this task when her child was older and better able to understand what was happening. This suggests there is a perception that being able to communicate adequately with her child may mediate how she is able to cope with the discomfort of doing this procedure. This resonates with work by Jacobsen et al. (1990), which showed that during painful medical procedures for children in hospital, common parental behaviours included attempts to explain it to their child.</p> <p>Parents experienced differing levels of responsibility, and for those with higher levels, being supported by a community nurse was particularly important. The findings show, however, that other parents in this study, regardless of whether they had increased responsibilities, valued the support they received from the CCTH team. The following section discusses this in more depth.</p>
<p>Theme 2</p>	<p>Title: Being supported</p> <p>Being supported socially and emotionally when care was delivered closer to home was highly valued by parents in this study, and community nurses appeared to be the primary sources of such support. For example, one mother reported: “I think ... it’s really good because you get to know them, so ... and any concerns you might have you can talk to them about it, and it just seems that it’s another form of support really” (Int 17, Mother)</p> <p>Not all parents in the study, however, felt that they were supported adequately. As described above, one parent described a need for more reassurance in administering complex regimens of medicine at home. For another family, whilst emotional support had not been sought from the community nurses, they nonetheless noted how their needs may have been overlooked: “You know, and perhaps you could have expressed what you felt and whereas we’re so busy caring for, for [child] that, you know, our needs perhaps didn’t</p>

	<p>come into it too much, did they?" (Int 3, Mother)</p> <p>Other parents also noted the need for additional sources of support, other than through the CCTH team:</p> <p>I think it would be nice if there was some sort of support group, you know, parent support group. (Int 9, Mother)</p> <p>Support in the form of 'other parents', however, may be less likely at home than in hospital. For example, two parents referred to accessing support from other parents whilst on a specialist hospital ward. The lack of 'other parents' when receiving CCTH, through whom support may be accessed, may help to explain a further finding in this study – that is, that parents valued supportive relationships with staff. Such relationships featured strongly in parents' accounts of receiving CCTH, and appeared to be a medium through which they felt supported.</p>
<p>Theme 3</p>	<p>Title: Relationships with staff</p> <p>That parents talked often about the relationships they had developed with staff, which was in most cases a community nurse, indicates they perceived this to be an important and integral aspect of the child's care. Relationships were often, though not always, described positively. Where relationships were described positively, three types were evident: a therapeutic relationship, a social relationship and an advocacy relationship. First, parents described relationships with practitioners that seemed to serve a therapeutic function. For example, many talked about 'chatting' with the community nurse, being supported emotionally, being able to discuss concerns, and being reassured and understood. One father, for example, said:</p> <p>"Well, you know, the nurses as well, they, they talk to us when we're down, don't they" (Int 1, Father)</p> <p>Second, the community nurse was sometimes referred to as a friend, or as part of the family and sometimes parents described behaviours typical of social relationships (e.g. communicating outside home visits about non-care matters). One mother said:</p> <p>"She was just like my best friend, you know, she was fantastic, and she still keeps in contact now. So we, we've built up a really good friendship." (Int 2, Mother)</p> <p>Third, some parents described how the community nurse provided additional support for their circumstances, such as arranging equipment, getting appropriate transport, addressing housing issues, liaising with other staff on the parent's behalf, getting additional funding and helping with financial issues. Such support indicates that community nurses also play an advocacy role. Each of these relationships demonstrates not only the extended needs of the family, but also the extended role the community nurse can play when care is delivered closer to home. In relatively few instances, where parents described less positive relationships with nurses, this seemed to be about a lack of support for the parent, and how nursing staff responded to parents' concerns. For example, one mother described a preference for one nurse whom she felt responded well to her concerns about her child's illness, whereas other nurses in the team had been less approachable:</p> <p>"... sometimes I feel with the others that I'm wasting their time a bit." (Int 5, Mother)</p> <p>Relationships may also have been mediated by whether parents had confidence</p>

	<p>in the CCTH team. Many parents described having confidence in the staff's expertise and competence, and often these comments were from those who described having a positive relationship with, or high regard for, the staff. Two parents who described lacking confidence in the service, also described less positive relationships with the nursing staff.</p>	
Author conclusions	<p>Conclusions & implications</p>	<p>Parents who received CCTH generally preferred this to hospital-based care where possible. An important part of this care was being supported socially and emotionally by CCTH staff, with whom parents developed valued relationships. Support appeared to be particularly important when parents assumed increased responsibility for part of their child's care. As parents may often take on such responsibilities as part of having CCTH, it is important that this is consistently met with adequate support.</p> <p>This in turn has implications for child health policy in England, which currently supports the increased delivery of CCTH where possible. Seemingly, one of the potential benefits of CCTH is the flexibility it offers to practitioners to respond to changing and fluctuating needs of families. Should the provision of such care continue to expand, support for parents should be considered a fundamental aspect of service development.</p> <p>The issue of parents assuming responsibility also presents further questions for research. Much of what is currently known about this stems from research on broader issues of CCTH. Specifically, research designed to address the following issues is needed. First, what are parents' reasons for taking on responsibilities as part of their child's CCTH? Second, how do parents want to be supported with these tasks? Finally, where tasks may be particularly distressing for the child, how does this affect the relationship between the parent and child, and the child's psychological development? These are important issues to address, as all have implications for the wellbeing of parents whose children are cared for closer to, or in the family home.</p>
Comments	<p>Anything additional worth noting</p>	<p>Full NIHR SDO report (Parker et al, 2011) has more details regarding methods and findings.</p>

APPENDIX 2
2 Study materials

2.1 Recruitment Leaflet: Families



- Want a say in where and how children's outpatient services are provided?
 - Want to help design children's services that meet your needs?
 - Want children's outpatient services closer to your home?
- Even if you have missed an appointment, we want to hear what you have to say.**

If you have any views about Birmingham Children's Hospital outpatient services or if you want to take part in the **PLACES** project, please contact the team.

Email:

Telephone:

If you would like to take part in this project, please get in contact with the **PLACES** project research team.

Research Team

Project Leader: Carole Cummins

Researchers:

Gemma Heath; Elaine Cameron

Project Administrator: Gina Carrelli

Contact Information

For more information or for this information in alternative languages or formats, please contact:

Gina Carrelli

Institute of Child Health
Whittall Street
Birmingham
B4 6NH

Telephone:

Email:



Version: 2 28/04/2011



Collaborations for
Leadership in Applied Health
Research and Care
(CLAHRC)

PLACES Project

**Paediatric Location And
Care Evaluations**

www.clahrc-bbc.nihr.ac.uk





PLACES Project

Paediatric Location And Care Evaluations

As part of the CLAHRC programme of research for Birmingham and Black Country, the PLACES project is evaluating where and how general paediatric outpatient services are provided by Birmingham Children's Hospital. In particular we are interested in the location and design of general paediatric outpatient services.

Researchers on the PLACES project would like to find out:

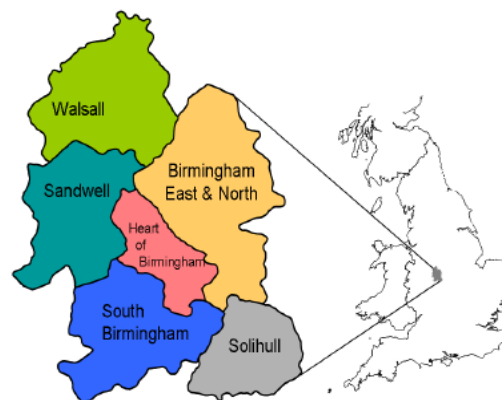
- What families think about BCH outpatient services.
- Where families would like to go for their outpatient services.
- How families feel about going to different places for outpatient services.

Parents and patients views are important for helping us to develop outpatient services which meet your needs and wishes.

What is CLAHRC?

Collaborations for Leadership in Applied Health Research and Care (CLAHRC) are partnerships between NHS Trusts and Universities.

CLAHRCs were established to undertake applied health research focused on the needs of patients and to support the translation of research evidence into NHS practice.



How can I get involved?

Parents

Parents can take part in this project by attending an individual interview Birmingham Children's Hospital outpatient services. These will be held at a time convenient for you and in places such as; Birmingham Children's Hospital, the University of Birmingham or even at your home. Interpreters can usually be provided if interviews cannot be conducted in English.

Children and young people

Children and young people can also take part in this study by attending an individual interview. We will be running interviews for children and young people at the same time as parent interviews, so you can bring your child along.

Children and young people will receive a **£10 Love2shop** voucher as a thank you for their help.

Refreshments will be provided for all and travel expenses reimbursed.

