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What processes will support effective shared decision making when health visitors and parent are planning to improve the wellbeing of babies and children within the context of the Getting It Right For Every Child (GIRFEC) Policy Framework?

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Abstract

Two key policy documents are having an impact on health visiting practice in Scotland: Getting It Right for Every Child (GIRFEC) (2013), which seeks to promote all children's wellbeing, and The Healthcare Quality Strategy for NHS Scotland (2010) which promotes person-centred care.

'Shared decision making' is integral to 'person-centred care'; however no research studies to date have linked shared decision making with health visitor practice. This thesis reports on a descriptive, qualitative research study, which was conducted in two health board areas in Scotland, in order to explore the processes that support effective shared decision making in health visiting practice within the context of implementing GIRFEC.

The design was in three phases and used Elwyn's Framework, of 'Choice, Options and Decision Talk' as a structure (1999b). Phase 1 consisted of audio recordings of 2 x health visitor: parent encounters when decisions were being made; Phase 2 consisted of semi-structured interviews with 9 x health visitors and 9 x parents who had made decisions within the last 6 months; Phase 3 involved 3 x focus groups reviewing the findings to date and reflecting on current issues when implementing GIRFEC. The framework method was used for analysis and two additional themes were identified: 'Issues' and 'Relationships'.

The health visitors demonstrated that they built up trusting relationships with parents; however there was lack of understanding and application of decision making theory which supports analysis, and an outcome focused approach to person-centred planning. This thesis identifies areas for health visitor practice development.

Chapter 1 – The Introduction

This thesis reports on a research study which took place in 2013-14 as part of a Clinical Doctorate programme. It focuses on the application of 'shared decision making' within health visiting practice.

As a registered health visitor, working as a practice development nurse, with responsibility for supporting teams of health visitors with practice improvement, this created opportunities for me to keep up to date with the context within which health visitors were working. It also created understanding around the ways in which political drivers were having an impact on practice during a time of significant change in health visiting, due to Scottish Government legislation and the implementation of the Getting It Right For Every Child (GIRFEC) Policy Framework (2013).

For over 150 years health visitors have had key public health roles within societies across the United Kingdom, with a particular responsibility for supporting the health and development of babies and pre-school children within communities or caseloads. The health visitor's role has continually needed to evolve, in order to be consistent with policies and cultures. At the time of the study the roles and responsibilities of health visitors were being redefined within Scotland, with some aspects of the role being subject to legislation within the Children and Young People (Scotland) Act (2014) (from this point referred to as The Act 2014).

1.1 Two key policies

Two key drivers were dominant for all those working in children's services for NHS Scotland at the time of the study, and these were Getting It Right For Every Child (GIRFEC) (2013) and the Healthcare Quality Strategy for NHS Scotland (2010). Both are described in greater detail within the next chapter, as they have

both influenced the development of the research question; however they are summarised briefly here.

Getting It Right For Every Child (GIRFEC) (2013) is a Scottish government policy framework which has evolved since its initial development in 2004. It is based on sharing principles and values across agencies and the importance of health, local authorities (predominantly education, social work and housing), police, the third sector and voluntary agencies working in collaboration. A key focus is to build services around babies, children, young people, their families and communities and to offer appropriate, proportionate and timely support and advice as required.

Health visitors have key roles and responsibilities within GIRFEC, which had not yet been enacted at the time of the study. These responsibilities included being the Named Person for every baby and child on their caseload. The responsibilities of the Named Person include supporting, promoting and safeguarding the wellbeing of babies and children through using the National Practice Model as a support to assessment, analysis, decision-making, planning and reviewing. The concept of parents and health visitors working together to ensure the best possible outcomes for babies and children is fundamental to the GIRFEC framework, which identifies that health visitors need to encourage parents to participate in gathering information, decision making, planning, and progressing and reviewing the plan, if additional help is required - but only if the baby's or child's safety is not at risk by involving the parents in this way.

The Healthcare Quality Strategy for NHS Scotland (2010) was written taking cognisance of views from a number of representatives from the population in Scotland indicating what they wanted from a health service, and their expectations were in agreement with the six dimensions of healthcare described by the Institute of Medicine (2014). According to the Institute, and other internationally renowned organisations, for healthcare to be high quality it needs

to be person centred, safe, effective, efficient, equitable and timely. The Scottish Government's quality ambitions, which are to deliver care which is safe, effective and person-centred, encompass these dimensions.

On the basis that, when implementing GIRFEC, health visitors will be expected to encourage parents to participate in decision-making (in relation to the wellbeing of their baby or child) a brief overview of literature was undertaken to find if there were any documented links between 'person centred care' and 'decision-making'.

According to The Health Foundation(2014) 'person centred care' in practice is demonstrated by the use of 'shared decision making'; where 'person centred care' is described as 'treating patients as partners' and 'providing a personalised service'(The Department of Health 2000), and 'shared decision making' is described in its simplest form by Elwyn et al.(1999a) as 'choice, option and decision talk'.

On further review there was evidence that shared decision making has been highly regarded as an approach within clinical practice since Charles et al. applied shared decision making theory to health professionals' practice in 1999(Charles et al 1999). The high level of respect it has had since may have been because the concept of shared decision making is congruent with The Human Rights Act (1998)and consequently underpins government guidance and policies and the Patients' Rights (Scotland) Act (2011)or it may be because it creates structure to encounters (Siminoff and Step 2005). However, advocates of using this structured approach in practice have claimed that they did so not only because of directives, and the structure it creates, but also because they believe that patients who had been involved in making decisions, which directly affect them, are more likely to comply with the planned interventions than those where decisions are made by professionals without involving the patients' views in a meaningful way (Edwards and Elwyn 2009). Although, to date, there has

been very little clear evidence that shared decision making directly improves health outcomes for patients, the approaches used within shared decision making, such as 'person centredness', have been closely linked to theories of self-efficacy which do provide evidence of improvements in patient experience, the achievement of personal goals, and consequently provide evidence of the delivery of person centred care(Adams and Grieder 2014). Of particular significance, at this time, was the lack of any evidence of research literature being available which made direct links between shared decision making and health visiting practice.

A more detailed literature review was subsequently carried out, which focused on shared decision making and this is described in Chapter 3 along with the search strategy used. This review confirmed that although there was evidence of a recent growth in the quantity and quality of published literature there were no published research studies which specifically looked at shared decision making within the context of health visitor practice. This gap in literature, the policy context and evidence that health visitor practice will be changing, and the lack of clarity around what education and support health visitors will need in the short to medium term, was the background to the development of the research question. Further exploration took place along with discussions with research supervisors, and consequently the research question, which has been addressed within this thesis is:

What processes will support effective shared decision making when health visitors and parents are planning to improve the wellbeing of babies and children within the context of the Getting It Right For Every Child Policy Framework in Scotland?

The study used a qualitative, descriptive approach which was informed by shared decision making theory, in particular Elwyn's Shared Decision Making Framework which was used to provide structure to the inquiry (Elwyn et al 2013).

1.2 An overview of the research design

In order to address the research question it was important initially to determine what was currently happening within health visitor/parent encounters where planning was taking place. This was approached by addressing the following three objectives:

- Objective 1 - What is currently happening within health visitor/parent encounters when decision-making is taking place?
- Objective 2 - What are the perspectives of the health visitors and the parents after their encounters – in terms of their perceptions of the process and satisfaction with the final decision?
- Objective 3 - What evidence is there that decision-making is shared between the parents and the health visitors?

1.3 Study setting

The study took place within two Health Board areas in Scotland, both with mixed demographics but one predominantly rural and the other predominantly urban, where GIRFEC principles were starting to be implemented into health visiting practice along with aspects of the Children and Young People Act (Scotland)(2014). Once ethical approval had been granted by the various authorities (identified in more detail in Chapter 6) data was gathered from participants (health visitors and parents) within health centres, clinics, community centres and within parents' homes. Details of the methodology, chosen methods for data gathering and data analysis are presented in Chapter 4.

The study was divided into three Phases. Phase 1 addressed Objectives 1 and 2. Data was gathered by recording two health visitor: parent dyads as they planned

interventions for a child, and then perceptions of the encounter were collected individually. Phase 2 addressed Objective 3. This consisted of recording individual semi-structured interviews with nine health visitors and then nine parents all of whom had been involved in making decisions about a child's wellbeing within the last six months (not necessarily connected with each other). Phase 3 created the opportunity for the eleven health visitors to participate in one of three Focus Groups - where data generated from Phases 1 and 2 were discussed and debated before the health visitors participated in facilitated discussions addressing the principal research question.

1.4 Structure of the Thesis

As previously indicated, Chapter 2 provides an overview of two key political drivers facing health visiting at the time of the study and provides further justification for this investigation and Chapter 3 provides a review of literature in relation to shared decision making.

Chapter 4 describes the choice of design, methods and the approach taken for analysing the data with explanations around the decisions. Chapter 5 identifies what measures were put in place for quality assurance. Chapter 6 reflects on the ethical considerations and the processes which were required to access the field. Chapter 7 describes the process of gathering the data on the two sites and the data analysis. Chapter 8 presents the key study findings from Phases 1 and 2 and Chapter 9 presents key findings from Phase 3. Chapter 10 reflects on the findings through discussion whilst Chapter 11 addresses the research question. The Appendices which follow include a paper ready to be submitted to a peer reviewed journal for publication.

Chapter 2 – Overview of two key policies

This chapter provides an overview of two key policy drivers which were having a direct impact on health visitor practice at the time of the study and were mentioned briefly in the last chapter. It provides the background as to why it is important for health visitors to work in collaboration with parents when making decisions and planning in order to improve the wellbeing of babies and children in the context of implementing GIRFEC.

The two key policies are:

- Getting It Right for Every Child (GIRFEC) (2013) and
- The Healthcare Quality Strategy for NHS Scotland (2010)

2.1 Getting it Right For Every Child

The Scottish Government is ambitious in wanting Scotland to be 'the best place to grow up' and is implementing a range of initiatives to support this aspiration, for example the Early Years Collaborative (Scottish Government 2013) in order to support practice through using the Model for Improvement (Langley et al 2009); the Early Years Framework (Scottish Government and COSLA 2008); and the Family Nurse Partnership (Scottish Government 2013).

Getting It Right for Every Child (GIRFEC) is a significant overarching cross-party policy framework designed to provide a national approach to the delivery of services for all babies, children and young people. It was founded on the United Nations Convention on the Rights of the Child (1990) (UNCRC) an international human rights treaty that grants all children and young people (less than 18 years) a comprehensive set of rights in addition to their human rights. GIRFEC's principles are in alignment with the UNCRC's fifty-four articles and include an understanding that anyone working with babies, children, young people and their families should give priority to their 'wellbeing' in order to ensure that each one

reaches their full potential. Within GIRFEC, Indicators of Wellbeing include being Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included (SHANARRI) - and they are identified within Part 18 of The Act (2014).

As aspects of GIRFEC were still to be incorporated into legislation, this meant that, once The Act(2014) was enacted, any professionals, agencies, and carers who worked with children and families (or worked with adult services where clients had responsibility for children or young people) and were employed by health boards or local authorities (or were subcontracted by these public services) would be required to abide by specific rules, particularly in relation to the provision and functions of a Named Person Service, information sharing, planning and the provision of targeted interventions(Scottish Parliament 2014).

Prior to enactment of the Act (2014) there was still a recognition that the time was approaching where these same organisations would be responsible for building support services around children and their families in a co-ordinated way. It was anticipated that working in a different way might challenge existing cultures, systems and practices within services, because providing a seamless service across agencies was not the way professionals had traditionally worked; although this approach of partnership working across services is in alignment with the Commission on the Future Delivery of Public Services (Scottish Government 2011)which identifies that it is only by increasing partnership working that public services can hope to meet the growing needs of the populations that they serve.

2.1.1 The Named Person Service

A key development within GIRFEC has been the creation of the Named Person Service, where health boards have a responsibility for providing a Named Person Service for babies and children who are under school age, whilst local authorities and private education establishments have responsibility for providing a Named Person Service for school aged children and young people, including those up to

18 years who are not attending school. At the time of writing, the expectation was that, in most cases, the Named Person for babies and preschool children would be the baby's or child's health visitor; and for school aged children it would be a senior member of teaching staff within the school where the child attended.

It was acknowledged that the application of GIRFEC would have a direct impact on all health professionals' practice, including those who were delivering adult services, but particularly on health visitors' practice. Although it could be argued that the roles and responsibilities of a health visitor, as the Named Person, were to be very similar to any previous role, it was recognised that there were some differences including the structures and tools available for them to use for assessment, analysis and planning. Getting to know families and building relationships with them in order that health visitors can safeguard, support and promote the wellbeing of all babies and children in their caseload was very similar to their current and previous roles; however the assessment and analysis process was to be more structured, through observation and discussion with parents and carers and the application of the GIRFEC National Practice Model as a framework – which was a new development(Scottish Government 2013).

2.1.2 The GIRFEC National Practice Model

The GIRFEC National Practice Model has a number of components which make up the model:

- The 8 Wellbeing Indicators –can be used initially as a check list on which to base observation and discussion and can then be used to judge if a full assessment is required; whether to progress to using My World Triangle, and perhaps other assessment tools, or not.
Then, if a full assessment is required, no matter how many other people are involved in the process, the wellbeing indicators can be used again to support planning processes (Scottish Government 2014).
- My World Triangle – is an ecological model which places the child at the centre of their own world and can be used as an assessment tool. It is

recognised that all the interactions that children have with those who support them and their environment is dynamic, which is in a state of flux as they grow and develop. It has been developed from the theoretical framework designed by Bronfenbrenner cited in Cleaver et al's publication (2011).

- The Resilience Matrix is based on resilience theory, and designed by Daniel, Wassell and Gilligan (2010) to support professionals to assess the impact of a range of factors on a child's life through balancing the strengths and pressures. It can also be used as a tool to support prioritising and planning.

In its totality, and together with other tools such as the National Risk Framework (The Scottish Government 2012), the whole of the GIRFEC National Practice Model can be used as a common assessment tool by every agency. Its use has the advantages of generating a common language across agencies and professionals. It can be used to capture routine information which health visitors and others collect about families and a baby or child's situation, and it can also be used to record changes over time in the baby's, child's, or young person's life.

In most cases where additional help is required to support a baby or a preschool child it will be the health visitor, as Named Person, who will co-ordinate the decision making and planning processes; unless a baby or child's safety is at risk or their health needs are complex – in which case a social worker, with statutory responsibilities around Child Protection, or a paediatrician could be leading the multi-agency or multi-disciplinary planning processes. In either of these examples, the health visitor would still to be the Named Person and be involved in supporting the planning and review processes.

As the Healthcare Quality Strategy for NHS Scotland (Scottish Government 2010) indicates that all health service delivery should be person-centred, decision making and planning at every level of these processes would be expected to be in collaboration with parents - if it is safe for the baby or child to do so and where

it is clear that the parents have the capacity and capability to give the baby or child's interests priority in their lives.

2.2 The Healthcare Quality Strategy for NHS Scotland (2010)

The Healthcare Quality Strategy for NHS Scotland (2010) (The Quality Strategy) is based on six dimensions of healthcare quality (Institute of Medicine 2014) with a particular focus on three quality ambitions (safe, effective and person-centred). The Quality Strategy (2010) identifies that delivery of a health service should be based on '*mutuality and partnerships*' with patients in relation to planning treatments (including shared decision making), and also '*improved partnership working*' with social care and the voluntary sector. The next section will focus on what else is identified about person centred care within the publication – as this is a 'quality ambition' which has most significance to the research question.

2.2.1 Person-centred care

The Quality Strategy (2010) is clear that there will only be consistency in the delivery of person-centred care if the environment supports a compassionate approach to every patient every time. It claims that this can only really be achieved if compassionate care is the cultural norm within an organisation, if services always respond to patients' needs, and if the quality of the service never disadvantages anyone, particularly those with protected characteristics identified in the Equality Act (2010). McCormack and McCance's (2006) literature review also identifies the important contribution that the environment and organisational culture makes to this ambition. According to The Quality Strategy (2010), consistency in person centred care with patients requires '*ambitious leadership, strong professional values and robust and effective governance*'.