2.2 Recruitment Poster: Families

Version : 1 04-08-10



UNIVERSITY OF
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Birmingham Children's Hospital **NHS**
NHS Foundation Trust



Paediatric Location And Care Evaluations

- ✓ Want a say in where and how children's outpatient services are delivered?
- ✓ Want to help design children's outpatients services that meet your needs?

Take part in the **PLACES** project and have your say

Ask reception for a leaflet or get in contact with the team:

For this information in alternative languages, please contact Gina.

Tel:

Email:



2.3 Invitation letter: Families



UNIVERSITY OF
BIRMINGHAM

Birmingham Children's Hospital **NHS**
NHS Foundation Trust

PLACES Project
Institute of Child Health
Birmingham
B4 6NH

Tel: [REDACTED]

Email: [REDACTED]

Dear

We are researchers at Birmingham Children's Hospital (BCH) and the University of Birmingham. We are carrying out a project called PLACES: Paediatric Location And Care Evaluations. This project is evaluating outpatient services provided by BCH.

We intend to include the views of parents, children and young people in this project and would like to invite you to take part. You can do this by participating in a one-to-one interview about BCH outpatient services. This will take about 1 hour to complete and will include asking about your experience of children's outpatient services and views on where children's outpatient services should be delivered. Interview data will only be used for the purpose of this project and participants will not be personally identifiable in any reports.

Refreshments will be provided for all and travel expenses reimbursed. As a thank you for their help, children and young people will also receive a £10 Love2shop voucher.

We would very much appreciate your help with this work and have included an information sheet for your interest. If you would like to participate please complete the enclosed contact information form and return it in the pre-paid envelope supplied.

Alternatively you can contact us by telephone: [REDACTED] or email:

[REDACTED]

We look forward to hearing from you.

Yours sincerely,

Gemma Heath

2.4 Invitation letter: Staff



PLACES Project
Institute of Child Health
Whittall Street
Birmingham
B4 6NH
Tel: [REDACTED]

Dear

We are researchers based in the Institute of Child Health (Birmingham Children's Hospital) and at the University of Birmingham. As part of the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) project for Birmingham and Black Country, we are conducting an evaluation of General Paediatric services led by Birmingham Children's Hospital NHS Foundation Trust (BCH).

We would like to ask you if you would be willing to take part in this evaluation. This would involve you participating in a short individual interview with one of the researchers or in a group discussion with a short presentation about the project.

Interviews should take around 40 minutes to complete and will include questions about your views on where and how BCH-led services should be delivered in the future.

Interview data will only be used for the purpose of this evaluation and interviewees referred to only by their job titles. Any personally identifiable information will be removed.

We would very much appreciate your help with this work and have attached an information sheet for your interest. We look forward to hearing from you.

Yours sincerely,

Gemma Heath

2.5 Information Sheet: Parents



What do I do now?

If you would like to participate in this project, please get in contact with the research team. Thank you .

Please note; Refreshments will be provided and travel expenses reimbursed. Interpreters can also be provided if English is not your first language.

Research Team

Project Leader: Carole Cummins
Project Manager: Alexandra Enocson
Research Fellow: Oyinlola Oyeboade
Health Psychologists in training: Gemma Heath; Elaine Cameron
Project Administrator: Gina Carrelli

Contact Information

For more information or to get this information in alternative languages or formats please contact:

Gina Carrelli

Institute of Child Health
Whittal Street
Birmingham
B4 6NH



Telephone:

Email:



Collaborations for Leadership in Applied Health Research and Care (CLAHRC)

PLACES Project

Paediatric Location And Care Evaluations

Information leaflet for parents



You are invited to participate in the CLAHRC **PLACES** project, carried out by researchers from Birmingham Children's Hospital and University of Birmingham.

Before deciding whether you would like to take part, please read the following information about the project and what participation will involve.

Thank you for taking the time to read this information sheet.

What is CLAHRC?

NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) are partnerships between NHS Trusts and Universities. CLAHRCs were established to undertake applied health research focused on the needs of patients and to support the translation of research evidence into NHS practice.

What is the PLACES project?

As part of the CLAHRC project for Birmingham and Black Country, we are evaluating where and how Birmingham Children's Hospital provides general paediatric outpatient services. In particular we are interested in the location and design of general paediatric outpatient services.

Your views as a parent are important for helping us to develop outpatient services which meet your needs and wishes.

If I take part, what will it involve?

What: Interview or group discussion about outpatient services.

How long: 1 1/2 hours.

Where: BCH or University of Birmingham or your home.

How: We will record what you have to say on a digital recorder.

Can I bring my children? Yes, we will be running groups for children and young people at the same time as parent groups.

If your child would like to take part, please bring them along.

What will happen to the recordings?

Voice recordings will be put onto a laptop computer and then stored on a secure server. Recordings will then be deleted from the recorder and from the laptop. They will be transcribed and analysed by the researchers and then transcripts will be stored in a locked cabinet, in a locked room. Data will only be used for the purpose of this project.

Do I have to take part?

No, participation is voluntary. You may withdraw from the project without giving a reason at any time. If you decide to withdraw, all data that has been collected from you will be deleted.

Are there any benefits or disadvantages to taking part?

There are no specific benefits to taking part in this project. However, the results of the project may influence the way in which BCH paediatric services are delivered in the future. You will not be disadvantaged by participating in this project.

Will my participation in the study be confidential?

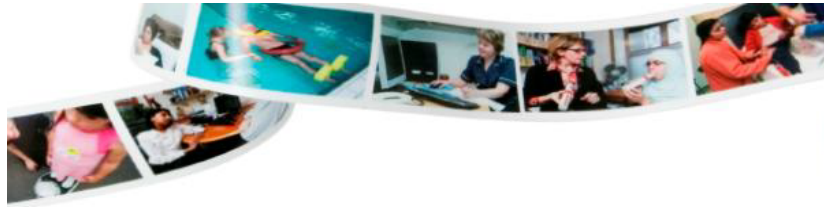
Yes. When we transcribe the interviews, all participants will be given a code name so that they cannot be identified from the report. Any other personal information will also be removed from the transcripts.

What happens after the study?

We will feedback findings to all participants at the end of the project. You will be able to access findings on a website, on posters at BCH and by attending project events.


**National Institute for
Health Research**

2.6 Information Sheet: Parents of young people participants



What do I do now?

If your child would like to participate in this project, please complete and return the contact information form or contact the research team by letter, telephone or email. Thank you.

Please note; Refreshments will be provided and travel expenses reimbursed. Your child will receive a **£10 Love2shop** voucher for helping us with our research.

Research Team

Project Leader: Carole Cummins
Researchers: Gemma Heath; Elaine Cameron
Project Administrator: Gina Carrelli

Contact Information

For more information or for this information in alternative languages or formats please contact:

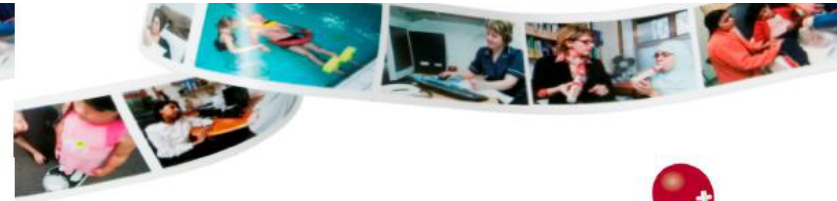
Gina Carrelli

Institute of Child Health
Birmingham Children's Hospital
Whittall Street
Birmingham
B4 6NH



Telephone:

Email:



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PLACES Project

Paediatric Location And Care Evaluations

Information leaflet for parents:
Young people participants



Version: 2 28/04/2011

Your child is invited to participate in the **PLACES** project, carried out by researchers from Birmingham Children's Hospital (BCH) and University of Birmingham.

For your information, this leaflet will outline what the project is about and what participation will involve. **Thank you** for taking the time to read this information sheet.

What is the PLACES project?

We are evaluating where and how Birmingham Children's Hospital provides general paediatric outpatient services. In particular we are interested in the location and design of general paediatric outpatient services.

Your child's experience and views are important for helping us to develop outpatient services which meet their needs and wishes.

If my child takes part, what will it involve?

What: Individual interview with a researcher about paediatric outpatient services

How long: Up to 1 hour

Where: BCH, Your home, University of Birmingham or a Community / Sure Start facility.

How: We will record what is said on a digital recorder.

Can I come? Yes, we will run interviews about outpatient services for parents at the same time as child and young person interviews.

Are there any benefits or disadvantages to taking part?

We hope that your child will enjoy taking part in this study. Project findings may also influence the way in which BCH paediatric services are delivered in the future. Your child will receive a £10 'Love2shop' voucher as a 'thank you' for their help.

What will happen to the recordings?

Voice recordings will be put onto a laptop computer and then stored on a secure server. Recordings will then be deleted from the recorder and from the laptop. They will be transcribed and analysed by the researchers. Transcripts will be stored in a locked cabinet, in a locked room. Recordings stored on the secure computer will be destroyed at the end of the study. Data will only be used for the purpose of this project.

Does my child have to take part?

No, participation is voluntary. Your child may withdraw from the project without giving a reason at any time. If your child decides to withdraw, all data that has been collected from them will be deleted.

Will participation in the study be confidential?

Yes. When we transcribe the interviews, your child will be given a code name so that they cannot be identified. Any quotations of speech from the interviews used in research reports will use these code names. All other personal information will also be removed from transcripts.

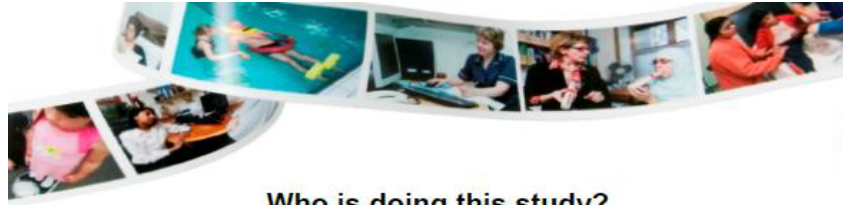
What happens after the study?

We will feedback findings to all participants at the end of the project. You and your child will be able to access findings on a website, on posters at BCH and by attending project events.



Birmingham Children's Hospital 
NHS Foundation Trust

2.7 Information Sheet: Young People



Who is doing this study?

PLACES Project Research Team



Researcher
Elaine Cameron

Researcher
Gemma Heath

Administrator
Gina Carrelli

How can I get more information?

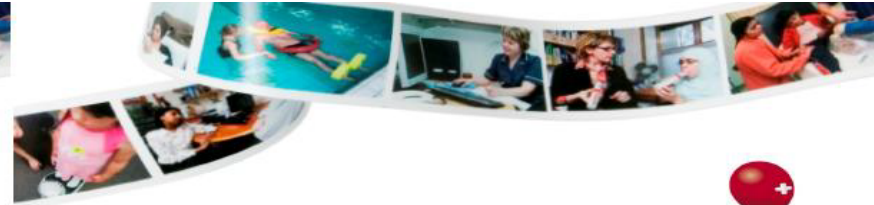
If you want to chat about the study or ask any questions, you can get in contact with Gina from the research team:

Institute of Child Health
Whittall Street
Birmingham
B4 6NH



Telephone:

Email:



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BIRMINGHAM



Paediatric Location And Care Evaluations

Information leaflet for young people



Version: 2 28/04/2011

What is this project about?

We want to find out where children and young people would like to go for their outpatient appointments.



We are interested in your views and experience of:

BCH outpatient's department
Different places for seeing the doctor
Having a BCH service near your home

What will happen?

If you agree to take part, you will be invited to an interview with a member of the research team about your experiences of visiting the Children's hospital.

The session will last about 1 hour and will be tape recorded.



Where will this study take place?

Interviews can be held in places like:

Your home
Birmingham Children's Hospital
Local community centre, SureStart centre or School
University of Birmingham

What will happen to the tape recordings?

The recorded discussion will be put onto a laptop and then stored on a secure computer. It will then be deleted from the recorder and from the laptop.

We will then write down everything that was said in the interview and keep it locked away. Only the researchers will be able to see this information. Recordings stored on the secure computer will be destroyed at the end of the study.

Next we will write a report about where young people would like to go for their outpatient services. This will include your experiences and views from the recorded interview.



Will anyone know it was me?

No. When we write down everything that is said in the interview, we will give everyone a code name and remove any personal information, so that other people do not know who you are from the report.

Do I have to take part?

No. It is entirely up to you if you want to take part. If you change your mind about taking part at any time, just tell the research team.

What are the benefits and risks of taking part?

- As a thank you for helping us, we will give you a £10 Love2shop voucher.
- Sharing your experiences may help us to improve healthcare services for young people.
- We do not think there are any risks to you.



2.8 Information Sheet: Staff

INFORMATION FOR VOLUNTEERS

We would like to invite you to participate in an evaluation carried out by researchers from the Institute of Child Health (Birmingham Children's Hospital) and University of Birmingham. Before deciding whether you would like to take part, please read the following information on why the evaluation is being carried out and what it will involve.

Thank you for taking the time to read this information sheet.

Project Title

Evaluation of Paediatric Satellite Services

Project Supervisor

Dr Carole Cummins
Senior Lecturer
Institute of Child Health
Whittall Street
Birmingham
B4 6NH
Email: [REDACTED]
Tel: [REDACTED]

Researcher

Gemma Heath
Health Psychologist in Training
Email: [REDACTED]
Tel: [REDACTED]

What is this project about?

NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are collaborative partnerships between a university and the surrounding NHS organisations, focused on improving patient outcomes through the conduct and application of applied health research.

As part of the CLAHRC project for Birmingham and Black Country, we aim to evaluate the need for and impact of General Paediatric satellite services led by Birmingham Children's Hospital NHS Foundation Trust and provided in other settings.

The results of this evaluation may help to determine whether satellite services are acceptable to and chosen by staff and other stakeholders.

If I take part, what will it involve?

If you agree to take part, you will be invited to participate in an individual interview with one of the researchers. This will be held in a convenient location for you. The interview is likely to last around 45 minutes to an hour, depending on how much you have to say. The interview will be audio-recorded on a digital voice recorder.

The researcher will ask you some questions about your views on the concept of 'Care Closer to Home', how BCH-led services are currently delivered and how you think they should be delivered in the future. The National Research Ethics Service (NRES) has confirmed that this project is a service evaluation not requiring research ethics committee approval.

What will happen to the audio-recordings?

Following each interview, audio-recordings will be transferred onto a laptop with password protection and deleted from the digital voice recorder. Laptops will be kept in a locked filing cabinet, in a locked room at BCH. Recordings will then be transcribed and analysed in light of the evaluation. Interview data will only be used for the purpose of this evaluation and interviewees referred to only by their job titles. Any personally identifiable information will be removed. Transcripts will be stored on a secure drive or in a locked filing cabinet in a locked room. At the end of the project, all data will be destroyed.

Do I have to take part?

No, it is a voluntary evaluation. If you agree to take part then you may withdraw your participation, without giving a reason, up to two weeks after the interview. If you decide to withdraw from the project, all data that has been collected from you will be deleted.

Are there any benefits or disadvantages to taking part?

There are no specific benefits to taking part in this evaluation. However, the results of the project may impact on the way in which BCH-led paediatric services are delivered in the future.

You will not be disadvantaged by participating in this evaluation. Our aim is to determine whether satellite services are acceptable to service-providers; we will not be investigating or reporting the professional competency of any individual.

Will my participation in the study be confidential?

It is important that the views of interviewees can be understood in the context of their positions within the trust or the wider community. Participation cannot therefore be

completely anonymous as interviewees will be referred to by their job titles. Any other personally identifiable information will be removed from the transcripts.

Interview recordings, transcripts, consent forms and any further participant details will be stored by the researchers in a locked filing cabinet, in a locked room. All participant materials will be destroyed at the end of the project.

What happens after the study?

A report of the results of the evaluation will be available after all of the data has been analysed by contacting the project supervisor. We aim to feedback initial findings to staff by autumn 2010.

Who is organising and funding this project?

This project is organised by Collaboration for Leadership in Applied Health Research and Care (CLAHRC) project for Birmingham and Black Country. The evaluation is being carried out by researchers from BCH and the University of Birmingham. Funding is provided jointly by National Institute Health Research and Birmingham Children's Hospital NHS Foundation Trust.

What do I do now?

We will contact you shortly to find out if you are interested in participating in this evaluation. Alternatively, you are welcome to contact the research team via telephone or email.

If you do take part, we will ask you to read a consent form and if you are happy, sign and return it to the researcher.

Thank you for taking the time to read this information sheet and for considering taking part in this project. If you require any more information, or have any further questions, please contact the researcher:

Gemma Heath

Email: [REDACTED]

Tel: [REDACTED]

2.9 Consent Form: Parents



UNIVERSITY OF
BIRMINGHAM



CONSENT FORM: Parents

Title of Project: **PLACES (Paediatric Location And Care Evaluations)**

Researcher: Gemma Heath

Please tick box

1. I confirm that I have read and understood the PLACES project information sheet and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
3. I give my permission for the interview to be audio-recorded.
4. I give my permission for anonymous quotations of my speech to be used in any research reports.
5. I understand that I will not be identifiable in any project reports.
6. I understand that interview data from this project will be securely stored by the researchers.
7. I agree to take part in the PLACES project.