The Quality Strategy (2010) indicates that there is a need for robust research evidence into what factors support person centred care, and that there are mechanisms in place to measure patients' experience and outcomes. It claims that there should be a particular focus on acquiring feedback about experiences of services from those who have complex health and social issues or long-term conditions. This has been the focus of researchers such as Dewar (Dewar and Mackay 2010; Dewar and Nolan 2013) who has focused on the care of elderly patients and involved them in the research process, and also by Law and McCann (2011) who identified, through feedback from health professionals, challenges associated with providing family centred care to families who were caring for a child with complex health needs.

The use of tools to measure the extent that person centred care has been delivered can provide useful feedback in relation to performance and can enable improvement measures to be put in place. The Health Foundation have published *Helping Measure Person-centred Care* (2014) which provides a range of tools that can be implemented in this way in addition to the Caring Dimensions Inventory.

NHS Scotland's commitment to the delivery of person centred care is evidenced through the development of the Health Improvement Scotland Person Centred Health and Care Collaborative (Health Improvement Scotland 2014) which, over the last year, has supported improvements in practice through training representatives from across Scotland in how to use the Model for Improvement (Langley et al 2009). These participants were encouraged to network and use technology and social media to share what they have learnt in their workplace when implementing changes. The Health Improvement Scotland Person Centred Health and Care Collaborative website links to a range of improvements which have taken place across health services, and health and social care partnerships.

Further examples are evident within a number of articles in journals which have focused on supporting improvement in the quality of interpersonal relationships and how to approach activities such as creating person centred care plans through reflecting on the use of language within the plan(Butterworth 2012).

2.3 Summary

It is clear, if information from both of these documents is taken together, that health visitors are expected to work in partnership with parents and in a mutual way when making decisions in order to improve the wellbeing of babies and children in the context of implementing GIRFEC. However, as already indicated, very little is known and understood about this area of health visiting practice, which is required if improvements in practice are to take place. Chapter 3 is an account of a review of literature which took place in an effort to understand this context and in order to support the development of a research question.

Chapter 3 – Review of the Literature

To get a wider perspective of the range of literature available, time was spent scoping how *mutuality* and *partnership*, as identified in The Quality Strategy (2010), were reported in current literature. A scoping approach, as identified by Arksey and O'Malley (2005), was implemented because it is described as a type of rapid review, which can be useful for mapping when the range of accessible literature is unknown, which was the case in this situation.

As understanding grew scoping was broadened to include the terms *relationship*, *collaboration*, *participation*, *involvement*, *empowerment*, *person-centred care*, and *patient centred care*. This process generated a wealth of literature from across a range of health, social care and education disciplines; however due to the requirement that the study focused on health visiting practice a decision was made to start by only mapping literature from within *nursing*, *children* (specifically *paediatric care*), and *health visiting* in order to establish what was available.

Although this was not a systematic review it was still apparent that cross cutting themes arose in the literature, relevant to health visiting practice. For instance the construct *self-efficacy* is referred to frequently across nursing literature when focusing on vulnerable groups (Swanson et al 2012; Hamilton 2004) and is also one of the key theories used within the Family Nurse Partnership Programme (Scottish Government 2013), a programme repeatedly arising under searches related to '*partnership*'. *Reciprocal relationships* was identified within the concept of psychodynamic nursing (McNaughton 2005; D'Antonio et al 2014) and linked with other literature identifying the emotional labour required by nurses when managing interpersonal relationships with patients (Mann 2005). Health visiting literature generated studies focusing on the value of the development of *interpersonal relationships* – including the concept of '*partnership*' when working with parents as featured in Bidmead & Cowley's work (2005).

It was also noted within this scoping exercise that there were many references to *shared decision making* providing evidence of effective practice when working in *partnership* during decision making (Siminoff and Step 2005; Montori et al 2006). However shared decision making, as a specific approach, was not described in any health visiting literature; and as there was the potential that this approach may have something to offer health visiting practice, and inform a research question, a review of literature, specifically examining 'shared decision making', was therefore undertaken.

3.1 Search strategy

In order to determine ways in which 'shared decision making' has been used in health literature a search was conducted using the term 'shared decision making' in titles and key words of articles. Databases included the OVID databases Medline and PubMed; EMBASE databases including CINAHL and the Nursing Reference Centre; and the Cochrane Library. This process generated 138 articles, of which 51 were direct accounts of research studies where some element of 'shared decision making' had been tested within the health service either by asking for patients' views, clinicians' views post training or decision making tools were being tested. Within the research studies it was noticeable how the frequency of publications has increased over the last 2 - 3 years from 1 or 2 research articles each year in the early 2000s to 7 – 8 articles each year in the last 3 years. Of the 51 studies 26 used a qualitative approach, 23 used a quantitative approach and 2 used a mixed methods approach. 24 were generated from within the hospital setting, 24 were generated from within primary care or the community setting and the remaining 3 were generated through a government department or university sources. The care groups who were investigated included patients attending breast oncology clinics (7 studies), paediatric clinics (4 studies), child mental health clinics (2 studies), adult mental

health clinics (6 studies), GP clinics for chronic medical conditions (11 studies), asthma clinics (2 studies) and from a community nursing setting (1 study). The remainder were a selection of students, GPs and surgeons testing out 'shared decision making' tools, processes or models (18 studies). As a result of scrutinising these research studies, by reviewing other relevant literature, including Edwards' and Elwyn's publication *Shared Decision Making in Health Care* (2009), by reading historical publications such as Maples' *Shared Decision Making* (1977), and then with the support of the software NVivo 10 (which was used as a data management system to support analysis of the literature) nine themes emerged which were discussed and debated throughout the literature.

These were:

- An historical reference to shared decision making
- How shared decision making has been defined
- The politics, ethics and values associated with shared decision making
- The links between relationships, communication and shared decision making
- Information transfer and the role of decision aids
- Training in using a shared decision making approach
- Facilitators and barriers to shared decision making
- The experiences of using shared decision making
- Ways in which shared decision making has been used within children's and young people's services

3.2 Historical reference to Shared Decision Making

Many of the papers provided a brief overview of how the concept of shared decision making (SDM) has developed and is linked it to the cultural context of the time. In the 1970s decision-making within organisations was generally the sole responsibility of those in senior management positions, and within these hierarchies the norm was not to ask lower ranked staff for their opinions. In fact within the context of organisations, such as within a prison, the suggestion of the

officer in charge 'sharing decision making' with other prison officers, was viewed as a risk to the integrity of the service (Murton 1976). For school teachers to have a voice within the running of schools at this time was also unusual (Weiss 1993).

According to Maple's (1977) work 'shared decision making' was defined as a process which incorporated a structured encounter where one person (the helper) supports another person (the help seeker) to identify a goal, identify the path which leads to the goal, and then to create a plan of action which will meet the goal. At the time of writing Maple worked as a social worker, and the examples used within the publication were in the context of children and families, where the 'helping relationships' took place predominantly with parents and teachers (but never the children). At this time in history 'paternalism' was the norm within professional encounters and within the health service the doctor's role was to diagnose the patient's condition, to decide what treatment the patient required, to fit them into a treatment plan and then to inform the patient of what they needed to do.

At the same time, optimum decision making was viewed in the main as a linear rational process (Siminoff and Step 2005). This normative approach assumed that the behaviour of consumers of services was aspiring to be purposive, logical, and goal directed. Probability techniques were used, including Bayesian or conjoint analysis. Although this approach is still recognised as being important to decision-making around diagnosis of medical conditions, and is valuable to a range of evidence based practice and scientific research, there is now recognition that this is not the only way that decisions are made within peoples' everyday lives. The behavioural decision-making theory, which was explained by Kahneman and Tversky (1981) and cited in Siminoff and Step (2005), identified that decision-makers do not always use normative models. This is due to variations in the context within which decisions take place, and variations in the

values that different people place on the choices and their outcomes. There are also imperfections in the understanding that different people have about the options available, which often take into consideration past experience and cognitive bias. Progress has continued to develop in this area of knowledge.

Over the last 20-30 years the culture within organisations and society in the United Kingdom has become less hierarchical and deferential, and human rights legislation has had an impact on employment law and how people are expected to treat each other at work(1998) This change in culture has also had an impact on local and national government legislation and policies, and how individuals expect to be treated within a democratic society, which in turn has had an impact on the services that individuals and communities expect from the health service and then within it how health professionals relate to patients. At a personal level, relationships have also changed and the expectation from society is that within partnerships and marriages each person has an equal right to expect dignity and respect from the other with neither partner having power over the other. This is supported by The Equality Act (2010).The nature of relationships has also changed within settings such as in schools, where children are now encouraged to have a voice through Pupil Councils, and in prisons, where all prison officers are expected to assess and manage risks. Within the health service there is an ambition towards a culture of shared governance within the workforce (Golanowski et al 2007)and 'shared decision making' with patients in relation to planned treatments and interventions (Edwards and Elwyn 2009).

3.3 How Shared Decision Making is defined

Initially, when the term 'shared decision making' came into common usage, there was a degree of clarity around how it was defined. However as the amount of discussion increased, debates around how to describe 'shared decision making' became more focused on the *process* of sharing decisions rather than on an

objective description (Charles et al 1997; Charavel et al 2001). Rather than concentrating on finding the words to define 'shared decision making', in order to create a shared understanding, there was a focus on viewing it as a philosophy with corresponding conceptual frameworks (The Lancet 2011). Consequently a number of models were created which could support the implementation of these processes into practice. This was also the point at which the term 'shared decision making' became predominantly used within the field of health, particularly within medicine; and until recently appears to have been dropped from current usage in other fields of practice where it had been used previously.

In its simplest form, Charles describes her concept of 'shared decision making' as a model which falls between two extremes (Charles et al 1997): between 'paternalism' (physician-directed) on the one hand – where the professional traditionally takes the lead and recommends the treatment - and 'consumerism' (patient-directed) on the other hand – where the physician is used as a resource for information to enable the patient to make their decision about which treatment they would prefer without necessarily considering the physician's views. Charles described the four characteristics that she would expect to be in place as a minimum in a 'shared decision making' encounter (Charles et al 1999):

- both the physician and patient are involved in the treatment decision-making process
- both the physician and patient share information with each other
- both the physician and patient take steps to participate in the decision-making process by expressing treatment preferences
- a treatment decision is made and both the physician and patient agree on the treatment to implement

Montori et al (2006) suggested that this model has its place within the hospital context where major choices are required 'here and now' but has made some recommendations about other factors which should also be considered when applying the model within community or primary care settings and particularly

where a patient has a chronic medical condition. These factors include considering the long term relationship of the patient not only with the doctor but with the whole primary care team, and also considering that there are often opportunities to revisit decisions and amend care plans to suit the changing context.

Elwyn et al. (2012) also proposed a three point model for 'shared decision making' based on 'choice, option and decision talk'. The model has three steps:

- introducing choice
- describing options - often by integrating the use of patient decision support
- helping patients explore preferences and make decisions

According to Elwyn et al. this model rests on supporting a process of deliberation, and on understanding that decisions should be influenced by exploring and respecting 'what matters most' to patients as individuals, and that this exploration in turn depends on the patient developing informed preferences.

As there was a general move from a descriptive definition of 'shared decision making' to a more deliberative conceptual model within the literature it also appeared to become more aspirational (Montori et al 2006). A number of criticisms were voiced about how 'shared decision making' was being portrayed, based on an unrealistic premise where patients require the ability to fully understand the technical information about the choices available and an ability to apply it to the context of their lives. There was a perception that for 'shared decision making' to be achieved both patients and physicians would need to have the ability to be partners in the process and to be able to participate in all phases, including information exchange, deliberation, and decision making, in an exceptional way.

Gafni et al. (1998) was aware of this aspirational viewpoint and chose to describe 'shared decision making' as taking place across a spectrum of reality. Gafni et al. identified that the optimum situation is when the physician is the 'perfect agent' and the consumer is 'truly informed'. Gafni et al. claimed that in fact physicians can only act as 'perfect agents' if they are fully aware of the patient's values, preferences, opinions and goals and can combine these with sufficient clinical knowledge. The consumer can then only make a 'truly informed' choice if they have sufficient clinical knowledge and the ability to combine this with their values, preferences and goals; the implication is that no individuals are able to be in a position where they hold the experience of the other, but rather that they are both having to partially contribute to a decision with partial knowledge. In other words, perfect 'shared decision making' is a theoretical construct. It was within this context that Legere et al (2010) embarked on a Cochrane review in relation to identifying interventions which improve the adoption of 'shared decision making' by healthcare professionals. Within the report they express their experience of being faced with the challenge of no clear definition of 'shared decision making', and frameworks being open to different interpretations, which created challenges when determining which studies to include within their review.

A new situation has arisen over the last few years which has the potential to add to the debate around a definition of 'shared decision making' and this has arisen because health services across the world are being scrutinised by populations and politicians against the six quality ambitions, or standards, as mentioned in Chapter 2 (Institute of Medicine 2014). Although these standards were initially aligned to medical services, they are now being expected from all health care delivery, and these standards are being included within national government policies across the world including in Scotland (Scottish Government 2010). As human rights legislation focuses on the rights of people's voices to be heard, the

concept of 'shared decision making' is viewed as an integral part of delivering patient (or person) centred care.

As politicians' and people's aspirations become focused on ideals and an ambition to change cultural norms within society, definitions of 'shared decision making' are starting to emerge on websites and in policy documents; and professionals, service users and politicians are adopting the language of 'shared decision making' alongside other ambitions for high quality health care. 'Shared decision making' is now being discussed within health professional practice and related to patient-centred care rather than only being discussed as a theoretical construct within the academic world (Coulter and Collins 2011). However, even with this change in culture taking place there is still a lack of consistency in how 'shared decision making' is currently perceived, and this lack of clarity is blamed for its low implementation in practice. Da Silva et al (2012) describe this as a 'mismatch between policy rhetoric and practice' and as an example of basic misunderstanding quotes health professionals defining 'shared decision making' as *'allowing patients to comment on the decisions that the clinician is making'*. Whether this confusion has occurred because the cultural norm is still for health professionals to take the lead in clinical decision-making is not clear, but the suggestion that it is due to professionals not having the skills to involve patients as equal partners in care is also expressed. Perhaps this misunderstanding is due to organisational systems not supporting 'shared decision-making' processes, or politicians being selective around which aspect of 'shared decision making' they focus on?

Some of these thoughts will be addressed within the next sections but in the meantime a useful working definition of 'shared decision making', which takes a pragmatic view, is:

"a collaborative process based on patients and providers considering options using the best available evidence and arriving at a choice which aligns with the patient's needs, preferences and values around social and cultural norms".

(Hain and Sandy 2013).

3.4 Politics, ethics and values related to Shared Decision Making

One of the criticisms of the Department of Health's publication *'Liberating the NHS: No decision about me, without me'* is that it is focussed on 'choice' rather than the new kind of partnership which is needed between professionals and patients in order to create a culture of 'shared decision making' (NHS Commissioning Policy 2012). Patients making choices without professional discussion and debate is 'consumerism' according to Charles et al (1999) and will not deliver good health outcomes for patients. Another criticism of how 'shared decision making' is being conveyed by governments is when it is described as a cost cutting measure (Hain and Sandy 2013). Two quotations from Renz et al's (2013) research study identify how some members of Medical Boards assume that 'shared decision making' will cost less:

'Our board has set a strategic goal of lowering total cost of care compared to market. Some [of the savings] will come from shared decision making'

and

'Shared decision making is consistent with our values of providing lower cost care and better quality care - it's the right thing to do for patients'

In order to accurately establish the impact of implementing 'shared decision making' into practice, the Health Foundation(2014),an independent charity, is sponsoring several projects which aim to make 'self-management support' the

norm for people with long term conditions. It is exploring how 'shared decision making' can be embedded into mainstream clinical practice.