Name

Date

Signature

Researcher name

Date

Signature

2.10 Consent form: Parents of Young people



UNIVERSITY OF
BIRMINGHAM



CONSENT FORM: Parents of Young People

Title of Project: **PLACES (Paediatric Location And Care Evaluations)**

Researcher: Gemma Heath

Please tick box

1. I confirm that I have read and understood the PLACES project information sheet and have had the opportunity to ask questions.
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving a reason.
3. I give my permission for the interview to be audio-recorded.
4. I give my permission for anonymous quotations of my child's speech to be used in any research reports.
5. I understand that my child will not be identifiable in any project reports.
6. I understand that interview data from this project will be securely stored by the researchers.
7. I agree for my child to take part in the PLACES project.

Your Child's Name _____

Name Date Signature

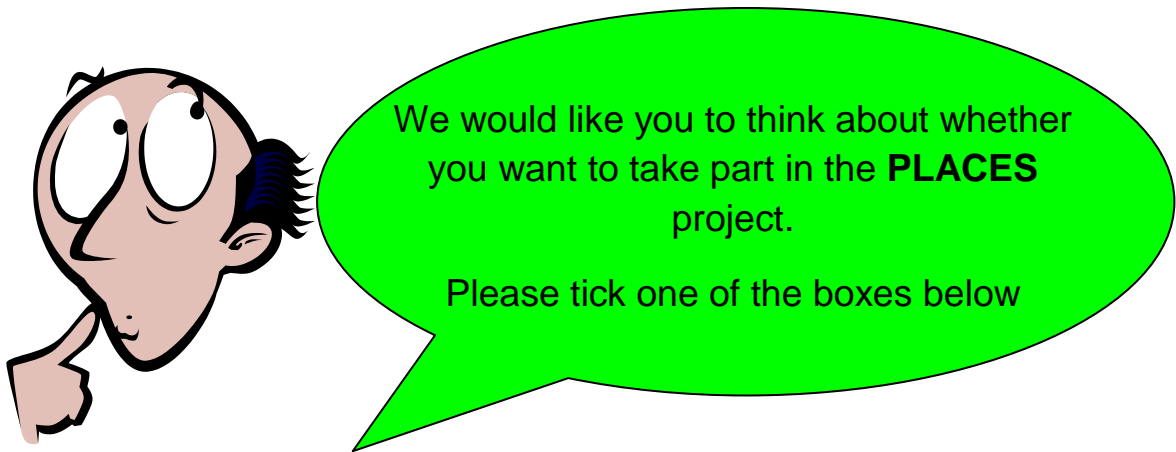
Researcher name Date Signature

2.11 Assent Form: Young People



Paediatric Location And Care Evaluations

ASSENT FORM: Young people



Yes I would like to take part in the PLACES project.



No I don't want to take part in the PLACES project.

Your name

Date

Signature

Your age:

Researcher name

Date

Signature

2.12 Consent Forms: Staff



CONSENT FOR VOLUNTEERS

Evaluation of Paediatric Satellite Services

VOLUNTEER'S STATEMENT

I have read and understand the above explanation. I have been given the opportunity to ask any questions and to discuss this evaluation with the researchers. I agree to take part in the project and I have been informed that I am free to withdraw at any time. I am happy for the session to be recorded. I understand that verbatim extracts of my speech will be used in the report and will be attached to my job title.

Participant name.....

Participant signature:

Date:

Researcher signature:

Date:

APPENDIX 3

3 MCRN young person group correspondence

3.1 Letter inviting review of study documents



UNIVERSITY OF
BIRMINGHAM



PLACES Project
Institute of Child Health
Whittall Street
Birmingham
B4 6NH

Tel: [REDACTED]

Dear

We are researchers at Birmingham Children's Hospital (BCH) and the University of Birmingham. We are carrying out a project called PLACES: Paediatric Location And Care Evaluations. This project is evaluating outpatient services provided by BCH.

We would like to include the views of parents, children and young people in this project and have drafted some documents for use in our research.

We would like to invite you to give us your feedback on the content and design of our supporting documents.

Please find enclosed the following documents for your thoughts:

- Information sheet for young people
- Consent form for young people
- Information sheet for parents
- Consent form for parents
- Project leaflet
- Project poster
- Invitation letter
- Contact information form

Thank you for your help with this work. We look forward to hearing from you.

Yours sincerely,

Gemma Heath

3.2 Summary of feedback on study documents

PLACES Project documents: Young person's feedback

What did you think about the information sheet for young people?

- Very informative and full of pictures which will keep the children engaged. However, there is an error in the section of the tape recordings.
- Mainly to the point apart from the part about what will happen to tape the recordings, which is a bit unnecessary. Bright, colourful, clear layout.
- Quite good to be honest, but the text and pictures are a bit naff.
- Good pictures, good colours to attract children.
- Pretty good leaflet to be honest. Vouchers are good.
- Bright colours, looks interesting. Boxes are good. What will happen to the tape recordings is unnecessary information; don't think people are that bothered. Back page is good.

What did you think about the information sheet for parents?

- No bad things to say.
- Very good, explained and detailed. More pictures needed though.
- Boring! Ever heard of colour, not just grey?
- Where are the pictures?
- Too complicated, even for parents. Where's the colour?

What did you think about the consent form for young people?

- Very good, simple and easy to understand.
- Very simple and clear which is good. Could be done on A5 paper.
- Good.
- They have made it interesting.
- Clear layout, bright and simple
- Should have on it: 'you don't have to take part though'

What did you think about the consent form for parents?

- No bad things to say.
- Not detailed enough I think.
- Boring.

What did you think about the project leaflet?

- The professional words need to be explained in brackets as people may not understand them.
- Good size, good use of pictures and bullet points.
- Good because there's colour.
- Interesting.
- I like the different sections. CLAHRC is a bit confusing.

- Too much writing, title is a bit small size.
- Put in brackets what paediatric means, people may not know what this means. Put a picture of Gina on the back, so people know what she looks like.
- No bad things to say.

What did you think about the project poster?

- Excellent. Informative. Colourful.
- Very bright and stands out. Very little info, which is good for a poster. I like the use of the front of BCH as a picture.
- Not bad, could be better to be honest.
- Bullet points are good and you know what it's about.
- Bright colours, good.
- No bad things to say.
- Very good and colourful.
- O.K

What did you think about the invitation letter?

- No bad things to say.
- Good, understandable.
- Good.

What did you think about the contact information form?

- Good and detailed.
- Easy to read.
- It's good, it's just information.
- No bad things to say.
- Good.
- O.K

APPENDIX 5

5 Interview schedules

5.1 Interview Schedule: Families

General Paediatric Outpatient Clinics

I would like us to explore your experiences of outpatient care for young people. Please think about your last outpatient clinic visit and recount the experience in as much detail as possible. This should include your thoughts and feelings as well as detail about the surroundings and events that took place.

Think back to your / child's last outpatient clinic visit and recount the experience.

- What was your / child's last visit to outpatients for?

Describing your experience (events and embodied)

1. Can you talk me through your / child's last outpatient appointment from preparing for the appointment to the time that you left?
 - **Describe** your experience of:
 - Preparing for and getting to the appointment
 - What happened once you arrived
 - During the appointment
 - When you left
 - **Describe** Main outpatients
 - Describe the room and layout
 - What did you do, see, smell and hear?
 - What did others do?
 - How did it make you feel?
 - What were you thinking?

Reflecting on your experience

- Looking back, how did you feel about the whole experience?
- What were the most important things for you?
- How could you make it better?
- How important was it to you that you went to the hospital?
- How worthwhile did you find the appointment?
- Is there anything you would like to add?

5.2 Interview Schedule: Staff

1. What do you think about the Department of Health's recommendation to move specialist services 'closer to home'?
2. How do you feel about the way BCH outpatient services are currently delivered?
3. What are your views on delivering General Paediatric outpatient services in community settings?
4. How do you think clinicians might feel about providing outpatient services in the community?
5. How do you think satellite clinics might influence the way clinicians work with other people?
6. What do you think would be the difficulties in setting up satellite services?
7. How do you think satellite services would impact on the quality of care that children and families receive?
8. Are there any other BCH services apart from General Paediatrics that should be delivered in satellite clinics?
9. How would you feel about personally being involved in the running of a satellite service?
10. Which patients would not be appropriate for a satellite clinic?
11. Where do you think the best place for satellite clinics would be?
12. How do you think families would feel about attending a BCH outpatient appointment in a community setting rather than the hospital?
13. How do you think families would perceive the quality of care in a satellite clinic?
14. Do you think families have an expectation of where they go for healthcare (Does it have to be a medical establishment?)
15. How do you think families would value a BCH-led satellite clinic in their community?
16. How well does the environment of BCH outpatient department meet the needs and expectations of families?
17. How do you think adolescents feel about visiting BCH outpatient department?
18. How do you think adolescents would feel about visiting a satellite clinic?
19. How easy or difficult do you think it is for families to come for an outpatient appointment at the hospital?

20. How easy or difficult do you think it would be for families to attend an appointment in a community setting?
21. Why do you think some families do not attend outpatient appointments?
22. What are the consequences of a missed appointment?
23. What do you think could be done to prevent non-attendance?
24. Where do you think General Paediatric outpatient services should be delivered?
25. Is there anything you would like to add?

APPENDIX 6

6 Thematic framework

Context: National, regional, local	
<i>Economic climate</i>	NHS budget, economic climate both local and national, credit crunch
<i>Political climate</i>	uncertainty, changes to government, coalition
<i>Healthcare Policy</i>	<i>Closer to home initiative</i> Department of Health, GP commissioning, 'Liberating the NHS'
<i>Commissioning</i>	<i>Tariff, Payment systems for patients, GP commissioning</i>
<i>Markets</i>	competition over who provides services <i>Ownership of services, who provides / pays for services, Healthcare as a business</i>
<i>Efficiency & Sustainability</i>	time, cost, 'waste of time', rental costs, cost of services, cost-effectiveness, economies of scale, cost per patient

Philosophy of Care	
Ideology of 'closer to home'	Attitude towards closer to home agenda and satellite clinic model
Patient-centred approach	Including biopsychosocial, holistic approaches, opportunities for health promotion, <i>Healthcare as a business, patient choice</i> E.g. <i>should patients choose where they go for healthcare?</i>
Equivalence to <i>Hospital care</i>	Comparisons with BCH, e.g. trying to match standards of care
<i>Equity in Service Provision</i>	<i>Distribution of services, inequity in access to services, postcode lottery, service distribution</i>

Organisation	
<i>BCH Position</i>	Aims, priorities of the Trust, driving force/motivations for setting satellite clinics up, Long-term strategy, <i>BCH attitude toward satellite clinics</i>
Constructions of BCH	BCH as removed, Ivory Tower, inaccessible, detached, insular, part of community, <i>self-image, what is BCH: A DGH or a 3rd centre?</i>
<i>Demand and capacity</i>	<i>Limited space and capacity at BCH relieving pressure, income generation Impact on BCH</i>
Change	Bringing about change e.g. persuasion, convincing, leveraging.
<i>Branding</i>	<i>Making families aware of BCH connection, e.g. use of BCH name, logos</i>

Infrastructure	
Processes	Notes management, transport, clinician transport, health and safety, infection control, lone working, transport of blood, governance, clinic set up, planning, booking in. <i>Administration Communication</i>

	<i>(e.g. referral letters, appointment letters) between health professionals and with families.</i>
Resources	Diagnostic testing, <i>Equipment, Objects required to run the clinic (e.g. diagnostic kit, blood pressure monitors) Investigations</i> <i>People outside of the core team of staff (e.g. play workers), interpreters, other services needed for satellite clinics (e.g. phlebotomy)</i>
Workforce	The core team of staff needed for a successful clinic.
Technology	Electronic notes, IT systems, remote access to electronic databases, electronic test results

Service Design	
Service Model / Alternative Models	'Drag and drop', urgent care, walk-in, direct referrals from local GPs, 'one-stop-shop', follow-up's only, service integration, telemedicine
Referral Process	Choose & book, direct referrals from GPs, normal BCH system, patient choice, screening process, making appointments collaboratively.
Care pathways	Onward referrals, patient journey, continuity of services, transition services, patient flow from service perspective
Case mix	Type of patients, screening out of inappropriate patients, deliberately not seeing patients in community who will need tests.
Volume of patients	Density of patients, number of patients/size of clinic.
<i>Difficulties with satellite clinics</i>	<i>Difficulties / constraints / problems</i>
<i>Balancing priorities</i>	<i>Compromise, what is most important. (e.g. cost-effectiveness versus patient experience) Justification for satellite clinics, benefits over cost, added value</i>

Outcomes (i.e. measures of success, ways of evaluating success)	
Quality of care	Perceived by families & actual quality of care provided
Attendance rates	No of DNAs
<i>Waiting times</i>	e.g. waiting times for appointments, time spent in clinic, fairness in waiting times
<i>Number of appointments</i>	only offering appointments when clinically appropriate, seeing patients in a place where investigations can be done, duplicate appointments
<i>Health Outcomes</i>	<i>Effect of clinic on child health status</i>

Lessons (learned, learning, to be learned, opportunities for learning)	
General Paediatrics at BCH	Experience of General Paeds at BCH

<i>General Paediatrics: satellite clinics</i>	Experience of General Paeds at pilot satellite clinics
Other services / specialities at BCH	phlebotomy, radiology, dermatology
Other organisations	Right Care, Right here; sure start; other NHS Trusts
Policy implementation	GP Fund holding, GPSIs, Darzi centres
Personal experience	interviewee's experience as a parent, also professional personal experience
Parent/ patient feedback	Feedback from families
Research evidence	Lessons to be learnt from research, evidence-based services, lessons from other research / research in other areas

Space and Place	
Location	Geographical area, catchment area, transport networks, population density, <i>distance</i>
Setting	Type of place, building, (parking?) <i>Facilities Usable items already within the establishment/integral to the setting (e.g. play facilities, drinking water, sink/hygiene facilities)</i>
Environment	Internal space, atmosphere, design, layout, whether it is 'fit for purpose', use of space, child friendly <i>Familiarity How 'comfortable' the setting is for families, how familiar it is for families</i>
Social context	Social setting in which the clinic is based, e.g. deprivation, culture, ethnicity, area of need, communities
Access	<i>Transport, Distance, Parking, Expenses, ease of access, convenience Bus routes, transport networks, parking fees, petrol, pay child care</i>

Families	
Perceptions of family experience	Patient journey, general family experience of outpatient appointment, patient flow from family perspective
Perceptions of family priorities	What families value most (e.g. child's health over distance to clinic)
Perceptions of family expectations	E.g. of the medical establishment, place, clinicians, tests, white coats.
Perceptions of family views	Attitudes, views, social and cultural norms / beliefs
Service-family interaction	Individual clinical encounter, encounter / interaction with staff and clinicians
Adolescents	Hospital and community provision of services for adolescents.
<i>Appointment times</i>	<i>suitable appointment time for family, out of hours appointments, taking time off work / school</i>

<i>Family satisfaction</i>	<i>Complaints and measures of family satisfaction</i>
<i>Service Promotion</i>	<i>'Spreading the word', social advertising, informal publicity, making services acceptable to families, family awareness of services, advertising, education about services, marketing</i>

Attendance	
Factors that influence attendance	forgetting appointment, child better/appointment no longer needed, health / service beliefs, language, cultural factors, admin issues (e.g. lost letters), healthcare professional factors, chaotic families
Consequences of non-attendance	Financial, cost to Trust, wasted time/resources, child protection issues, delayed diagnosis/treatment.
Interventions to reduce non-attendance	Reminders (letter, phone, text), penalties, parental education/information on consequences of DNA.
Responsibility for attendance	Is it responsibility of G.P / hospital / parent to ensure appointment attendance

Working Practices	
Professional role	Perception of own or other's roles, including empowerment, professional pride, GP commissioning, GPwSI.
Relationship between primary and secondary care	e.g. barriers, gaps, advantages, (both positive and negative), working relationships
Knowledge and skills transfer	e.g. education, information, explanations, teaching, training, Trainee doctor training, training GPSI
Joined up working	Any instances of working together from two or more different disciplines (e.g. GP and Consultant working on same case), working across care sectors
Changes in working practices	Impact / changes in working practice. Outcome in terms of changes to working practices (e.g. Saturday / evening clinics) <i>Clinician workload, Changes to clinician workload, Consultant moving around</i>

Staff and Stakeholder views (views should be coded as the person who holds the view)	
Hospital clinicians views	Attitudes, resistance, views, perceptions of other's views and attitudes
Community clinicians views	Attitudes, resistance, views, perceptions of other's views and attitudes
Non-clinician views	Attitudes, resistance, views, perceptions of other's views and attitudes