Despite the challenges that are being faced currently around ways in which 'shared decision making' has been interpreted by politicians, one of the reasons why it is such an appealing concept to many is that it creates consistency with the language which is used when aspiring to provide high quality service delivery. It appears to be the most ethical and moral way to deliver high quality care. Saba et al (2006) promote 'shared decision making' as an ideal and ethical model for patient-physician communication and Dolan (2008) claims that it is fundamental to providing truly patient-centred care. All who met at the Salzburg Global Seminar (2011) agreed that 'shared decision making' is still a philosophy as well as a 'way of doing things' and central to this philosophy is the belief that patients have a vital role in decision making processes, and that their values and self-determination should be considered equal alongside scientific knowledge.

Although, to go back to Gafni et al (1998) cited in Charavel (2001), they pointed out that even if transfer of information from physician to the patient is feasible, transfer of the patient's preferences and values to the physician is more complicated and, even if possible, has the potential to be very time consuming.

Challenges which are identified within the literature, which also have the potential of creating a negative impact on 'shared decision making' in practice, are the forces at play in relation to clinical practice guidelines, which frequently need to be applied, coupled with quality audits of processes and outcomes which also need to be completed to meet government targets (Montori et al 2006). The challenge is that practitioners may be torn between meeting the needs of the patient or the desires of the system.

There are also other ethical and moral challenges related to patients making decisions about their treatments which have been identified in literature; for

example patients deciding not to take antipsychotic medication, or deciding not to take treatment for an infectious disease, both of which could have a negative impact on the health of others around them. Many would say that a crucial part of implementing 'shared decision making', and in so doing circumventing some of these challenges, is by focusing on the establishment of partnerships between the patient and the professional. The importance of establishing partnerships is reinforced within current literature within the next section.

3.5 Communication and relationships within Shared Decision Making encounters

Siminoff et al (2005) consider relationship building as a crucial part of the decision making process as, in their experience, patients are all different and it is the only way to be able to engage with the patient and to provide a service which suits them; particularly within the current context where there are more and more choices being generated for patients. They describe relationship building as the '*vehicle required for decision making*' and a fundamental way of improving the patient's experience. Siminoff et al's (2005) work, within the context of cancer treatment, describes the doctor-patient relationship as a socio-communicative process which involves entering into a relationship, exchanging information, establishing preferences, and then choosing a course of action. With this in mind, they developed a Communication Model of Shared Decision Making (CMSDM) which is based on four assumptions from health communication theory:

- that the interaction is transactional between at least two people
- that people send both verbal and non-verbal messages to each other
- that the physician is the person who sets the communication climate
- that the patient is able to express how they feel and put their views forward

According to Simonoff et al (2005) the three factors of the Communication Model of Shared Decision Making are:

- Patient-physician antecedents
- Communication climate
- Decision processes

Patient-physician antecedents - or the pre-existing factors which have the potential to influence the communication - are described as:

- Socio-demographic characteristics – such as social strata, ethnicity, age, and gender
- Personality traits – such as introvert/extrovert; past experience; capacity to engage
- Communication competence—such as an ability to understand and express their views

Siminoff et al (2005) claim that patients' preferences for participation in decision-making processes vary widely but that there is some knowledge around tendencies, with those with more disease severity, older patients, less well educated and male patients being more inclined to take a passive role - although this is in no way absolute.

When Montori et al (2006) discuss the Charles et al (1999) model and identify ways in which it needs to be modified, in the context of managing chronic medical conditions, they identify that one of the advantages of supporting patients in primary care is that there is the opportunity to build a relationship which can become stronger over time as patient, doctor and the team work together.

Hain and Sandy (2013), from within a community setting, also identify that collaboration amongst patients, families, and healthcare professionals is key to implementing 'shared decision making' and Truglio- Londrigan (2013) reinforce this experience - as within her research study, which took place within the field of community nursing, the 'shared decision making' approach often involved inter-disciplinary and intra-professional workers work alongside voluntary and third sector agencies to ensure patient-centred care.

A number of authors refer specifically to the need for 'partnerships' in order to establish 'shared decision making' - as opposed to just good relationships - but with the quality of the relationships being a pre-requisite to establishing partnerships.

According to Chan and Mak (2012) partnership provides the framework for open negotiation and discussion about decision options and preferences. According to Siminoff (2005), partnership creates the freedom for each party to contribute information and preferences in order to arrive at the best possible outcome for that particular patient and it accepts deviation from 'rational' decision making and the multiple roles and behaviours which are likely in these interactions. According to Montori et al (2006) partnership also supports clinicians being able to express their values and preferences explicitly to the patient, and why they hold these views, which enables the patient to make sense of what is relevant to their situation. One way of clinicians communicating openly to patients about their views, according to Brody (2007), is to assume the habit of thinking out loud about the diagnosis, the options, what option is recommended and why, and inviting the patient to engage in the conversation. Brody describes this as the Transparency Model.

Hain and Sandy (2013) argue that the ability to engage in partnership requires mentoring opportunities for the professional in order that they develop insight and interpersonal skills in order to increase their skills and confidence in caring for patients who are fully engaged participants. According to Hook (2006), cited in Hain and Sandy, an environment where individuals engage in a trusting, honest, and open dialogue relies on the encouragement of reciprocity and empathy which in turn relies on the professional's ability to self-reflect and self-regulate.

Containment, reciprocity-in-action and empathy can improve patients' feelings of self-efficacy - which will increase the likelihood of them being able to express

their views where decisions are indicated - this is particularly true where children are involved in discussions which will have an impact on their care.

Hain and Sandy (2013) identify that for partnerships to be effective, professionals, patients and families need to clearly understand their roles, what this means to them, and how to become active contributors. Siminoff and Step (2005) also identify that a key area of practice, which each participant needs to understand, relates to information sharing. In their study, within the field of breast oncology, how information sharing was managed right at the beginning of the development of the relationship determined the degree of partnership which developed over the time of the care. The use of decision aids and information exchange were key themes to supporting relationships within these research studies and are explored within the next section.

3.6 Information transfer and the use of decision aids in the Shared Decision Making encounter

Transfer of information, values and preferences between patients and health professionals is challenging. A consistent theme in the 51 research studies is that some patients want more information than they get, whereas some are happy with what they get already.

Deirckx et al (2013) consider it important that the health professional identifies not only whether patients want more information but the medium of information, whether literature, websites, DVDs, audio recordings or a spoken explanation. Loh et al (2007) identify that lack of information from health professionals, when sought by patients, is the reason that many patients are reluctant to engage consistently in their treatment. In Loh et al's work some specific groups of patients identified that they wanted more information; for instance, depressed patients had a greater interest in treatment decisions. According to Da Silva (2012) finding out the needs of patients in terms of their desire to be informed will

take a shift in the thinking of many current health professionals who still expect to be the holders of knowledge.

Of the 51 research studies examined, seven specifically mentioned the use of decision aids as a means for facilitating information transfer and supporting decision making. Although decision aids are not available to support decision making in relation to every condition which may present within the UK health service, it is of significance that the most common areas of practice where they are available for use are reflected in the conditions within the research studies. This is most likely to be because specialist areas, which are showing an interest in implementing 'shared decision making', are also creating suitable decision aids to support practice. Drake et al's (2010) experience of attending the Center for Shared Decision Making in New Hampshire USA, where decision aids are offered to all patients, is acknowledged as being exceptional according to King and Moulton (2006); however they claim that creating decision aids for every part of the American healthcare system would be a 'gargantuan task'.

According to Simmons et al (2010) decision aids demonstrated an ability to increase patients' knowledge, reduce decisional conflict, and reduce the proportion of patients who were passive in the decision-making process or remained undecided within psychiatric services. Coyne et al's (2013) review identified that from within 25 new studies there was indication that decision aids improved knowledge and created realistic expectations, enhanced active participation in decision-making, lowered decisional conflict, decreased the proportion of people remaining undecided, and improved agreement between values and choices.

Despite clear evidence in favour of their use in Davis' (2003) study, the GPs did not always use the decision aids that were available in practice. Elwyn et al (2013) suggest that the reason may be more than a reluctance to use the decision

aids and more likely to be a resistance to engage in 'shared decision making'.

They identify that research studies demonstrate that innovations are more likely to be adopted if they create an advantage to the clinician and, from Elwyn's research experience, trying to fit 'shared decision-making' into existing workflows is a challenge (even if they don't conflict with existing priorities, targets and incentives) because asking clinicians to portray options, to support patients to weigh pros and cons and engage their families in a decision making process is more demanding than making a positive recommendation for treatment.

Consequently, it is her view that failure to use the resources is more about the challenge of implementing 'shared decision making' than using decision aids.

This is consistent with other research which identifies that if there is a commitment to using a 'shared decision making' approach in the first instance, decision aids are seen as supporting to the process – a resource which enhances the partnership approach and supplements the exchange of information.

However, if there is not an initial commitment to the approach, decision aids are highly likely to be ignored or used reluctantly (Hain and Sandy 2013).

This information on the use of decision aids has significance for implementing 'shared decision making' in practice and is consistent with the belief that specialist training is required to enable 'shared decision making' to be implemented in practice in a way which is congruent with the philosophy and creates a partnership approach for the benefit of the patient (Hain and Sandy 2013).

3.7 Training in Shared Decision Making for health professionals

Da Silva (2012) states that the only way to increase the amount of 'shared decision making' in practice is to increase the amount of training opportunities that there are for health professionals.

According to Matthias et al (2013), as 'shared decision making' always takes place within a context, the focus of any training programme should be on teaching skills in fostering open, trusting relationships and challenging professionals' attitudes where they don't accept that patients and professionals should have a more equal role in decisions about care. This is consistent with Hain and Sandy's (2013) work who propose that the skills required range from technical communication and interpersonal skills to more fundamental changes in attitudes about the relative roles and expertise of patients and professionals. Matthias recommends teaching 'The Four Habits Approach to Effective Clinical Communication' to support training in 'shared decision making', and they are identified in Table 1.

TABLE 1 THE FOUR HABITS APPROACH TO EFFECTIVE CLINICAL COMMUNICATION

Habit	Behaviours
Habit 1:	Invest in the beginning Communication behaviours Create rapport quickly Elicit full spectrum of patient concerns Plan the visit with the patient
Habit 2:	Elicit the patient's perspective
Habit 3:	Demonstrate empathy Assess patient attribution Identify patient requests Explore impact of symptoms on patient's life Respond to patients' emotions Discern empathic opportunities Express empathy verbally and nonverbally
Habit 4:	Invest in the end Deliver diagnostic information Provide education Engage in shared decision-making Close the visit (ask for additional questions, confirm next steps, end on a personal note)

Kassam et al (2006) identify eight competencies along similar lines, and Col et al (2011) propose five areas of knowledge and skills which are essential for 'shared decision making' to be successful within inter-professional teams, which are:

- understanding the concept of 'shared decision making'
- acquiring relevant communication skills to facilitate 'shared decision making'
- understanding inter-professional sensitivities
- understanding the roles of different professions within the relevant primary care group and
- acquiring relevant skills to implement 'shared decision making'

According to Allaire et al (2012) the approach to training should always use principles from adult learning, which is interactive and accessible, and includes teaching in the use of decision support tools.

In 2005 Elwyn created the OPTIONS tool to quantitatively measure the extent to which shared decision making had taken place within an encounter, after the event, in order to be able to support teaching, learning and improvements in practice (Weiss and Peters 2008).

3.8 Facilitators and Barriers to Shared Decision Making

Research studies identify that there are a number of key facilitators to implementing 'shared decision making' in practice. Many of these have been identified previously, such as partnership building enhanced through effective communication, professional insight (Hamann et al 2012), a positive approach to the clinical process and a positive approach to patient outcomes (Col et al 2011).

Training in 'shared decision making' plays a significant role in impacting on practice (Charles et al 2004). Multimedia programmes, brochures, question prompt lists and decision aids, visual aids, and patient information booklets were all seen as facilitators in Upton's research study (Upton et al 2011).

Some research studies identify the supportive roles that nurses create in preparing patients for decision making discussions with doctors through building relationships with them (Frank 2009). On the one hand this is evidence of the valuable role that the team may be able to make in supporting decision making processes; whereas on the other hand it may be pursuing a traditional hierarchical view of roles in practice.

Despite the range of factors which support 'shared decision making' in practice, there are a number of key barriers to implementing 'shared decision making' in practice which are identified within the research studies. They are differentiated here into barriers in relation to the system, the health professional (frequently identified as the physician within the original publications) and the patient or client.

'System barriers' include 'time pressures' according to a number of authors (Bélanger et al 2011; Renz et al 2013; Upton et al 2011); however in Duncan et al's (2010) review of two research study interventions to increase 'shared decision making' in mental health care there was no increase in consultation times noted and it was also suggested within Upton's (2011) work that time was not a barrier to 'shared decision making' as in general practice patients can be easily invited to attend another appointment. There is evidence from Renz et al's (2013) study that competing priorities created barriers to 'shared decision making', and this included the introduction of the quality outcome framework (QOF) into primary care practice - which provides financial incentives to general practitioners for the performance of key tasks. The need to delay decisions to follow default patterns of care has been identified by Belanger et al (2011); and lack of evidence that 'shared decision making' translates into improved patient outcomes is seen as a barrier to implementation by health professionals according to Upton et al (2011).

'Health professional barriers' include lack of training (Towle et al 2006), different understandings around what 'shared decision making' is, and lack of self-efficacy and familiarity with 'shared decision making' (Upton et al 2011). Also health professionals having insufficient information to make a decision about treatment at the first consultation, cultural differences between the patient and the health professional and difficulty knowing how to frame the treatment options for the patient in a way that they understand were all identified as barriers (Towle et al 2006; Bélanger et al 2011).

'Patient/client barriers' to implementing 'shared decision making' in Charles et al's (2004) research includes the patient/ client having received conflicting recommendations from various specialists, having misconceptions about the disease or treatment, being too anxious to listen to what the health professional has to say, not understanding the information which is provided, having difficulty accepting the diagnosis, having other health problems alongside the current diagnosis, bringing too much information to discuss in the consultation, wanting to make a decision before receiving all the information, requesting a treatment not known to be beneficial and refusing a treatment that may benefit them. Belanger et al (2011) have also identified challenges associated with patients wanting to participate more in deciding on their treatment than the physician would like them to and patients' families overriding the decision-making process and having unrealistic expectations.

3.9 How health professionals and patients experience Shared Decision Making

Truglio-Londrigan (2013) identifies that few studies describe the experiences of 'shared decision making' from a nurses perspective; however what seems to be clear from scrutinising current literature is that very few studies have identified any health professional or patient/client experiences of 'shared decision making'

and according to Saba et al (2006) the literature which exists reveals inconsistent findings.

In Bainbridge et al's (2006) study, which focused on patients receiving care from physiotherapists, they felt 'listened to'. In Beiber et al's study (2006), where fibromyalgia syndrome patients were randomly divided into two groups, the ones provided with 'shared decision making' interventions showed more satisfaction with decisions than the comparison group patients who were provided with information only.

Although there is knowledge that patients who actively participate in end of life decisions often have positive experiences through the latter stages of their life, there is no clarity about whether following some of the models of 'shared decision making' (compared to building up close relationships with those providing care) created any advantage (Frank 2009).

In Towle et al's (2006) study, all the physicians valued the Informed Shared Decision Making model and thought that they (and other physicians) had put it into practice; however, the evidence from the transcripts indicated that their practice in 'shared decision making' was limited.

The findings in Thorne et al's (2013)'s study focuses on the diverse ways that cancer patients experience 'shared decision-making'; which was on a range.

Charles et al. cited in Peek et al (2008) has acknowledged the potential for different patient perceptions about 'shared decision making' and has called for research exploring the sociocultural and illness contexts in which patients understand and experience 'shared decision-making'. Caldon et al (2011) identified how concerned health professionals were about patients being overwhelmed by the content in a specific Decision Aid which was being tested – but apart from these examples the research evidence is very limited at present

both in relation to health professionals' and to patient/client's experiences of 'shared decision making' in practice.

3.10 The use of Shared Decision Making within paediatric practice

Within this review of the literature, six studies were identified where shared decision making was related to paediatric practice. It was evident that there are a number of paediatricians and child psychiatrists who are supportive of using shared decision making in practice on the basis of their findings in research studies. Butz et al (2007) is an example of a paediatrician who sees this approach as a positive experience for children and their parents when addressing asthma, as according to their study it enhances the self-confidence of the child, it supports parents to encourage the child to manage their own condition and promotes paediatricians to display positive role model behaviours.