Theme 1: Organisational factors	Theme 2: Policy	Theme 3: Service Design
<p>Sub-theme 1: Space and Place</p> <p><u>Space & Place</u></p> <ul style="list-style-type: none"> • Location • Environment • Setting • Social context • Access <p><u>Outcomes</u></p> <ul style="list-style-type: none"> • Quality of care <p><u>Families</u></p> <ul style="list-style-type: none"> • Service-family interaction • Adolescents • Perceptions of family experience <p><u>Staff and stakeholder views</u></p> <ul style="list-style-type: none"> • Hospital clinician views • Community clinician views • Non-clinician views 	<p><u>Philosophy of care</u></p> <ul style="list-style-type: none"> • Ideology • Patient-centred • Equity • Equivalence <p><u>Families</u></p> <ul style="list-style-type: none"> • Patient choice <p><u>Outcomes</u></p> <ul style="list-style-type: none"> • Quality of care <p><u>Context</u></p> <ul style="list-style-type: none"> • Political • Economic • Healthcare policy • Commissioning • Markets • Efficiency & sustainability 	<p><u>Service Design</u></p> <ul style="list-style-type: none"> • Service model • Referral process • Care pathways • Case mix • Volume of patients • Difficulties with satellite clinics • Balancing priorities <p><u>Outcomes</u></p> <ul style="list-style-type: none"> • Number of appointments • Attendance rates <p><u>Infrastructure</u></p> <ul style="list-style-type: none"> • Processes • Resources • Workforce • Technology
<p>Sub-theme 2: The Ivory Tower</p> <p><u>Organisation</u></p> <ul style="list-style-type: none"> • BCH position • Constructions of BCH • Branding • Process of change • Demand and Capacity <p><u>Families</u></p> <ul style="list-style-type: none"> • Perceptions family expectations • Perceptions family priorities <p><u>Staff and stakeholder views</u></p> <ul style="list-style-type: none"> • Hospital clinician views • Community clinician views • Non-clinician views 	<p><u>Staff and stakeholder views</u></p> <ul style="list-style-type: none"> • Hospital clinician views • Community clinician views • Non-clinician views 	<p><u>Lessons</u></p> <ul style="list-style-type: none"> • Policy implementation • General Paediatrics at BCH • General Paediatrics Satellite • Other organisations • Personal experience
<p>Sub-theme 3: Impact on HCPs</p> <p><u>Working Practices</u></p> <ul style="list-style-type: none"> • Professional role • Relationship between primary and secondary care • Knowledge and skills transfer • Joined up working • Changes in working practices <p><u>Staff and stakeholder views</u></p> <ul style="list-style-type: none"> • Hospital clinician views • Community clinician views • Non-clinician views 		<p><u>Families</u></p> <ul style="list-style-type: none"> • Service promotion <p><u>Staff and stakeholder views</u></p> <ul style="list-style-type: none"> • Hospital clinician views • Community clinician views • Non-clinician views

APPENDIX 7

7 Analytic Memo 'Philosophy of Care'

Definition

Ideology versus practicality: Care Closer To Home (CCTH) is perceived as desirable but difficult to achieve. Financial and practical difficulties (e.g. ensuring equivalence in standards and equity in service provision) challenge the philosophical ideology underpinning paediatric CCTH.

Codes

Ideology of CCTH; Patient-centred approach; Equivalence to hospital care; Equity in Service Provision

Summary of data

- Ideology and patient-centeredness

Participants view paediatric CCTH as intrinsically desirable, a sound theoretical principle for keeping children out of hospital and guiding health service re-design: ***“Only the patients who need specific investigations they can only get in the hospital really need to attend the hospital.”*** (Consultant 7, p. 1, line 7). In addition, participants were keen to convey their support for a user-led agenda in which new services incorporate families’ perspectives, as well as being responsive to the needs of communities. This was contrasted with the present service design which was perceived as reflecting the needs of the organisation: ***“We need to be very different in how we deliver services based around what the patients and their families need and I think at the moment we’re not, we’re still focused on what’s easier for us”*** (Manager 1, p. 20, line 464); ***“The preservation of the institution, rather than the needs of the population they actually serve, seems to me to be the predominant interest”*** (Consultant 7, p. 3, line 69).

The ideology of providing care that is both closer to patients’ homes and tailored to their needs was further contrasted with the practical and financial difficulties of delivering ‘hospital’ services in community settings. So, although closer to home policies were philosophically presented as unproblematic, the process of actually setting up and maintaining clinics in terms of finance and infrastructure was seen as far more challenging: ***“What we’re talking about is logistics and possibilities and that’s not necessarily the same as kind of philosophical approach is it?”*** (Consultant 8, p.14, line 324).

Does this mean that participants supported CCTH in theory, but not in practice? *“Behind it in theory but the practice is often more complex than the theory”* (Executive 1, p. 4, line 73). Does this call into question the interviewee’s commitment to delivering paediatric CCTH? Perhaps the reluctance of participants to fully commit to implementing this policy relates to uncertainty about whether a new government will endorse the initiative? Given that interviews spanned the introduction of a new government / White Paper, the political and economic context was clearly present in participants’ views, leading many to examine the costs and benefits of CCTH: ***“We’ve got to strike the balance between improving access and improving choice... And what’s actually affordable”*** (Executive 5, p. 16, line 364).

- Equity, equivalence and fairness

The CCTH policy was also contested on ethical grounds. Many participants depicted a moral obligation of providing outpatient services in community settings which were of at least an equivalent standard to hospital care: *“You would never want to take something out into the community that’s any different than you’d be happy providing here”* (Manager 3, p. 10, line 226). Participants also suggested that if patients were given appointments on the basis of their geographical location, this could create a ‘postcode lottery’ in which access to paediatric health services is defined by the area in which a patient lives: *“If you start pulling patients out of, based on their geographical area from the total waiting list... people in that particular clinic might be seen earlier if it’s a first appointment... So that kind of might create a double standard”* (Consultant 1, p. 7, line 205). Thus, far from having the desired outcome of improving access, some participants suggested that decentralisation of services may actually reduce access for some families: ***“If you just transfer a clinic from a hospital to a community setting, you’ll improve access for some and reduce it for others”*** (Executive 5, p. 11, line 340).

Deviant cases

One G.P did not think that paediatric outpatient care should be moved closer to patients’ homes. However, the GP’s surgery is geographically located close to the hospital, which could explain his views?

Points for further consideration

- What are participants’ motivations for putting policy into practice?
- What is the CCTH agenda intended to achieve (e.g. keeping children out of hospital, improving access, relieving demand on hospitals, reducing DNA)?
- Are consumerist ideals (e.g. convenience and satisfaction) compatible with sustainability in the NHS?

APPENDIX 8

8 BCH Outpatient Report

Collaboration for Leadership in Applied Health Research and Care (CLAHRC)
Paediatric Location And Care Evaluations (PLACES) Project

Exploring parent and patient experiences of General Paediatric Outpatient Services provided by Birmingham Children's Hospital

Gemma Heath, Birmingham Children's Hospital
Dr Sabi Redwood, University of Birmingham
Dr Sheila Greenfield, University of Birmingham
Dr Carole Cummins, Birmingham Children's Hospital

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Summary Report

This report is a summary of the data taken from a larger, qualitative study; CLAHRC
PLACES Project: Exploring parent and patient experiences of General Paediatric
Outpatient Services provided by Birmingham Children's Hospital.

In this report, we briefly describe the background to the wider project and methods
used, before providing a descriptive summary of data relating to positive General
Paediatric outpatient experiences and potential areas for improvement. We are
currently carrying out in-depth analysis of these interviews using a descriptive
phenomenological approach. A full report including findings from the in-depth analysis
will be available once completed (approximately June 2012).

Background

The rationale for moving paediatric outpatient care into the community and closer to
patients' homes has included the potential benefits of keeping young people out of
hospital and reducing health inequalities by improving patient access and health
outcomes. New models are assumed to be preferred by families, but shifting services
away from their traditional setting has implications for healthcare experience, because
the physical and symbolic location of care can hold complex meanings for service-users.

Aim & Research Questions

The aim of the study was to explore parents' and patients experiences of General
Paediatric outpatient services provided by Birmingham Children's Hospital at the main
hospital and at two community-based satellite clinics; one in a health centre and one in
a children's sure start centre.

To meet this aim the following research questions were addressed:

- What are the experiences of parents and young people attending General Paediatric outpatient appointments provided by Birmingham Children's Hospital?
- What are the essential differences between the experience of outpatient appointments delivered in the hospital and the experience of those delivered in community settings?

Methods

Between June and December 2011, 27 interviews were carried out with 14 parents and 14 young people (aged 8-16 years), all with experience of attending General Paediatric outpatient services provided by Birmingham Children's Hospital. Interviews were conducted either in the participant's home or in a room at Birmingham Children's Hospital and had an average duration of 40 minutes. Interviews were audio recorded and transcribed verbatim. All participants provided informed consent prior to the interview, agreeing to have anonymised quotations of their speech used in reports and publications.