Fiks et al, within the field of child psychiatry, promotes this approach with parents, children and young people as they claim it increases partnership working within an area of practice where historically there has been a degree of mistrust of the psychiatrist by the parent; Fiks et al have completed a number of research studies using qualitative approaches (Fiks and Noonan 2013; Fiks et al 2012; Fiks et al 2011a; Fiks et al 2011b)

In one study 30 clinicians were interviewed using semi structured interviews to gather their views about using 'shared decision making' in practice with parents of children with Attention Deficit Hyperactivity Disorder (ADHD), before then interviewing 60 parents of children between the ages of 6 and 12 years with ADHD. The data analysis from the transcriptions used a modified grounded theory approach. Themes identified included 1) parents and clinicians conceptualising ADHD differently from each other 2) barriers to 'shared decision making' from the clinician's perspective, which included lack of available

evidence based options 3) 'shared decision making' extending beyond the parent/clinician dyad to include others within the parents' social group.

The findings indicated that some clinicians saw 'shared decision making' as a means of encouraging parents to accept what they wanted them to do, whereas the parents indicated that they mistrusted clinicians whom they perceived as biased.

Recommendations in this study included the need to improve the practice of the professionals through training, increased support within organisational policy, and accessible evidence treatments to be provided as options.

Fiks et al (2011a) reported on another study which used a 'free-listing' approach, in which parents and clinicians wrote down what came to mind when thinking about ADHD. The findings identified differences in perceptions of the impact of ADHD on the lives of those affected. Parents talked most about the impact of ADHD on family life, whilst clinicians were under the impression that the biggest impact would be on the child's learning, education and time at school. This was an example of differences in understanding which Fik et al argue could lead to differences in understanding and priorities when making decisions about treatments.

Merenstein et al (2005) conducted a quantitative study, which was interesting despite its complex design. The study sample was parents of children with acute otitis media who were randomly divided into three groups. The aim was to identify whether providing these parents with a vignette, where a 2 ½ year old child had an acute ear infection, but where the fictitious parents were treated differently, at the same time that their child was unwell, would have an impact on each parent's view as to whether antibiotics should be prescribed for their child. One group of parents were given a scenario where the fictitious parents received a paternalistic approach, the other two received scenarios which described various degrees of

'shared decision making'. The findings were that those in the most paternalistic groups were significantly more likely to expect antibiotics for their child (4.9% more) than those in the 'shared decision making' groups; and those who were provided with a description of an encounter where shared decision making was practiced predicted that they would be significantly more satisfied with the encounter.

An assumption of this study is that the parents' beliefs would remain the same whether applied to their own child or the one in the vignette.

The final study by Golnik et al(2012)describes a quantitative study with parents of children with autism who were surveyed. Indications were that there was higher satisfaction with care and treatment choices offered where a 'shared decision making' approach was adopted, although there was no evidence of improvements in outcomes.

3.11 Summary

In summary, it is evident within the literature that shared decision making has developed over time and has been understood in different ways, ranging from a philosophical ideal, to a much more pragmatic model which can be used in practice. Academics working closely with those in practice (predominantly medical doctors) have created practical frameworks, check lists and decision aids to support using this approach in practice. Although currently there is limited evidence of improvements in health outcomes from using this approach, there is evidence that when shared decision making processes are used, the patients' experiences are more positive, and the approach used and the aspirations from the decision making are congruent with person centred care. Both shared decision making and person centred care rely on the development of a trusting relationship between the practitioner and the patient, with both parties having the ability to express their views on the issue, and the ability for the patient to be able

to identify what matters to them. For shared decision making to be effective it relies on the practitioner participating in appropriate training and strong supportive leadership within the organisation.

It was because there was a clear steer towards using a person centred approach when delivering care in health visitor practice, and an expectation that when implementing GIRFEC that health visitors will need to be able to demonstrate evidence of working in partnership with parents when planning, that literature around shared decision making was reviewed; however there was no evidence of shared decision making frameworks being used in health visitor practice and as a consequence the research question was developed.

What processes will support effective shared decision making when health visitors and parents are planning to improve the wellbeing of babies and children – within the context of implementing the Getting It Right For Every Child (GIRFEC) Policy Framework?

The next chapter outlines the aim and the objectives of the study, the methodological approach and the proposed research design.

Chapter 4 – Methodology, Research Design, and Methods

As indicated in Chapter 3 the term ‘shared decision making’ is understood in literature both as a philosophy as well as a process and it is also used to describe behaviours in practice, particularly amongst health professionals. Although shared decision making is promoted in Scottish Government guidance, there are no published research studies which focus on shared decision making within health visitor practice.

This chapter presents the aim and research objectives of this thesis and the research design which was created to generate understanding about the links between shared decision making and health visiting practice. It includes justification for the methodology and methods chosen to fulfil this ambition.

4.1 Aim

The overall aim of this study was to address the question:

What processes will support effective shared decision making when health visitors and parents are planning to improve the wellbeing of babies and children – within the context of implementing the Getting It Right For Every Child (GIRFEC) Policy Framework?

4.1.1 Research Objectives

To explore:

1. What is currently happening within health visitor/parent encounters when decision-making is taking place?
2. What are the perspectives of the health visitors and the parents after their encounters – in terms of their perceptions of the process and satisfaction with the final decision?

3. What evidence is there that decision-making is shared between the parents and the health visitors?

4.2 Research methodology

4.2.1 Background

This study started from a position where there was little published evidence available in relation to health visitors sharing decision making when planning interventions with parents, and there was also a lack of understanding about social structures, behaviours and cultures within this area of practice. According to Ritchie et al (2014) a lack of knowledge base lends itself to taking a qualitative approach as this approach can develop a basis to further understanding.

4.2.2 A qualitative approach

Seale (2012) provides a definition of a qualitative approach as being one which tries to use first hand familiarity with the topic to create hypotheses. Historically authors have defined a qualitative approach by what is expected from the study; identifying that an inductive, interpretivist, data driven study which captures the participants' perspectives defines a qualitative approach as opposed to a positivist approach which is more objective (Koch 1995; Morse and Field 1996; Thorne 1991). However more recent authors such as Silverman (2005), Ritchie et al (2014) and Seale (2012) focus more on the methods used and processes applied, and define a qualitative approach by features such as the nature of the relationship between the researcher and the participant, the nature of the social context and the extent of collaboration with participants. Silverman (2005) argues that determining whether or not a qualitative approach is used is related to how the issue has been framed and what methods are required to address the research question, rather than a philosophical standpoint, where a leaning towards unstructured or semi-structured interviews and focus groups is indicative

of a qualitative approach. There are many different qualitative approaches based on different world views; however within this study an exploratory, descriptive approach was taken, due to the lack of existing knowledge and understanding. It was also an inductive as opposed to a deductive approach, in which the purpose of the research study revolves around testing or confirming hypotheses when a substantial amount is known about the topic already.

4.2.3 An exploratory approach

Robson (2007) identifies three main approaches within qualitative studies: they are exploratory, explanatory or emancipatory. This study took an exploratory approach on the basis of the lack of pre-existing research evidence. Exploratory research has also been described as formulative research, and it is ideal for use as an approach where the problem is not clearly defined (Ritchie et al 2014).

There are warnings about the need for caution around drawing definitive conclusions using this approach; however it can be useful for determining whether an issue actually exists or not (Seale et al 2007). Exploratory research may not provide enough information to allow decision making to take place but it does provide enough insight into a situation to allow understanding around possible next steps. Data gathered using this approach can generate understanding about the meanings that people give to their situations and it can uncover what issues people are concerned about. The analysis process can support the creation of conceptual frameworks

4.2.4 A descriptive approach

Seale (2012) describes qualitative research studies as either 'naturalistic' – where the focus is on *what* is happening when little is known and where the outputs tend to be descriptive – or one of 'realism' which looks at *how* reality is constructed once evidence is available. These are terms which are frequently used within the discipline of psychology. This approach is also traditionally based

within the school of phenomenology which is the study of experience and consciousness (Flood 2010). This study is descriptive and there will be no assumptions regarding cause and effect. Nevertheless, according to Flick (2014) it is possible to make suggestions of conditions that may be having an impact from within descriptive work, which can then be tested at a later date.

The next part of this chapter focuses on the research design and the methods chosen to address the questions.

4.3 Research design

The study was conducted in three phases as follows:

4.3.1 Phase 1

Phase 1 was designed to address Objectives 1 and 2. As within the literature review no research evidence was identified which determined whether 'shared decision making' encounters are taking place or not when health visitors are planning with parents, a decision was made that the research design for this study would include audio recording health visitor/parent encounters during planning without the researcher being present.

4.3.1.1 Audio-recordings of decision-making encounters

This method of recording encounters is commonly used in decision making research where the natural interaction between participants is likely to be affected or changed by the intrusion of the researcher. The plan was to audio-record, transcribe and analyse the data to explore the interactions and decision-making processes used.

Before embarking on this part of Phase 1 it was acknowledged that this method has limitations. One of these is the documented impact of the Hawthorne effect where behaviours of participants are directly affected by being part of the study (Seale 2012). In order to minimise this risk the plan included ensuring that the

health visitor and parent knew each other well, the venue was familiar, as it would be for 'usual care', and that the digital recorder was small and, as much as possible, unobtrusive.

4.3.1.2 Questionnaire

Following the encounters each parent and health visitor involved in the planning meetings were to be asked to individually complete a standardised questionnaire, designed to identify their perceptions about the extent to which shared decision making had taken place. Elwyn's OPTIONS questionnaires were used (Elwyn et al 2013)– the one validated for use with clinicians (dyad ^{OPTION} clinician) was issued to each health visitor and the one validated for use with patients (dyad ^{OPTION} patient) was issued to each parent. (Appendices 10 and 11).

Although the questionnaire is validated as a measurement tool designed to generate quantitative data, in this case it was to be used to compare and contrast the findings from the analysis of each of the encounters from a stance of exploration and interpretation rather than to make judgements about whether shared decision making had been achieved or not (Weiss and Peters 2008).

Before embarking on this part of Phase 1 it was acknowledged that there are also limitations associated with questionnaires. In this context it could include participants wanting to create a different perception by, for instance, making the encounter look more meaningful than it really had been or by making it appear in a different light (either worse or better). The plan to mitigate this risk included ensuring that each participant did not see the other person's completed form, and that all individual responses would be aggregated and made anonymous.

4.3.2 Phase 2

Phase 2 was designed to address Objective 3. Semi structured interviews were conducted with health visitors and parents who had participated in planning

meetings where decisions had been made within the last 6 months, though not necessarily in relation to the same child. Semi-structured interviews were used in order to explore participants' experiences and perceptions of the processes and to identify the extent of shared decision making within the encounter, the degree of satisfaction with the final decisions, and what happened next. Development of the interview schedule was based on Elwyn's work on shared decision-making (Elwyn et al 2013) (Appendices 8 and 9).

4.3.2.1 Semi-structured interviews

The interviews in Phase 2 were designed to complement the Phase 1 encounters through parents and health visitors being asked to recall their experiences of decision –making events which had taken place within the last 6 months.

Doody and Slevin (2013) describe the process of interviewing in detail and explain the various purposes of unstructured, semi structured and structured schedules. They identify the importance of using a less structured schedule and incorporating open ended questions, which participants can answer easily and can respond to in their own words, when the researcher is interested in participant's lives and their experiences. A semi structured approach to interviewing was chosen for this study in order to incorporate questions which would inform if and how Elwyn's theoretical framework had been implemented - balanced with other questions which would provide insight into the experiences of the participant being interviewed.

Flick (2014) supports using a responsive interview style as a way of increasing its effectiveness, as this encourages the interviewer to build a relationship with the participant within the process, ensuring reciprocity within the interview, and discouraging confrontation in order to generate more of a willingness on the part of participants to express their views. Flick also describes the concept of 'talk as data' which is characterised by an open approach where participants are

encouraged to 'tell their story' or create narratives. In this context, narratives are defined as the informant telling 'how everything started', 'how things developed' and 'what became'. Flick identifies that it is possible for narratives to be incorporated into semi structured interviews, and this approach was therefore taken within this study when interviewing the parents in Phase 2.

According to McCann and Clark (2005), in addition to the data from the dialogue, interviews can also contribute to understanding the context as there is the opportunity for the researcher to view the person's body language when explaining a situation, and through being able to probe ideas it is also possible to get clarification if there is uncertainty.

McCann and Clark (2005) identify that interviews can be expensive, can be intrusive, and according to Seale (2007) some claim that interviews can be susceptible to bias with the participant saying what they feel the researcher wants to hear and the researcher not wanting to ask questions which may undermine the participant's confidence or self-esteem.

Al Yateem's (2012) study outlines ways in which the quality of audio recorded interviews can be improved with appropriate planning; for instance the importance of the questions, predominantly open with no leading questions and, as indicated for Phase 1, the use of a small recorder which can be unobtrusive, preparing interviewees and the room in advance and the interviewer knowing the interview schedule thoroughly before the event in order to create the feeling of a conversation. Building a relationship beforehand encourages honest responses, and aggregating data from a number of interviews and identifying common themes (rather than singling out any particular perspective) also improves quality.

4.3.3 Phase 3

Phase 3 was designed to address the principal research question. Once all data from Phase 1 and 2 had been anonymised and analysed, three health visitor focus groups were convened in order to review the findings. The aim was to generate ideas of ways in which practice could be improved when health visitors and parents are sharing decision-making in the specific context of planning for improving a baby or child's wellbeing when implementing GIRFEC.

4.3.3.1 Focus Groups

When designing the study and choosing the methods, focus groups were viewed as particularly valuable for this phase because, according to Hyde et al (2005a), participants are able to give each other ideas which can lead to a deeper understanding of what is being discussed. Within this context participants were being expected to project forward and consider the impact on practice of the implementation of GIRFEC - following enactment of the Children and Young People (Scotland) Act (2014) - therefore a collaborative approach was considered appropriate.

Although McLafferty (2004) claims that focus groups are not as strong at providing robust evidence as observation or interviews, it is still acknowledged that they can provide a rich understanding of each participant's knowledge and, according to Hyde et al (2005b), focus groups can also provide insight into the culture and evidence of how participants relate to each other. Focus groups are also recognised as being particularly valuable if used within a range of different methods focussing on the same research question. Other positive aspects of this method include claims that focus groups can be helpful at recruiting participants who may not feel confident about being interviewed on their own (Flick 2014). Ritchie et al (2014) identify that groups can self-regulate in terms of ensuring that extremes of views are likely to be challenged by other participants and that there

is the advantage of being able to cross check data from another source. Focus groups can create understanding around different perspectives on one question and how the differences of opinion interact, whether aligning or in direct opposition.

Various authors recommend a range of ideal numbers of participants within focus groups: this varies, with some recommending six to eight and some eight to twelve. While most advise not less than 4, McLafferty (2004) highlights the benefit of small numbers, stating that the smaller the number the deeper the conversation, that small groups are more manageable, and that if participants know each other they need less moderating.

Before embarking on Phase 3 it was acknowledged that there are limitations associated with conducting focus groups which could include dissonance between the researcher's ideals and reality in practice (McLafferty 2004). Also, as it is a time consuming process, only a small number of topics would be able to be covered. It was also acknowledged that facilitation requires expertise, conflicts of opinions can occur within the group, and there can be issues with confidentiality. Hyde et al (2005b) identify that interactions, and the impressions that participants want to give to each other, can have an impact on outputs, with dominant views quashing other views. McLafferty (2004) suggests that it is often difficult to come to a consensus within the time available and it is more likely for there to be divergence of opinion rather than complete agreement. In order to reduce the risk of an unrealistic number of topics needing to be discussed, the plan in the research design was that the findings from Phase 1 and 2 would be discussed first, and then a discussion would be facilitated in relation to what this would mean for the future. Comfortable and accessible venues were identified, groups where colleagues knew each other were created, they were informed beforehand

of the format and who would be within their group and ground rules around confidentiality were discussed at the beginning of each group.