Findings

A number of features were discussed which reflected the experiences of parents and young people who took part in the interviews. These were:

- Waiting
- Environment
- Entertainment
- Cleanliness
- Parking
- Interactions with staff
- Care

These represent areas talked about by families, highlighting positive experiences and areas for improvement. Each of the topics is summarised below, with some examples of what participants' said. However, this is a summary and only includes brief extracts from the data. The depth and wealth of the experiences and stories shared in the interviews will be best appreciated by reading the full study report when completed.

Waiting

All participants discussed the time they had to wait in the outpatient department before being called into their appointment to see the Consultant. Most felt that they had to wait too long past their appointment time to be seen. This led many parents and young people to describe feeling frustrated at times.

“The last time... we had to wait quite a long time, and that is my experience of the outpatients, I have had to wait a long time, the clinics are usually running late, I think the last time we went it was oh gosh, it was about an hour we had to wait, it really was quite a long time... it was probably an hour long wait for a ten minute appointment... it was very very stressful really, I think stressful is the wrong word actually, a bit sort of frustrating, you feel wrestles, I felt wrestles, I felt like I just wanted to go up and say how much longer am I going to have to wait but you know, there’s no point because they don’t know how much longer you’re going to have to wait, so, we just had to bear with it really. Very rare I’ve had an apology about the time waiting” (Parent 4)

“I just get on edge mostly... I just find it really stressful with the kids, I mean it’s not a hospital thing; it’s not that, it’s just... all that waiting and all those things and they get on edge and they get bored, so you know, its fine but it’s stressful. Its only when it’s really busy as well, it gets really busy sometimes... (Parent 6)

“Sometimes you get angry. You start asking, you start noticing all the people coming in after you and they’re getting in before you and that makes you feel a bit odd. Like, you’re like, you start thinking how come they come after me and they got served so quick and our Dr is taking so long and then you get frustrated because if you come late, the hospital gets angry and whenever you get there on time, you never get called in on time. You always get called in late” (Young person 6, age 15)

They also felt that waiting so long meant that the outpatients department was not set up very efficiently.

“I think if you’re planning services that cause you regularly to be waiting in excess of half an hour for your appointment then there’s something amiss, because if it happens all the time, then you know that can’t be very efficient. There must be something within that system that’s not working well” (Parent 5)

Some parents also described the impact of this waiting on their clinical interactions.

“I think when you’ve waited a long time and you are aware of all the other people waiting, it’s very difficult because you then try and rush everything through because you’re aware there’s everybody else sitting outside waiting. So it does put you slightly ill at ease I think” (Parent 5)

Many parents talked about the uncertainty of not knowing how long their appointment might take and not being able to plan anything else in their day. This meant that hospital appointments caused more disruption for families as they cannot predict how long they will have to wait.

“Every time is different, there’s no same time, every time is different. But sometimes you do wait a lot, you have to wait a lot, about half an hour an hour” (Parent 7)

“You just don’t know because the last one I was literally in and out and I put a two hour ticket on and there’s times I been there and I put an hour on and we’re sat there waiting still, haven’t even gone in” (Parent 11)

All participants agreed that waiting to see the Consultant after seeing the nurse for height and weight measurements should not exceed 30 minutes past the specified appointment time.

“Not longer than half an hour I suppose, ‘cause it makes the appointment more fraught you know, if you’ve got a child who’s hungry or tired or you know, you’re impatient” (Parent 2)

Many parents described how they just like to get the appointment over with as quickly as possible.

“I just want to get in and out and not have the whole drama of going to the hospital and then trying to find parking and paying umpteen pounds and waiting for hours...” (Parent 5)

“I don’t like hanging around, I like to just get in, get done and go home” (Parent 6)

Environment

Many parents and young people described the outpatient department as a very big open space, with high ceilings and lots of room for small children to run around. However, participants discussed that at times the main outpatient waiting area can become extremely crowded, noisy and ‘chaotic’ which in turn can create a stressful experience for families.

Noisy and busy

“At times it can be very busy, very busy to the point where it’s actually very noisy as well because I think it’s just the fact that it’s a big open sort of hallway... I do find at times when it is really busy is that it is incredibly noisy” (Parent 1)

“Chaos, yeah it just seemed quite loud, a lot of talking, a lot of people” (Parent 2)

“It’s noisy like hell in there, is very loud” (Parent 7)

“It’s just very very loud, it’s really loud because of the passing things and the kids and things, it’s not really anything in particular it’s just like a loud buzzing noise what with all the kids in there” (Parent 6)

“It was crowded. Even though I’m sure it was organised, it seemed like it wasn’t... I hate being crowded, it makes me feel all hot, I get quite moody, it feels like I’m isolated and I can’t move and so like, you stay there because there’s not any room to go, so you just stay in that spot and there’s people running across, kids running across obviously not adults and there’s parents shouting at the kids to stay like in one part and obviously most of the kids don’t listen, so the parents get angry, so they scream even more and then you end up getting a headache” (Young person 1, age 14)

“When I’m sitting down its loud... it’s the kids just screaming when they run around like when they’re playing tig around the hospital... we just move away from it all sometimes, away from all the toys and people, just so it’s a bit quieter, move to an area that’s quieter” (Young person 4, age 14)

Being away from the main waiting area was described as preferable for families waiting.

“Once they’ve called you, then they call you again through to another waiting area... it’s much more relaxed in that little corridor then ‘cause you’re out of the waiting room, you’re just in the little corridor, you can still wait for 20 minutes in there, but it is much more relaxed” (Parent 4)

The decor was generally described as colourful and lively. It was very important to young people that that the waiting room is colourful.

“When you walk in and there are all these lovely colours and things to play with. It’s mostly the colours... if it was really dull I would feel really down, but if it is really stimulating then it brings your day up...you walk in and there’s all these colours like different, because like each wall is a different colour and I find it really like cool” (Young person 5, age 14).

“It’s very colourful, it’s colourful and very like clean and it’s very lively. All the people and all the colours and it’s very clean and all the, it’s like nursery and you’ve got the tables and all that everything, so organised and colourful...it is nursery; you’ve got toys there” (Young person 6, age 15)

Some parents did suggest however that the main waiting area could do with some modernising.

“I think it probably could be spruced up a little bit, you know it could be a bit brighter, it could sort of have perhaps sort of a more modern look there... it could perhaps be a little bit fresher” (Parent 1)

A number of participants discussed that the outpatient waiting area environment was appropriate for young children but less so for older children. Many participants, especially young people, therefore suggested having a separate area for adolescents.

“There could be like a room where kids go in... like a teenage room or something. And then like, not a TV like, but like one of those things that like, do you know when you’re in the doctors when it says your name across?” (Young person 4, age 14)

“You could have like separate place may be like for teenagers and little kids. Like separate areas and that’s it...Like all the teenagers come on this side, all the big people and all the little kids be like on one side of the hall so it’s kind of like divided” (Young person 6, age 15)

“You could maybe make it a little bit quieter, so there could be like maybe like the little children could have a really loud room and be like a little bit separate... Like split it a little bit and then, so like the little kids are in their room with the toys and then the older kids are in their room with some like books for like older kids and stuff” (Young person 7, age 12)

One parent also commented on the lack of breastfeeding facilities in the department.

“I don’t think there is a dedicated place (for breastfeeding) and that would probably be really useful to have it known and advertised in big letters or whatever, there’s a room for breast feeding and for that to be available, would be really useful and then to have some like bottle warmers for people that needed it” (Parent 2)

Entertainment

Similarly, the entertainment in outpatients was described as good for small children, but adolescents and parents felt that older children and teenagers were not catered for.

Young children

“It’s great because it’s always clean and there’s all these different things for the children to play with which is nice... you know it’s really big and there is kind of enough space for him (son, age 2) to run around a bit” (Parent 6)

“They’ve got the fish which a lot of children do like... perhaps things like where they put out things like colouring, paper and you know, ‘cause that takes children’s minds off things and my kids always love doing things like that... they could do with having something like that out, some crafty things” (Parent 4)

Older children

“For her age (14) there is nothing to do... there is nothing to do there, so she’s bored out of it... it’s boring to be there, I’ll be really honest with you, I’m not going to say ‘yes it’s really good’ because you do get fed up because you got nothing to do” (Parent 7)

“There’s only stuff there for toddlers, there’s nothing there for my age or people older than people, there’s nothing there for people like us, there’s only toddlers and children’s areas, that’s it, there’s nothing much else there to be honest” (Young person 8, age 15)

“I would say it’s more babyish in there than like for my age. It’s kind of like more childish but I still go on the rides there... I would say it’s alright because it’s good to entertain the little children, but when it comes to like my age, there’s nothing for us to really do, I just end up sitting there” (Young person 9, age 11)

“There’s like tunnels for like the tiny people, but there’s not actually anything for like 12, 11 year olds and sometimes when they’re waiting especially they get really bored and they start moaning and then the noise rises again” (Young person 1, age 14)

Cleanliness

All participants who commented on the cleanliness of the outpatients did so in a positive way and approved of the provision of antibacterial hand gel within the department.