4.3.4 Triangulation

Although there are differences in opinion of the definition and purpose of triangulation, it is generally viewed as being an approach which can enhance the quality of the research study by using number of different methods to address the same research question (Flick 2014). Although Silverman (2005) considers it to be a valuable theoretical perspective, he warns that in practice findings from different methods are not always congruent. Some authors such as Denzin, cited in Flick (2014), identify the challenges associated with using multiple methods when there are fundamental differences in time, space, and people. However within the examples given within the text, the description seems to be one of using different methodological perspectives, which is more akin to taking a mixed methods approach as described by Cresswell and Clark (2011). Within the current study, if Silverman's (2005) simple definition of 'different ways of looking' is applied, but within the same methodological approach, then triangulation took place.

4.4 Study setting

The setting for the study was originally to be one health board in Scotland. This health board was chosen as it included both urban and rural areas, and with mixed demographics in both areas, where GIRFEC principles were starting to be implemented into health visiting practice along with aspects of the Children and Young People Act (Scotland) (2014).

4.5 Sampling

Despite a variety of views in the literature around what constitutes an acceptable sample of a research study – largely dependent on the philosophical viewpoint

taken in the study – there is agreement that whatever the approach, the quality of the sample has a direct impact on the quality of the study. Flick et al (2014) define a sample as a *selection of cases from a larger population*; the selection in quantitative studies being driven by representativeness but within qualitative studies being selected by applying inclusion/exclusion criteria which are directly related to the aim of the study. Whereas probability sampling is most likely within quantitative studies (as a hypothesis is often being tested), within qualitative studies non-probability methods are predominantly used to select a sample, as attention is focussed on the characteristics of the population.

There are a range of different approaches to sampling within qualitative studies but they share two key aims - the first is to ensure that all the constituents (which are the focus of the study) are covered and the second aim is to ensure that there is enough diversity to allow for exploration. A number of authors describe the nature of 'purposive sampling', where participants are selected on the basis of criteria informed by the principal aims of the study and the gaps in knowledge (the research question) (Seale 2012; Ritchie et al 2014; Robson 2007; Cresswell and Clark 2011). Within purposive sampling a number of selection strategies are identified and the decision about which strategy to use is based on the opportunities which are created, whether it is representativeness or diversity which is required – in other words whether it is the depth or breadth of information which, on balance, is sought (Flick 2014). The different strategies for selection include:

- Extreme or deviant cases – to support understanding across the whole field (breadth)
- Typical cases – to support a consensus of opinion (depth)
- Maximal variation in the sample – to create a range of opinions (breadth)
- Intensity of interesting features – (depth)

- Critical cases - asking others who should be interviewed (breadth and depth)

In addition it is also possible to select:

- Sensitive cases – in order to present positive findings – but this would create bias
- Convenience cases – the easiest to access in the circumstances – (where there might be difficulty with access and recruitment)

This study was to include two groups of participants – health visitors and parents – who were currently engaged in active decision making in relation to the wellbeing of a baby, infant or pre-school child.

4.5.1 Inclusion Criteria

A purposive sampling approach was used with the aim of recruiting health visitors with maximal variation in relation to caseloads: urban and rural, deprived and affluent. Convenience sampling was used for parent participants who were to be recruited through their health visitors. The inclusion criteria for each phase of the study are identified in Table 2.

Health Visitor	Parent
Health visitors will need to: <ul style="list-style-type: none">• be registered as a Public Health Nurse/Health Visitor• be currently practicing as a Health Visitor• not be working as a Health Visitor in the same health board area as the researcher is currently employed	Parents will need to: <ul style="list-style-type: none">• have the capacity to be able to provide consent• be the birth parent or adoptive parent and a primary care giver of the child• be over 16 years of age
In addition – to participate in Phase 1 - the health visitor will need to be able to recruit a parent in a situation where they are in the process of making a decision in relation to the wellbeing of a baby or child on their caseload	In addition – to participate in Phase 1 - the parent will need to be in a situation where they are in the process of making a decision in relation to the wellbeing of their baby or child
In addition – to participate in Phase 2 – the health visitor will need to have supported a parent to make a decision in relation to their baby or child's wellbeing within the last six months	In addition – to participate in Phase 2 – the parent will need to have made a decision in relation to their baby or child's wellbeing within the last six months
In order to participate in Phase 3 the health visitor will have participated in Phase 1 or 2	Not Applicable

TABLE 2 INCLUSION CRITERIA FOR PARTICIPANTS

4.5.2 Sample size

Ritchie (2014) states that the sample size within qualitative studies can be relatively small because the findings are not intended to be generalizable and there will be no need to provide information which is statistically significant. However the sample does need to be big enough to provide enough data in order

to address the research question. Silverman (2005) also agrees that applying a formula to sample size in qualitative research is inappropriate but states that thoughtful consideration is required in order to recruit adequate participant numbers as too few may not provide adequate depth or breadth, but too many may produce superficial or unwieldy volumes of data.

Seale et al (2012) identify that, if the criteria are clear, then even if the number is small it is still possible to get all the information that is required. They describe how some methodologies have clear guidance around sample sizes (for instance in grounded theory data is collected until there is 'saturation') however they suggest that this approach can also be applied to other types of qualitative studies as often there is a point of 'analytical redundancy' where no new information is being generated.

Hopkins and Irvine (2012) identify the value of recruiting for focus groups from within another arm of the study as very often this highlights those who are already interested in the work.

4.5.3 Proposed sample size for this study

Based on these views and taking into consideration the time available to undertake the study, Table 3 identifies the sampling size for each phase of the study.

Phase	Method	Health Visitor	Parent
1	Audio recording of Health Visitor /parent encounters Questionnaires	5 x dyads	
2	Semi- structured interviews	10	10
3	Focus groups	2 – 3 groups with between 4 and 6 participants in each	Not Applicable

TABLE 3 PROPOSED SAMPLE SIZE

4.6 Data analysis

Roulston cited in Flick (2014) describes data analysis as being a sequential process of 1) data reduction 2) data reorganisation and 3) data representation – whatever the methodological approach. However Seale et al(2007) prefers to define levels of analysis, and describes a process of developing *models* from the data which influences the creation of *concepts* (defined as an idea from a situation), which then enables the generation of *theory* and ultimately the possibility of *hypotheses* – which may in time be appropriate to test.

Within quantitative studies data is collected in direct response to proving or disproving a hypothesis where there already exists a substantial evidence base. Large numbers are used in order to ensure statistical significance, and theory is generated on this basis. Methods tend to be objective and focus on large scale recruitment such as surveys and testing, in order to create clarity in relation to cause and effect. Qualitative studies can complement this approach by being used to investigate contexts where little is already known, or where a deeper understanding around phenomenon is required, or where the interpretation from the perspective of those directly affected is important. Data used in qualitative approaches is generally audio recordings, interview transcripts, observations, field notes, and can be from social media. Flick (2014) identifies the choice of data analysis methods that are available to researchers with this form of data and which are appropriate to use - ranging from content analysis, to conversational analysis, to grounded theory coding. The key message, particularly evident amongst recent publications, is that the method of analysis must be appropriate for the data that needs to be analysed and the output required, whether generated from a qualitative or a quantitative perspective.

Within the current study the plan was that data generated would be predominantly transcripts from health visitor/parent encounters, completed

questionnaires, transcripts of health visitor interviews, parent interviews and focus groups. To provide structure, Elwyn's Shared Decision Making Framework (Elwyn et al 2013) was evident within each of the Phases, but as the initial knowledge base was so sparse, there was scope at every stage to explore developing themes.

Following from the recommendation that the approach to analysis should be reflected by the data gathered, and anticipating that a large quantity of data would need analysed, the development of a coded system of themes from each of the cases in this study was justified, where Elwyn's Framework was to be used and built upon. The quantity of data to be generated also warranted the use of computer software – and within the research design NVivo 10 was accessed.

Flick (2014) discusses the advantages and challenges associated with choosing between theme based analysis and case based analysis and the merits, despite the complexity, of combining them. Framework analysis is such a method that combines both and as it is possible, with training in the use of NVivo 10, to generate a matrix after coding each case in relation to each theme. This was the method chosen for this study, as the matrix can be interrogated in a structured way, which is of value to an area of study where relationships between themes have not been explored in this way before. Silverman (2005) states that the combination of using verbatim transcripts and software in analysis contributes rigour and Flick (2014) states that it increases transparency, therefore improving quality. Robson (2007) also reinforces the importance of research studies being approached systematically, sceptically and ethically in order to stand up to scrutiny. Chapter 5 focuses on how this study's design planned to ensure a high standard of research quality and Chapter 6 reviews ethical issues and how they were managed.

Chapter 5 – Quality Assurance

This chapter provides an overview of how this study was designed in order to address issues of quality.

Ensuring a high standard of quality, or rigour, within a research study is crucial if it is going to be credible and useable. There are a number of ways that rigour can be achieved in a study, for instance by ensuring validity and reliability (Ritchie et al 2014), where validity is defined as the extent to which a study actually achieves what it sets out to achieve (Robson 2007) and where reliability refers to the accuracy of the process (Flick 2014).

Each of these three terms (rigour, validity, and reliability) will be explored within this chapter and will be used as justification for the range of quality assurance measures which were planned for this qualitative descriptive explorative study.

5.1 Rigour

‘Rigour’ within the Oxford English Dictionary is defined as the *‘quality of being extremely thorough and careful’* which is consistent with Ritchie et al’s (2014) description of a rigorous study as being one which is *‘well-designed and well conducted.....well founded and provides trustworthy evidence’*.

Within literature there seems to be differing views around where responsibility lies for making the judgement as to whether rigour has been achieved in a study, or not, with some authors laying the responsibility on the researcher to ensure evidence of rigour in their study (Ritchie et al 2014) whilst others clearly place the responsibility on the reader to accept or dismiss the findings according to how rigorously they feel the study has been conducted (Rolfe 2006). Although the majority of authors take the view that it is a shared responsibility, it is clear that there should be a spirit of ‘openness’ on the part of the researcher to allow

readers to scrutinise the study; however there are clearly limitations on what the researcher can achieve in this respect due to their obligation to maintain confidentiality and anonymity within many research studies, both in order to protect the participants and also to gain approval from ethics committees to allow the study to progress. Consequently this often prevents researchers from ever being able to provide raw data to those who may want to scrutinise the study in depth. Also, for practical reasons, only a limited quantity of information can ever be included within publications and, as this is where the majority of readers acquire most of their information about research studies, this reduces opportunities for the studies to be able to be scrutinised at a deep level. In reality it seems that ensuring and assessing rigour needs to be a shared responsibility between the researcher and the reader, as there are practical limitations on both sides which means that there needs to be a level of trust, on the part of the reader, around most researchers' work and their studies' authenticity.

Despite these challenges there are a number of actions, highlighted in literature, which researchers can take to improve rigour. Breen (2007) claims that rigour is increased when researchers only undertake research outside their own organisation. Other examples of rigour being enhanced are at least two researchers reviewing transcripts (as opposed to just one) (Hopkins and Irvine 2012), a clear explanation of how the themes developed within the record of the study (Flick 2014), and evidence of the researcher using critical reflection to review processes within the study (Mealer and Jones 2014).

In the context of focus groups, Goodwin and Happell (2009) claim that strong opinions in focus groups can reduce rigour, but state that this can be prevented by an experienced moderator; whilst McLafferty (2004), also referring to the quality of focus groups, claims that if the moderator is directly involved in the

study, and is sensitive to the issues which are being discussed, this will also enhance the rigour of the study.

From the perspective of the reader assessing rigour - a number of authors discuss the advantages and disadvantages of using checklists. Barbour (2001) claims that there is a real risk associated with quantitative-style measure checklists being applied to qualitative research inappropriately; although there are a number of tools such as the Critical Appraisal Skills Programme (CASP) (Vallido et al 2010) which are specifically designed to assess qualitative studies. Even so Porter (2007) is still not satisfied that a small number of qualitative tools are appropriate for all qualitative studies due to the range of different methodologies to which they may be applied. Porter is more inclined to recommend that each reader should make an individual judgement about the research they are reviewing based on whether the relationship between the knowledge and practice is feasible and whether they are confident from the description that the issues identified are accurate.

Based on this evidence, and in order to ensure rigour within this particular research study, the proposal included:

- a decision that the researcher would not recruit from a geographical area that she currently worked within (Breen 2007)
- the researcher agreeing to employ an interpreter if a parent, whose first language was not English, wanted to participate in Phase 2 (Fryer et al 2012)
- measures being put in place to support any prospective parents who wanted to participate, but whose ability to read or write was limited; for instance including the possibility of a verbal explanation of the information leaflet through support from another person, who was independent from the study, and also supporting the completion of the consent form if required
- measures being put in place to ensure that focus groups were managed and that they comprised of small groups of people who knew each other

well and that the principal researcher moderated the focus groups; meaning that she knew the research topic and the study well

- the research supervisors would take an active role in independently analysing a small number of the transcripts and would engage in discussion with the researcher around the themes in order to enable consistency
- the use of a reflective diary to provide evidence of critical reflection in order to support the learning of the researcher (Mealer and Jones 2014)

5.2 Validity

The Oxford English Dictionary defines 'validity' as '*logically or factually sound*'.

Ritchie et al (2014) refers to validity when assessing the correctness or the precision of a research study and divides them into three types

1. Measurement validity – where the tool measures what it set out to measure
2. Internal validity – the extent to which links made between statements and conclusions can be substantiated
3. External validity – the extent to which the study's findings can be applied to other settings

Cresswell and Clark (2011) are satisfied to use the term validity in relation to a quantitative or a qualitative study, however with a different meaning associated with each context. In a quantitative study they view validity as meaning that scores received using a tool are meaningful and accurate, whereas within qualitative studies they refer to the data collection processes being accurate.

Maxwell (cited in Flick 2014) divides the different types of validity further where:

1. 'descriptive validity' relates to factual accuracy
2. 'interpretive validity' refers to the meanings relating to the statements from the participants being accurate
3. 'theoretical validity' relates to concepts being accurate and valid
4. 'generalizable validity' relates to the way the concepts can be transferred to other contexts and
5. 'evaluative validity' relates to the framework being used for analysis being adequate

Flick (2014) prefers to take a simpler view, judging the validity of a study by whether the researcher could actually see what they claim to see. According to Flick there tend to be three common errors amongst researchers, which are:

1. Identifying relationships where there are none – or identifying them incorrectly
2. Rejecting relationships when they actually exist
3. Asking the wrong questions

Whilst some authors take an overview that validity relates to the correctness or the precision of the study, other qualitative researchers have either accepted the terminology literally or amended criteria in order to create a 'fit'. A number of qualitative researchers have chosen to reject the term completely and have looked for different criteria and different language to describe the concept of validity such as 'truthfulness' or 'authenticity' (Ritchie et al 2014).

Porter (2007) and Seale (2012) state that in both qualitative and quantitative studies there do need to be different words to describe whether the account accurately represents the findings. Porter (2007) and Robson (2007) identify researchers who prefer to use the term 'trustworthiness'.

The Oxford English Dictionary defines 'trustworthiness' as *a firm belief in the reliability, truth or ability of someone or something* – which applied in this context could be the researcher and their study. Guba and Lincoln (1989) judge the concept of trustworthiness against three criteria: namely credibility, transferability and dependability, where credibility refers to others recognising the experience as close to their own, transferability as to the findings from the study fitting other social contexts and dependability as referring to a situation where the research study is written in a way which allows the reader the opportunity to make a judgement about the quality of the work.

Whichever term is preferred; there are a range of ways identified by authors to enhance the validity or trustworthiness of a research study.

- Ritchie et al (2014) claims that validity or trustworthiness are enhanced through triangulation
- Hyde and Howlett (2005a) consider that giving participants the opportunity in focus groups to cross-check the discussion with practice increases the trustworthiness of the data whilst
- Whiting and Sines (2012) presented information from findings, in the form of mind-maps, back to participants in order to confirm that meanings were plausible - this is sometimes described as 'member-checking'
- Silverman (2005) claims that one way of increasing validity/trustworthiness is to provide evidence that the findings were based on all of the relevant data collected rather than a few well-chosen examples
- Jessiman (2013) claims that trustworthiness can be related to the recruitment process and suggests that researchers should be honest about the strategies they use
- Fryer et al (2012) reinforce that validity is something which must be considered and acted upon all the way through the study and not just thought about at the end

Within this study the plan from the beginning was that validity or trustworthiness would be enhanced through:

- triangulation – acquiring knowledge about shared planning using different methods
- agreeing on codes with researcher supervisors
- not only describing data clearly but also creating clarity around meanings and how they got there based on responses from participants
- checking out for plausibility with participants at different stages
- ensuring truthfulness was evident throughout the study
- using the computer software package NVivo 10 to manage all the data – creating an ability to ensure that all data was considered
- ensuring that a range of different views from participants were expressed within the thesis and publication
- creating trusting relationships between the researcher and the participants

- giving due attention to sampling and recruitment processes

The next part of this chapter will focus on the importance of ensuring reliability within a research study.

5.3 Reliability

The Oxford English Dictionary defines reliability as being '*consistently good in quality or performance; able to be trusted*'

Flick (2014) identifies that, in relation to quantitative studies, reliability refers to whether a repeat of the test with the same variables will produce the same results, whilst acknowledging, if it is a qualitative study, there clearly needs to be a different interpretation. Ritchie et al (2014) argue that this application of the term reliability cannot be applied to a qualitative study, particularly if a constructivist viewpoint is taken. This challenges whether a single reality can ever be captured in the first place. Certainly for those who believe that qualitative research is, by its very nature, dynamic, they argue that any event is never going to be able to be repeated. Seale et al (2007), however, do not dwell on these philosophical standpoints and instead describe a very pragmatic way of increasing reliability in a qualitative study. They consider that the researcher can record and transcribe verbatim, before analysis, as opposed to the researcher taking notes during the interview or focus group and then trying to make sense of what was said. Reliability in this context, it is claimed, can also be increased by the degree of consistency with which instances are assigned to the same category by different analysers. The terms 'confirmability' and 'dependability' are sometimes preferred in this context.

Another way of ensuring reliability, according to Robson (2007), is by using the same researcher interviewing the participants throughout. Seale et al (2012), when referring to reliability, remind their readers that postmodernists dispute the possibility of uncovering 'facts', 'realities' or 'truths' behind speech and

consequently think it is inappropriate to attempt to make judgements about the 'accuracy', 'reliability' or 'validity' of interviews. From the theoretical perspective that what people say should not be taken literally – but instead used as evidence of their experiences in speech which they have packaged as their experiences – this draws attention to a view that experience is always embedded in a social web of interpretation and re-interpretation. From a researcher's point of view, this perspective of not necessarily taking participants' views literally but instead comparing what was said across a number of accounts (particularly comparing similar experiences), creating an interpretation, and taking the interpretation back to the participants for 'checking' before generating concepts and theory, can all add to reliability. Within this approach of interpretation and the creation of meaning it is important to also reflect on the context of the interviews and discussions.

According to literature there are a number of ways to enhance reliability in studies; consequently within this study the proposal included:

- recording soft utterances in transcriptions – such as '*uhuh*' and '*mmm*' consistently – as these indicate responses and add quality to the interaction
- using a computer software package (such as NVivo 10) to ensure that patterns reported actually do exist
- having research supervisors code data (blind) and then comparing notes
- if describing what happened having data to back it up
- using field notes to back up reliability
- showing the readers the procedures used to ensure that methods were reliable, and conclusions were valid

5.4 Summary in relation to assuring research quality

As a warning Tong et al (2007) state that:

‘Poorly designed studies and inadequate reporting can lead to inappropriate application of qualitative research in decision-making, health care, health policy and future research’

In order to ensure that this research study was going to be of a high standard, that outcomes were going to be credible, and that the findings were going to be able to positively influence health visitor practice, it was imperative that this research study was rigorous, valid, reliable, and trustworthy. This chapter has outlined how these various components were addressed within the research design; however another key area of research practice, which is crucial when providing evidence of a high standard of quality, relates to how ethical issues are addressed within the research design. Identifying the ethical issues for this study and how they were addressed in the research design are the focus of the next chapter of this thesis.

Chapter 6 – Ethical considerations

According to Seale (2012) and Flick (2014) four principles of research are:

- Non maleficence - researchers should avoid harming participants
- Beneficence - research on humans should produce some positive benefit
- Autonomy or self-determination - the values and decisions of participants should be respected
- Justice - everyone should be treated equally

Before any contact was made with prospective participants, it was essential to gain ethical approval from various authorities due to clear directives, based on laws, which relate to accessing patients and staff in the health service for the purpose of research studies. These directives comply with the Data Protection Act (Data Protection Act 1998) and the Declaration of Helsinki (World Medical Association 2014) and as part of the research process the researcher agreed to abide by them. Favourable ethical opinions were gained before data gathering started, and a description is given at the end of this chapter of what occurred in relation to this part of the research study process.

There are a number of areas which raise ethical issues within research studies, and how these risks were managed within this study are outlined in the following section of this chapter.

6.1 The recruitment process

Recruitment has the potential to create ethical risks - for instance there is the risk of coercion, or the risk of treating people unfairly, and without dignity or respect (Silverman 2005). For these reasons it is important that prospective participants are given enough time to consider and to make an informed choice as to whether to participate or not. It is important, according to Seale et al (2007), that prospective participants know why they have been approached, what participation will involve, the purpose of the study, what will happen to their

information, and what will happen if they change their mind. In this study all of this information was provided in the information sheets, which were separate for the Health Visitors (Appendix 1); for Phase 1 Parents (Appendix 3) and for Phase 2 Parents (Appendix 4). The plan was that the researcher would meet with the health visitors in their teams, provide them with information about the study, answer any questions, and distribute the 'indication of interest' form. The health visitors were also asked to consider recruiting one of the parents on their caseloads, and to give them either Phase 1 information leaflet (if they, as the health visitor were also willing to participate in Phase 1) or Phase 2 information leaflet – both of which had information about how to contact the researcher if the leaflet generated interest.

6.2 The consent form and the consent process

Robson (2007) describes the consent process as 'sacrosanct' because of the ethical risks associated with a participant not knowing what they are committing to and as a consequence the consent process is a very important part in any research study. For this reason the consent forms were easy to understand, included an acknowledgement that the participant had read and understood the information sheet, and also indicated that there had been the opportunity to ask questions. The consent forms which were used in the study are attached as Appendix 2 (for Health Visitor Participation); Appendix 5 (for Parent Participation for Phase 1); and Appendix 6 (for Parent Participation for Phase 2). Copies of each of the completed consent forms were available for the participants to retain. The plan was that there would be at least one week between recruitment and consent to allow time for consideration, and that the consent process would take place immediately before the recordings of the encounters in Phase 1 or the interviews in Phase 2.

6.3 Inclusivity and fairness

Seale (2012) identifies the importance of using language which is easily understood by participants throughout a study, and identifies that it is unethical not to open research out to those with communication difficulties or where English is not the first language. The plan was that if a prospective parent participant required an interpreter to explain the information sheet, to support the consent process, and to support the interview process and they had also indicated interest in Phase 1 (with the health visitor's support) then as the encounter was with the health visitor and part of routine care it would be expected that an interpreter would be funded by the Health Board; however if a parent wanted to participate in Phase 2 and an interpreter was required to support these activities then the researcher would fund the service.

6.4 Researcher's role

A decision was made from the beginning of the study that the researcher would not recruit from the area that she worked in at the time due to the potential for confusion over roles and the risk of ambiguity between the role of a researcher and a health visitor manager. McDermid et al (2014) identifies the issues which can be generated by undertaking a research study amongst colleagues. Robson (2007) refers to this as being an 'insider researcher', and Seale et al (2007) emphasise the importance of the researcher and participants being able to build a trusting relationship – which may be difficult when there is a manager: employee relationship already in existence.

6.5 Sensitive subjects

It was anticipated that health visitors might choose to discuss topics which were of a sensitive nature, such as cases where there were child protection issues, examples of domestic abuse, a child with a disability or with a life threatening

condition. Silverman (2005) emphasises the importance of understanding the research experience from the participant's perspective, and the importance of the participant being able to maintain dignity throughout the process. In order to reduce the risk of unnecessary emotional upset, and the potential for loss of dignity, the researcher would stay focused on the interview schedule as much as possible so as to reduce the risks of participants using the interview inadvertently as a therapeutic encounter. It was recognised that the health visitors may have emotional reactions to relationships which they had developed with parents, or may choose to focus on examples which they, in hindsight, felt could have been handled better by themselves or others. As the researcher had extensive experience of interviewing clients and staff and knew the importance of supporting dignity it was anticipated that this would be achieved by offering the opportunity to take time out in the interview and to stop the interview prematurely if necessary. The contact details and support systems in the workplace, and for the parents, were to be known before starting data gathering.

6.6 Confidentiality and anonymity

Robson (2007) outlines that because qualitative research involves people it follows that it will also affect people. Seale et al (2007) point out that participants have a right to confidentiality which includes their identity, and the places and location of the research; and then expands in a later text by identifying that maintaining confidentiality can be really challenging in small studies where there are only a few participants. In these cases the ethical risk of inadvertently breaking confidence is great and could create distress and an unwillingness of a group of people to participate in research in the future (Seale 2012).

A number of strategies were to be used to minimise the risk of breaking confidence; for instance in relation to protecting identity within the interview recordings there was a plan that the only people listening to them would be those

who were directly involved in the study in the University. Names and other identifying features would be removed at transcription. For health visitors, they were assured that no information would be shared (except in exceptional circumstances where someone was being put at risk) with colleagues or their manager; and that any published findings would be aggregated and any quotations anonymised (Appendix 1). A similar assurance was given to parents in relation to any personal identifying features, aggregation of the findings and anonymity of the quotes, and they were also informed that the content of the questionnaire from Phase 1 would not be shared with their health visitor, and that information generated from the Phase 2 interview would not be passed to their health visitor unless they personally told them what they had said (Appendices 3 and 4). These points were also outlined within the consent forms (Appendices 2, 5 and 6).

6.7 Impact of participating

It was recognised in the proposal that as this was a student study there was not the means to reimburse health visitor participants for their time. Although permission was to be sought from their employer to participate during work time there would not be an ability to secure 'backfill' to help them with their workload. Within the Information Leaflet (Appendix 1) it was outlined, however, that there was the potential for professional learning and development.

The parents were also told within their information leaflet that it is common for participants to feel satisfied when participating in a research study, such as this, which will help support improvements in health visitor practice (Appendices 3 and 4).

6.8 Evidence of poor health visitor practice

Given the nature of the questions, and the ways in which they were to be asked, it was perceived as unlikely that evidence of poor professional practice would be identified during the research process; however the agreement was that the researcher would discuss any concerns with the respective health visitor manager should this occur – and this information was included in the Information Sheets (Appendices 1, 3 and 4).

6.9 Issues around the safety of adults or children

In order to ensure that all prospective participants were aware that there were some exceptions to the promise of complete confidentiality, all of the information leaflets outlined that if the safety of a child or an adult was at risk or there was evidence of poor health visitor practice, action would be taken (Appendices 1, 3 and 4).

6.10 Storage and protection of data

The Health Visitor's Information Sheet indicated that data would be anonymised and any identifying features would be removed by the researcher before analysis so that no ideas could be attributed to one individual. All the information would be treated in the strictest confidence and signed consent forms stored in a locked cabinet in a locked office in the Health Centre where the researcher works, or on a computer which is password protected or kept secure on a password protected device, and that the final thesis held by Stirling University and any publications would include a combination of different participants' views.

6.11 Safe transfer of data to other devices and systems

All data, which was held on recording equipment, would be transported between sites as safely as possible using a locked briefcase. The protocol and the NHSREC application indicated that when audio recording devices were to be

used the recordings would be transferred to a file on a computer, which is password protected, as soon as physically possible - and cleared from the recording device at this stage. The 'back up system' would also be password protected.

6.12 Safe destruction

Once the research study was complete, the final report written, the thesis completed and the academic award granted the field notes and transcripts would be preserved in a locked filing cabinet in a locked room for 10 years and then destroyed.

6.13 Personal safety

Robson (2007) identifies that it is important that researchers are protected from abuse, trauma or compromising positions and consequently within the proposal it was outlined that to reduce any risk to the researcher's personal safety when conducting the interviews with parents the researcher would write to the parent's health visitor and explain her intention before undertaking a parent interview in the home (Appendix 7). This was to establish if the health visitor was aware of any risks associated with the venue (e.g. violence or aggression in the family, aggressive animals in the home, or known criminal activity amongst any family members which could put the researcher's safety at risk). If there was no response to the initial letter and the parent showed a preference for conducting the interview in the home an email or telephone call would take place in order to establish that, in the health visitor's opinion, the setting was safe. The researcher also acquired the Lone Worker Policy for the health board she was gathering data within and complied with it as much as possible. An indication that the researcher would be approaching the parent's health visitor was included in the Parent's Information Sheet for Phase 2 (Appendix 4) and a request for

permission to inform their health visitor about the study was included within the Parent's Consent Form (Appendix 6).

6.14 Dissemination of findings

As already outlined Seale et al (2007) stress the importance of confidentiality within research studies and assurance was given within the information leaflets that any information in publications would be anonymised and aggregated with the views of other participants. However, it could be argued that **not** disseminating the findings after the contribution that participants had kindly made was also unethical. Within the information sheet to the health visitors it was outlined that there may be the possibility in the future for them to join the researcher in disseminating the findings to colleagues in order to learn from them and to positively influence health visitor practice.

6.15 Obtaining favourable ethical opinions to allow data to be gathered

Based on the proposal NHS IRAS application forms were completed and these were submitted to the School of Nursing, Midwifery and Health Research Ethics Committee, University of Stirling, who gave approval for the study to progress on 21st May 2013 (Appendix 12).

The IRAS process was then followed which involved securing Indemnity Insurance and a Sponsor (Appendices 13 and 14).

As part of the process application was made to the East of Scotland Research Ethics Committee 1 (EoSREC 1) and following a meeting, at which the researcher attended, and after a small number of amendments to the Participant Information Leaflets, a favourable response was received on 24th October 2013 (Appendix 15 Favourable Opinion Met 24th October 2013).

Following this NHSREC process, application was then made to a Health Board Area for Management Approval to recruit health visitors from their staff and parents from the health visitors' caseloads.

Research and Development Management Approval was granted on 4th November 2013 based on all the information about the study which was identified in the IRAS Application process.

The reason for all of this preparation was to ensure that the quality of the study would be high, that patients, NHS staff and the researcher would be safe, and that the study would be conducted ethically.

The next chapter will describe what took place in detail during recruitment and data gathering; however it is important to note at this stage that, due to logistical problems associated with recruitment in the first health board area, application was required to NHSRES to enable this single site study to become a multi-site study and this was approved. Management approval for data gathering in a second health board area was granted on 27th May 2014 (Appendix 16)

End of study paperwork was submitted to EoSREC 1 on 17th November 2014 (Appendix 17).

Chapter 7- Gathering and managing the data

Data gathering took place in two stages. Following health board research and development management approval from the first health board area the researcher made contact with the health visitor line manager, whom she had spoken with previously about the study, to discover that the line manager was just about to take an extended amount of time off work for personal reasons; however contact details of the four team leaders for the four health visiting teams within the area were provided and the researcher contacted each one by phone in order to arrange to attend team meetings to recruit participants to the study.

7.1 Recruitment

Reception from health visitors at the three meetings the researcher was invited to, and attended, was very positive – however recruitment to the study was disappointing. There were potentially a few reasons for this. Firstly the line manager was absent from work and this would have been the person who would have been the contact person; but also the Care Inspectorate announced their programme of scrutiny of children's services in the area at the same time as meeting with the teams.

In total three health visitors volunteered along with one parent. This amounted to one health visitor: parent dyad for Phase 1 and two health visitors for Phase 2, and then there were a few weeks when nothing was heard – despite phone calls and emails to the team leaders as a gentle reminder. There was, however, appreciation of how challenging the working environment was at the time.