“The cleanliness of the hospital, I noticed in between every visit they were wiping everywhere even the seats parents had sat on and everywhere I noticed as people were coming out, they had got healthcare assistants going in and wiping the seats which I think is a very important aspect when you’ve got so many people in an environment like that” (Parent 4)

“Being clean which it is, there’s loads of those hand gel things everywhere which is great” (Parent 6)

“It was all sort of like clean...It just like looked clean. There was hardly anything like on the floor or on the walls and everything and it kind of smelt a little bit clean” (Young person 7, age 12)

“There was those hand things which was reassuring to have those... all the floors and everything are clean” (Young person 1, age 14)

Process

Many parents described difficulties with hearing their name being called out by the nurse or Consultant due to noise in the outpatients, or being seated in the wrong area.

“Somebody just comes and shouts your name and obviously sometimes you can’t hear it... I mean I know you’ve been checked in so they know that you should be there somewhere but I was worried about missing the appointment” (Parent 2)

“When they were calling the people through the healthcare, I don’t know if they were healthcare assistants or nurses they seemed to be getting quite sort of stropy because people couldn’t actually hear what they were shouting... unless your name is distinctive you can’t really... you can’t actually hear them calling you properly, I mean the one person she had to call three times and she didn’t seem very happy about the fact that she had to call him” (Parent 4)

“You’re like very alert to like hear your name and your number and all that, because you have to start when you come in. You’ve got to listen out for your number to check in, what desk it is and you have to go to the right desk” (Young person 6, age 15)

Parents suggested that a screen with names calling them in to their appointment would be helpful.

“Whether they could actually have your name written up on a screen so that if you were further away you would see it as well, that would be helpful being able to see your name as well as hear it might be good” (Parent 2)

In addition, more communication about clinic running times on a screen was suggested.

“I don’t think they keep you very well informed... I think it would probably be very useful if they put those, you know those white boards saying which Drs are in clinic on that day and underneath they could just write on them, instead of having to say there’s a 30 minute delay or an hour delay and then it’s like at least then you know what to expect you can think, ok I’ve got an hour I can go to the toilet I don’t have to sit here holding in case they come out and want me to go in” (Parent 6)

Generally families liked the ticket system as you go in through the outpatient door. They described it as working well and easy to understand.

“When we walked in, we pulled a ticket, it’s quite an easy system, you understand the system, it’s not like you know there’s no problems there, pulled a ticket, wait then they call you up to the desk” (Parent 4)

“When you go in, you just get a ticket, that part’s really good” (Parent 7)

“Booking in that felt fine and that’s very quick. It all seemed pretty organised to me” (Parent 2)

Cafe

Participants also really liked the cafe in the outpatients, but they wished it could be open for longer, especially as they feel they can’t leave the main outpatient area once ‘booked in’ for their appointment.

“The only think that gets a bit irritating is that they shut that cafe thing, so you can’t get stuff to keep the child happy... they always seem to be closing as we arrive and it’s really frustrating because you’re like ‘ahhh I’ve booked in now, I can’t go up to the shop and get something’ and when you’re there for a long time it is frustrating, even if the cafe didn’t stop open, even if they just had a machine or something in there so that you don’t have to walk out because if you walk out then you’re going to miss your thing... or at least they could have a water fountain thing there or something” (Parent 6)

“Sometimes the shop closed early, then you can’t... other people wanted to go to the shop, but the shop was closed” (Young person 3, age 7 and 11 months)

Parking

Parking was described by parents as difficult to find and extremely expensive.

“Saturday morning is great because you can just park in the hospital car park, if you’re going in the week, you end up in the one across the road or somewhere else and then it gets very expensive... so, yeah. Car parking, access is a problem, yeah” (Parent 5)

“Parking is a nightmare there at the hospital and it’s really expensive as well” (Parent 6)

Other parents were more annoyed with the system of having to predict how long they would need a car parking ticket for.

“I haven’t got a problem with paying for parking, but that system there, I know it aint got nothing to do with you, but that system there I think that should be addressed... there should be you take a ticket, carry it into the children’s and pay for it there, depending on if you been an hour or four hours, pay accordingly. Because half way through can you imagine telling your doctor... sorry I don’t mean to be rude but I got to go and put a ticket on so I don’t get a fine, you know it’s happened to me twice... I can imagine people sitting there you know and you’re trying to talk to the Consultant but you got this thing in the back of your head, what time is it?” (Parent 11)

Interactions with staff

Most participants were very happy with the way staff interacted with them during their visit to the outpatient department.

“Everyone’s really nice and you know, I’ve not had any bad experiences, people have always been polite, friendly you know, approachable to my son and stuff” (Parent 2)

However, some thought the staff could be a bit friendlier towards young people.

“The staff seem very stressed and from my observations just sitting there they don’t seem really like they look after children, they’re not very child friendly... in the outpatients department, there didn’t seem to be much you know, child friendly-ness, you know, which I think children need to make them feel more relaxed” (Parent 4)

“The lady who’s there when you get the ticket, she’s like, not moody but yeah a bit moody like, ‘cause when, sometimes you’ll forget your ticket and sometimes she’ll just get a bit moody like, like ‘oh excuse me, you forgot your ticket’ like, but in a moody way which sometimes gets on my nerves” (Young person 4, age 14)

Care

All participants were very satisfied with the care they received from the General Paediatric team. They talked about feeling listened to and having their concerns taken seriously and really appreciated the child-centred approach taken by Consultants.

“The care was fantastic, it was you know, he (Consultant General Paediatrician) explained, he took the time, he had the patience to explain to (my son) about his condition about the allergies he has got and about the present level of research in relation to the condition” (Parent 1)

“They never once questioned the fact that I wanted a follow up appointment, so I was very satisfied with that, you know they’re not pushing me out of the system... I found reassurance with it from the Children’s Hospital, you know, because they did tell me that you know, it was quite normal and you know, they told me how to deal with it” (Parent 4)

“In the General Paediatric department, the care has been fantastic... Dr (Consultant General Paediatrician) at the Children’s, she like listened to everything and she was like, didn’t judge anything you know what I mean and like actually listened to it all and took it seriously... it was all the after care as well and the fact that she just listened when you spoke to her, she didn’t fob you off or anything” (Parent 6).

Saturday Appointments

A number of families also had experience of Saturday clinics. These were liked by many families as they often presented easier parking and a less busy environment. Parents also commented that Saturday clinics fitted in well with their busy working lives.

“The last couple of appointments I’ve had in the outpatients were on a Saturday and that for me was really helpful... and that then made parking really easy ‘cause their front car park was free and ‘cause it was only a short visit, like I was there for about an hour and a half or something that was really convenient” (Parent 2)

“The last appointment was on a Saturday morning and it was fabulous! We were, we hardly waited at all, there was hardly anybody there, it wasn’t busy, I think we went, you know, it was lovely. Saturday morning appointments that we’ve had have been great... compared to a mid week outpatient appointment which can be a very lengthy wait... the experience of going on a Saturday is entirely different to in the week. It’s much more relaxed; I felt I had much more time. I could speak for longer with the Consultant which was better, so yeah good experience of Saturdays” (Parent 5)

“Saturday’s are actually much much easier for me because I don’t have to worry about school runs or anything, I can just take him and just the two of us go together. So I much prefer the Saturday ones because it’s also much quieter up there and you generally don’t have to hang around as long waiting” (Parent 6)

Conclusions

This report provides a descriptive summary of data taken from interviews with parents and patients who have attended General Paediatric Outpatient services provided by Birmingham Children’s Hospital. It is clear from this overview of raw data that families are generally satisfied with the care they receive from BCH. There are however a number of areas that would contribute to an improved overall outpatient experience. These include the following recommendations from families:

- Waiting to see the Doctor should not exceed 30 minutes past the appointment time.
- Having names on a screen as well as being called out when it is their appointment.
- Having a dedicated and clearly advertised room for breastfeeding.
- Keeping the cafe open for longer / having a vending machine or water fountain.
- Having more things to keep teenagers entertained or a separate area for older children.
- Having a different / cheaper car parking system.
- Ensuring a colourful outpatient environment.
- Ensuring staff are friendly towards families.

Findings from the in-depth analysis will provide further exploration of experiences allowing for more informed recommendations and robust conclusions to be drawn.

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