Discussion took place with research supervisors, and the decision was made to approach another health board area. There was then the discovery that to progress it was needed to convert the original application to the NHS Research Ethics Committee from a single-site study to a multi-site study through NHS

Research Ethics Service. This service was approached and all the information from the original IRAS Application process was made available to them electronically; however there were difficulties at this stage due to staff absence within their office – which was only discovered when there was no response to the original request and telephone calls of inquiry revealed the difficulties. This prompted phone calls from both health board research and development leads, but to no avail; however it was the telephone calls from the research supervisors which prompted a positive response, and permission was given to the second health board area to progress with their management system research permission process.

Technically health boards have 30 days from the start of the application process to respond to the request, and so it was another month before authorisation to collect data in the second area was granted.

The researcher made immediate contact with the Manager in one of the CHPs in the second health board area who gave support locally. Contact was then made with the two line managers who also gave support, and a series of recruitment sessions were conducted with the researcher when health visitor teams were meeting already.

There were some challenges around these meetings in that the researcher was working full time in another health board area and had commitments as part of her role and responsibilities there; however one week paid leave was kindly granted by the researcher's line manager to collect data, and very quickly health visitors in the second health board area started to come forward as participants and to recruit willing parents.

7.2 Gathering data

One further dyad was recorded as part of Phase 1 – but no further offers for this Phase were received. However, very quickly a further nine health visitors volunteered to participate in Phase 2 and a larger pool of health visitors recruited nine suitable parents – as some of the health visitors did not have the capacity to be interviewed themselves but were willing to discuss with and recruit one of the parents on their caseloads. Informal discussions indicated that there was interest in the study from health visitors due to the study's relevance to practice.

There was a great deal of interest in meeting for the focus groups in Phase 3 – which involved meeting three times with small numbers - involving eight of the health visitors again.

In summary, challenges to the process of data gathering included:

- The Ethical Approval Process taking many months in order to complete the extensive number of forms and to wait until a Research Ethics Committee could accommodate the application
- The contact line manager in the first health board area becoming unavailable at the same time as management approval was granted
- Not being known by the team leaders or health visitors in the first area
- The lack of capacity and unwillingness of the health visiting staff to participate once scrutiny by the Care Inspectorate was underway
- Difficulty with communication with NHSRES due to them being so short staffed - in order to give permission to approach a second health board area
- The time it then took to await a response from the second health board area
- Logistical issues around health visitor participants and the researcher being able to meet up to conduct the interviews – due to other demands on all their time
- Last minute changes of dates and times when meeting with parents – due to unexpected occurrences such as an ill child and other demands around their other responsibilities and commitments (it was felt appropriate to

always give the impression to parents that the researcher was more flexible in terms of her available time than in reality was the case, due to an appreciation of them giving of their time to this study)

What went well

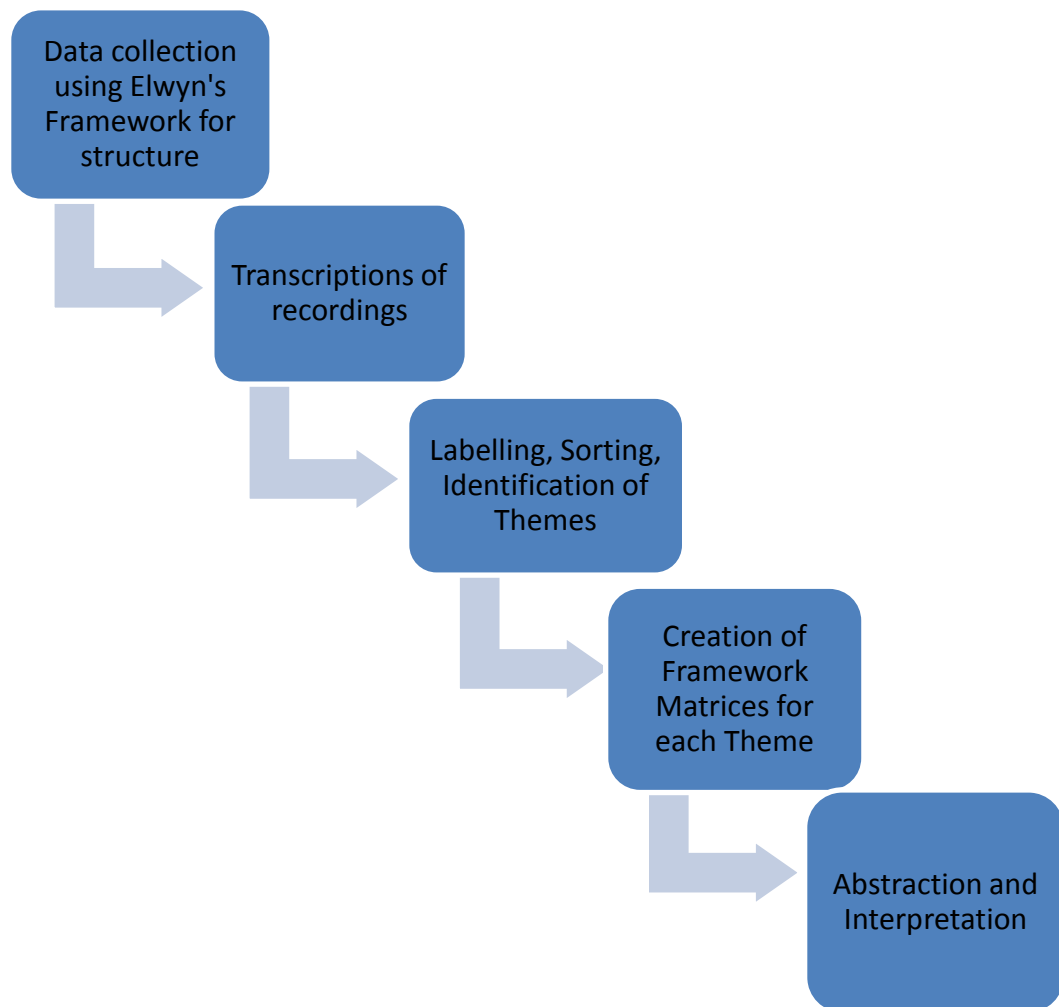
- Unstinting research supervisors' support throughout the difficulties with the ethics processes
- Positive reception from health visitors and their managers in both areas – and particularly the number who participated from within the second area
- Support from the researcher's line manager – not only in terms of the one week given to collect data but also the flexibility that that time was able to be taken to fit round the availability of participants
- Funding from NHS Education Scotland, via a bursary, which created an ability to finance professional transcription services and printing costs for the parents' information leaflets
- Training in NVivo 10 from the University of Stirling – which then supported the researcher to be analysing the data as it was transcribed and supported the ability to be able to feedback key findings to participants at Phase 3

In summary, data gathering was a challenging process. Lessons learned have been to never underestimate the time needed for recruitment and data gathering processes. As the second health board area was an area where the researcher had worked in the past, and therefore the health visitors were known, it was appreciated that this probably contributed to the positive responses.

7.3 Data analysis

Following consideration of approaches to data analysis identified in Section 4.6, a decision was made to adopt the analysis process used by the National Centre for Social Research, and NVivo 10 was used as a data management tool to apply this framework method. Gale (2013) and Srivastava (2009) describe in detail the advantages of using this approach which is increasingly being used in applied health research, and a visual version of what is described in Ritchie et al (2014) is presented in Figure 1.

FIGURE 1 DATA ANALYSIS USING THE FRAMEWORK METHOD (RITCHIE ET AL 2014)



As Elwyn's Framework had been used to help create the data gathering tools it was anticipated, during the design process, that the data analysis would be straightforward because links between the data and the themes would be clear; however this was not the case, as additional themes emerged relating to topics which did not fit neatly into the existing themes.

Once all of the transcripts from each of Phases 1, 2 & 3 had been coded (in NVivo they were referred to as Nodes) 267 different codes emerged from the data which were sorted into sub themes. The sub-themes predominantly fitted into one of nine themes; three from Elwyn's Framework and six new themes. One of the additional themes, *identifying the Issue*, appeared to relate to a crucial part of the shared decision making process. And a second additional theme *Relationships* was like a thread which ran through every one of the other themes.

There were, in addition, other themes, which were collections of additional sub themes and codes. These sub themes and codes predominantly focused on aspects of health visitor practice; some of the codes described processes which are intrinsic to health visiting practice and within health visitors' control such as patterns of working, whilst other codes related to extrinsic factors such as financial constraints, policies, information technology systems, and processes which influenced practice but which health visitors had very little power or influence over. Although these themes were of interest, in terms of understanding the context within which health visitors were working, due to the time constraints of the study it was decided to put this information to one side and focus on Elwyn's original three themes, along with the two additional themes of *Identifying the Issue* and *Relationships* as they had the potential to make the biggest contribution to directly answering the research question. The specific findings, and how they relate to the research question, are described in more detail in the next chapter.

Chapter 8 – Findings from Phases 1 and 2

This chapter presents the findings from the analysis of recordings of two encounters and four questionnaires from Phase 1, and eighteen semi-structured interviews from Phase 2.

As indicated in the last chapter, the analysis process involved systematically reviewing all transcripts, coding them, and finally identifying areas from the transcripts which related to themes from Elwyn's Framework; these were *Choice; Options; and Decision Talk*. During this process NVivo 10 was used to manage the data and to create matrices which linked each theme with each of the cases and supported the analysis process (Figure 1). The transcripts were then analysed for any additional themes.

It became evident from the data that, for health visitors and parents to make shared decisions, it was important that there was a shared understanding around the nature of the issue under review, what needed to be discussed and what required a decision. Wood (2013), working within the Information Services Division of the Scottish Government, encourages all health visitors and school nurses to record 'issues' as part of the National Child Health Programme when they assess and review babies, children and young people at routine assessments and reviews. Wood defines an issue, in this context, as anything which relates to '*a baby's, child's or young person's health, development or wellbeing*'.

Wood's broad definition of an issue was used as a starting point when analysing the data from Phases 1 and 2. Within the data it became evident that the level of concern about an issue was sometimes different for the parents than it was for the health visitors. *Issue* was consequently identified as an additional theme, in order to create the opportunity to explore what was happening in practice.

It also became evident that the theme of *Relationships* was cross cutting every interview and encounter, as is understandable, as the quality of relationships is fundamental to both health visitor practice and each stage of the shared decision making process (Chapter 3 Section 3.5).

What follows in this chapter are interpretations of the information from the transcripts and the questionnaires from Phases 1 and 2 in relation to the five themes of *Issue, Choice, Options, Decision Talk, and Relationships*. This is then followed by links between these interpretations and how they address Objectives 1 –3, first identified in Chapter 1, which relate to what processes currently support shared decision making in health visitor practice.

8.1 An *Issue* was identified

The two recorded encounters in Phase 1, and the eighteen recorded semi-structured interviews in Phase 2, provided evidence of discussions about complex situations in which multiple layers of communication occurred. It was however noted, across both Phases, that the level of concern about the issues which were addressed varied between the health visitors and the parents, and that issues relating directly to the baby or child's wellbeing were not always the issues which were the focus of decision-making.

Phase 1

In each of the two cases the health visitors and parents made an initial choice about what they wanted to make a decision about – the issue (in both cases they were linked to bureaucratic processes). However, decisions about other issues, which linked directly to the children's wellbeing, although not the initial focus, were given equal if not more time and attention.

In Phase 2 accounts were recalled where:

- both health visitors and parents shared understanding around the nature of the issue in relation to the baby or child, and agreed that this was their focus of concern
- parents required support in their decision-making as to when to request assistance from another service (in relation to an issue affecting their baby or child) to enable the service to offer support in the medium to long term. In these cases the health visitors' main focus was on the process, and their concern around its impact on the parents. For the parents, who did share some concern about the process of requesting assistance, it was not felt to the same extent
- a parent articulated clearly that they didn't believe that there was an issue in relation to their child's speech; however the health visitor maintained that there was and the child's speech development remained the focus of the health visitor's concern
- parents did not participate in services which were designed to address the issue but neither did they express their opinion about the issue; the health visitors did have concerns about the issues whereas there was lack of clarity around the parents' level of concern
- the health visitor identified a new issue affecting a child whose name was on the child protection register; although the parent and child attended the service for support and advice, it was very difficult under the circumstances to determine the parent's level of concern about the issue and whether attendance would continue after deregistration

8.1.1 Decisions about a child's wellbeing received more attention than decisions about processes

Although in both encounters in Phase 1 the initial focus of attention was to be on decision making associated with completing forms or health service processes, in practice there were a number of decisions related directly to children's wellbeing, which were addressed during the discussions, and received at least the same time and more attention from the parent.

In the first encounter the intention was to make decisions about what should be included within some forms....

HV ...*So I've done it for both, obviously a lot of the things are the same but I've tried to individualise it a wee bitty when it comes down to their health needs because they're slightly different that way.....*

.....which developed, during the encounter, into conversations about the child's sleep pattern....

Parent....*Cause last weekend was horrendous. Even (Child)'s sleeping went backwards....*

Phase 1 HV & Parent 1

And in the second recorded encounter the intention was to make a decision in relation to whether the health visitor would continue to support the parent and child, or transfer over to the school nursing service

HV..... *So what we kind of are going to look at today is we've got a couple of options from the health side, from the health visiting, sort of our viewchildren at this stage can be transferred onto the school nurse*

.....which developed during the conversation into concern about the child's fluid consumption....

Parent...*See there's just no rhyme or reason for her drinking anyway, I mean, it's not necessarily because her blood sugar's high or because she's been running or... there's nothing, I mean, sometimes she'll sit there and finish a bottle and other times she'll have a sip.....*

Phase 1 HV & Parent 2

8.1.2 Parents and health visitors shared concerns about the same Issue

It was evident from the interviews in Phase 2 that the one time when parents always believed that there was an issue was when they were the ones who approached the health visitor with their concern. This related to a number of cases and a number of behaviour issues such as tantrums in public places, poor sleeping patterns, and poor eating habits, or issues with speech development. In each example the health visitor took the concern seriously and acted upon it until there was a satisfactory resolution.

It was really hard cause everybody was watching me in the place and at the same time I'd already had a kid and I knew kids do things but (Child) was just uncontrollable, and I got to the stage where I thought I need help here. I knew I needed help.so that day I broke down in the room and they sent me in to see (GP) and he says to me 'd'you want to speak to your health visitor?' and I says 'yes please',and that's when (HV) came on board.

(Phase 2 Parent 1)

It was apparent within the interviews that many of these parents had gained insight into their child's behaviour or development by observing children of a similar age to their own child, and this was mentioned when justifying their personal concern to the health visitor.

...so that was a kind of highlight, then the thing that triggered it was well from mum's point of view, when she went along to (Playgroup) in (Town) and she compared him to other children of the same age

(Phase 2 HV 4)

In some cases parents recalled that the issue had been identified when the health visitor was undertaking a routine review. In these cases the health visitor was known to the parent and appeared to be trusted by the parent and there was no hesitation in accepting the findings from the review and any support which was available.

He had some delayed speech and we'd been keeping an eye on it and had a bit of a chat about it and decided so initially he was referred for speech and language and that seemed to be going okay

(Phase 2 Parent 2)

It was evident from health visitor interviews how helpful being able to use an evidence-based assessment or screening tool to support the stage of the child's development was in practice, as this supported discussion about the issue with the parents in a structured way, and could also be used as a focus when reviewing the child a number of weeks later in order to identify any change.

What I think as well... because what I did again was I did another SOGS development assessment with them again six months later and I said 'let's look at where he's gone now' so I could look and say, 'let's emphasise the things that he's moved on on, that he's doing well, and then let's focus... you know, but if you look he's still slightly below here so, you know, how about we get him along for this speech and language appointment?'

(Phase 2 HV 2)

8.1.3 Parents needed to request assistance from another service

Within the interviews three health visitors spoke about the challenges associated with supporting parents to work through 'request for assistance' processes to other services, which would be available to offer support to the child in the future. Some of the difficulties they experienced were not necessarily related to the fact that the parents did not recognise that there were issues with their baby's or child's health, development or wellbeing, but that the service required an application process which the health visitor and parents needed to work through together, and this was very often at a time when there were other decisions needing to be made around the current direct care of the baby or child. Health visitors also spoke about the need to be sensitive with these parents and cautious when completing the forms, as their experience of completing this process in the past and of reflecting on the needs of the baby or child was likely to raise emotions for the parents. This is because the processes often reinforced that their baby had multiple complex issues and would never be a 'normal' child as he or she grew older.

I phoned the pre-five education team – I told the parents 'I understand you're not ready for referral' because of course they have to fill in a form with their perceptions of their problems that accompanies mine, so if they're not ready to do that the referral can't be made, but I'm also aware from the pre-five education side they need to be making, you know, plans for where this child will go.....so it was a very softly, softly saying 'I understand as much as I can where you are but we have to make the phone call.....'

(Phase 2 HV 3)

One health visitor spoke about the difficult situation that she experienced where a mother was finally convinced to make the application to the Pre 5 Education service, which the health visitor had suggested, on the basis that the child had a congenital disability and would require support from this service in the future. The health visitor and mother completed the application together but the request for assistance was 'rejected' on the basis that things weren't 'bad' enough. The health visitor had made a conscious effort to provide a strength based perspective, so as not to upset the parents, as it was assumed that the diagnosis would provide the necessary insight into the need for the service; however after a phone call to the service, and some amendments, the request was accepted on resubmission as it was clear that the application process had been entirely appropriate for the child's condition.

You know, you've identified a need and you know what you think needs to be done, and even sometimes if you know there is a service there that exists, these services don't always take you on, and sometimes the patients agreed to the referral or the request for assistance and you've worked closely with them because it's hard because you're saying that they need that wee bit extra support or help and sometimes it takes a while for us both to get to the place where they're comfortable with that, and you make the decision and they agree to it and then the service doesn't take them on because they're not sure that that meets their criteria...

(Phase 2 HV8)

8.1.4 Parents were clear that they did not believe there was an Issue

In one case the parents were clear with the health visitor that they didn't believe that there was an issue with their child's speech; there was, however, also a suspicion that the mother had an undiagnosed learning disability herself.

They didn't really agree with what I was saying.....they said they didn't really think that there was much problem with the speech and that they could understand the child's speech what was there

(Phase 2 HV2)

8.1.5 Parents did not attend services designed to address the Issue

In cases where parents did not attend appointments it was also apparent within the interviews that there were other issues affecting the family, such as poverty, housing concerns, substance misuse, mental health problems, social isolation and domestic abuse – which raises many other issues around a family's ability to prioritise and access services. In these cases, although there were 'failures to attend' it was not possible to assume that the parents had no concerns about the issues. These challenging situations which the health visitors identified, and some families were experiencing, are explored within the Discussions chapter.

A child in the family was identified as needing a speech and language assessment and was discharged oh, two if not three times for non-attendance

(Phase 2 HV1)

Of note there was one case reported where a mother had agreed with her health visitor that her twins may have some developmental delay and had signed a consent form indicating her agreement that her children should be assessed by the multi-agency Pre 5 Assessment Team. The meeting with the Team took place, however the father was also present at the meeting and was very aggressive towards the professionals and particularly to the health visitor, claiming that there was 'nothing wrong' with his twins. The mother also claimed at that point that she had been pressurised into giving consent and the couple withdrew their children from the system.

From the health visitor's perspective this event had a negative impact on the relationship between the mother and the health visitor in that for many months the conversations were brief and the mother wasn't as open as she had been previously – however it did resolve some time later when the mother required help in relation to another younger child's behaviour; the contact had been

prompted following a police report which was sent to the health visitor following a domestic abuse incident.

their speech was delayed, their eye contact – there was concerns about their development. We at that point referred these children to Pre 5 Assessment Team and mum agreed with the referral, but when we went to the referral meeting, dad arrived and at that point mum told everybody at the meeting that she hadn't consented to the referral and that she'd felt quite pressured into it. And I was left feeling dreadful but she'd done that because the dad was angry that we were there, and she'd turned to him and went 'well this wasn't explained to me, this just happened'.

(Phase 2 HV8)

8.1.6 A child's name was on the Child Protection Register and a new Issue emerged

In a case, which was described by one of the health visitors, the names of a family of children were on the Child Protection Register at the same time that the health visitor was supporting the mother to decide whether to request assistance for her son from dietetics due to being a 'fussy eater'. In this case the health visitor found it very difficult to establish if the mother had the same level of concern as herself because of the impact of having statutory involvement at the time.

It was interesting to note that there was another perspective to the account as the health visitor was concerned about potentially '*setting the mother up to fail*' by agreeing to go through the request for assistance process when there had been a history of failing to attend other appointments in relation to speech and at a time the parent's care of her children was being scrutinized. 'Fussy eating' is an issue which often has repercussions within the home, through the child's behaviour, but there could also have been risks to the child of malnutrition. From all accounts progress was made once the parent started to attend appointments with the dietician and put the recommended strategies into practice at home. The health visitor, however, remained sceptical about whether engagement with the

dietetics service and implementation of strategies would continue after deregistration of the children.

I think now, you know, he's been at nursery and having lunches and things, you know, his packed lunch is limited, really limited and she knows it is, especially when she compares it to her younger children who eat anything, and I think it's just now that she feels that she's in a place where she can address it. Whether there's an element of feeling that she has to address it because of the process she's going through, and that it's easier to comply to get me off her back, there's possibly an element of that, but I suppose time will tell. There has been some improvements, so you know.

(Phase 2 HV1)

Having explored the variety of perspectives which were evident in relation to *Issues* the next section explores *Choice*, which is the first of three stages within Elwyn's Shared Decision Making Framework (Elwyn et al 2012).

8.2 There was *Choice*

According to Tiffen et al (2014) decision making within the clinical setting can be defined as

'a contextual, continuous, and evolving process, where data are gathered, interpreted, and evaluated in order to select an evidence-based choice of action'

'Choice' within Elwyn's Framework refers to the stage where the clinician 'steps back' in this process and acknowledges that it is possible to make a choice between options in collaboration with the patient, by means of a rational process.

The encounters and interviews in this study were conducted on the basis that parents and health visitors were making, or had made, conscious decisions, following recognition that they could choose an intervention related to supporting a baby's or child's health, development or wellbeing. It was evident throughout the interviews and encounters that the extent to which choices were or were not offered by health visitors varied; however what was offered focused every time on achieving wellbeing for the baby or child in the short, medium or long term.

In the data there were cases where health visitors and parents described scenarios where they felt choices had been made, but it was difficult to see at what point shared decision processes had been implemented. There were other cases where it was possible to identify that decisions had been made together whether to try out an intervention or not whilst waiting for a response from another service. There were cases where there was a shared decision to delay a request for assistance on the basis that interventions would be tried within the family in the meantime to improve a child's development; and there were cases where families were complex and parents were given a choice as to which issue to address first.

Within the shared decision making literature the reference to choice predominantly relates to patients and health professionals making shared decisions about which treatment option to select (Charles et al 2003); however in the cases within this study there were no choices between services. Elwyn's Framework also refers to 'doing nothing' as an option (Elwyn et al 2012); however in these contexts in relation to issues around a child's wellbeing 'doing nothing' was never presented to the parent as a choice.

There was one case where the health visitor felt that choice was removed due to a lack of clarity around which health professional was taking the lead in the care of the mother and baby, and the health visitor's lack of understanding around what the range of options were.

This was how *Choice* was reflected across all of the data:

Choice was not offered

Lack of choice was evident when parents approached health visitors in a distressed state, either because they were struggling to cope with their baby, and they were looking to the health visitor for solutions, or because of a toddler's

unsociable behaviour which was causing disruption within the family, and the parents were becoming desperate.

We used to put her in her bed and then she would just get out the bed and run right round it again thinking it was funny and I'm saying (child's name) it's not funny, mummy and daddy's got to go to sleep, (brothers) got school, we need to get to sleep' but she just would not sleep, and so we weren't getting any sleep, we were arguing, we were... were all crabbit, we were all tired, I was like a walking zombie

(Phase 2 Parent 8)

In most of these cases the parent had made a decision to approach the health visitor; however the health visitor rarely then offered choice to the parent or spent time in shared decision-making. In each case, a solution was provided by the health visitor and help was sought or a referral was made to another service.

In other situations, which were given as examples of decision making by participants, but where parental choice again was not evident, each of the issues related to clinical situations; for example a rash around a baby's mouth, a baby losing weight, a baby crying continuously. In these cases it was the health visitor who clearly made any decision, instructed the parent what to do next, and the instructions were followed.

Discussions about the appropriateness of this type of response from the health visitor is discussed in the next chapter – however it is noted at this stage that in these situations the health visitors and the parents believed that decisions had been made in partnership.

8.2.1 A choice was provided to delay the request for assistance

Although choices were provided in some situations between requests for assistance being delayed or not, this was always offered with the understanding that the child's best interest was a priority, that no harm would be caused due to any delay, and a review appointment (through the national Child Health System

Recall Process) would be made for an appropriate time to review the child's development or condition.

INT: Have you ever had a situation after a 30 month review where you've actually thought 'mmm, just keep an eye on that'?

HV2 Yes, yes I have, yes. Again that's been speech and language again.....I think I ask them whether they think, you know, whether it's something they're concerned about and I think it depends as well what siblings, how their speech has developed as well, you know, and what sort of the home situation is. And as you say, just by saying to the parents, you know, speech is a bit delayed, what do you want to do, but you know, we could just see how we go and review it at this point in time and, you know,.... follow it up and see how they're coming on then?

INT: Yeah, yeah, and do you use the child health surveillance programme?

HV2: Yes.

(Phase 2 HV 2)

It was however expressed that giving this option to parents has become more difficult recently and health visitors were more reluctant to delay, even if their professional judgement lead them to this decision and it was the parents' preference. This was because, following the implementation of the national 27 – 30 month review, managers and other partner agencies had created pathways which children and parents were expected to follow to ensure that the child was ready and able to learn as soon as possible.

the push for children to be meeting their developmental milestones has now put pressure on I think to where, if we're doing a 27 months check, if we'd identified a speech issue, maybe not a significant one but a less significant one, you know, maybe historically we would've kind of just monitored that, now I guess we're referring much earlier.

(Phase 2 HV 1)

8.2.2 A choice was given as to which issue to prioritise first

There were a number of families who lived within very complex situations – either because of one or more children with multiple issues, or because of many issues spread across a number of people within the family, including adults. This sometimes created the situation where there was a need to choose which issue to address first.

so I said 'right, we'll discuss them one at a time and we'll see what one's the most important for you, so what one do you think is most important for you at this moment in time?' and it was the sleep thing

(Phase 2 HV 5)

One of the challenges that became clear within these complex situations was that perhaps from day to day, and certainly from week to week, the priorities of the family changed to keep up with changing life circumstances. These complex situations meant that choices and options were only relevant at a given point in time and the priorities around decision making changed very quickly.

their household was quite busy, so we had the two little girls, one's three and one's one and a half, both running about in the living room, and we had mum and dad – mum's quite quiet and dad is quite... not vocal, but you know, he's quite chatty. So we had a lot of noise, the television was on so it was quite a kind of noisy visit, and we were trying to hone in, as you said a minute ago, on any particular issue which was quite difficult at the time because they were throwing a lot of issues at me! So, you know, 'she's not sleeping all night and her behaviour's terrible and she's not eating properly' and this and that, so there was a lot of different things

(Phase 2 HV 5)

8.2.3 Other professionals were involved but lack of clarity interfered with choice

There was one example where a health visitor could not provide a mother with a choice of what to do next or who to involve – as the health visitor was not able to determine what the range of choices were. This was directly related to the community midwives maintaining their contacts with the mother after two weeks due to their concerns and no discussions around who would be taking the lead in the mother and baby's care. There was difficulty in communication between the midwives and the health visitor as there was the added challenge of more than one midwife from the Team being involved. In some respects, this situation should have provided the mother with more choice due to a larger pool of available people to support her. Instead, it led to professional frustration and a confused mother due to lack of clarity around which professional was leading and how to progress.

INT: Okay. Were there any other kind of options that you remember discussing at that time?

HV Not really, not initially because I wasn't very sure actually what the midwife's plan was.....didn't have the discharge paperwork from the midwife,I didn't know actually the paediatrician was involved, it was only through the mum that she had told me. So I didn't know what the long term plan was.....I didn't have all the information.

(Phase 2 HV 7)

8.3 There were *Options*

Discussion about Options is Stage 2 of Elwyn's Shared Decision Making Framework (Elwyn et al 2012).

8.3.1 Health Visitors needed to be aware and understand other services to outline options

It became evident that the only way that health visitors could offer viable options to parents was if they were aware of what services other organisations and professionals were able to offer, and had a really good understanding about their systems and processes. Health visitors also needed to understand the most up to date criteria for support from a service in order to make appropriate requests for assistance.

In addition, health visitors identified that they needed to know in what ways the agency would communicate with the health visitor in order for the health visitor to be able to offer continued support to the family

INT: *Mm hmm, the parenting programme, yes you don't hear...*

HV: *No you don't hear back.*

INT: *...back from them, so you've no idea whether the parent is actually attending or not?*

HV *No, we don't know, no and I had a child on the register and I didn't know whether they were attending or not.*

(Phase 2 HV7)

It was evident that some health visitors had worked in communities for many years and had a wealth of local knowledge about organisations and their systems and processes; however some health visitors found it challenging to gain information from some services to give to parents to help with decision-making.

(HV)'s actually a very well versed health visitor, I can't speak for all health visitors, but (HV) has a wealth of experience and, I mean, she gave me everything that I needed, I was comfortable with the process and I didn't feel at any point that I was kind of getting led into the dark...

(Phase 2 Parent 7)

Yeah. Some of the challenges sometimes is as health visitors not absolutely 100% knowing what the service is able to offer or how it's actually going to pan out

(Phase 2 HV 5)

Written or online information was considered helpful and was often readily available from the Third Sector organisations although not always available from health services.

I would say the only thing is it's a shame she didn't have any kind of... it wasn't until we actually got into the whole process of it that (Organisation) sent through information about it in a leaflet. It's a shame that the health visitors don't have some kind of leaflet to give out, that would've been good because she did tell me everything but you're so hyper with it all that you do forget a lot of things

(Phase 2 Parent 2)

Some parents were already involved with other services and able to acquire detailed information about additional services through this contact.

Yeah. I went back to see her and interestingly, not only did she attend but at the end of it she was referred to another service because they have a... there's a new service in (Town) which is there to look at gaps... there's a pilot in (Town) and basically it's got a year and so at the end of the (Parenting Programme) I think it identified that she had still ongoing issues and there wasn't anywhere else and actually interestingly I got a phone call off the worker down there to tell me that they had taken her on and actually because there was court dates and things coming, they were able to provide her with childcare and support...

(Phase 2 HV 8)

Creating Teams around Children, or bringing together a Network of Support, was identified as a productive way of informing parents directly what was on offer, resolving any difficulties with communication, and was viewed as a very effective, efficient way of collaborative planning for the baby or child.

I think that processes have worked, you know, the liaison with everybody that's involved, you know, we have a team around the child, the parents can come to the meetings and so they've seen all the professionals who deal with the child in the community in the one place, and I think the message that that gives the parents as well that nobody's taking decisions in a vacuum, that everybody talks to one another and they can come and talk to everybody at the one timeIt's a lot of work but I think ultimately it does simplify the decision making process when it can be done with a team approach as well.

(Phase 2 HV3)

8.3.2 There were limits on options

There were comments made by health visitors that fiscal constraints had meant that there had been limitations in the options that health visitors were able to offer to parents from within the community and how the criteria for requesting assistance had changed as a consequence; although there was an example where an organisation changed their criteria to meet a need:

So they actually had agreed to do a four to five group because a few had phoned up with 'we got this, they don't meet it, what can you do?' So I'd phoned up and said 'I have this four year old, what can you do?' and they agreed to that.

(Phase 2 HV8)

And one health visitor spoke about her positive experience of having additional staff within the Health Visiting Team who could support on-going work.

But you know, we're a small team, there's only me here, but we have good skill mix, you know, I have a staff nurse and I have a nursery nurse which I know in other areas they don't have that luxury so, you know, we're quite well placed.

(Phase 2 HV1)

8.4 **Decision Talk took place**

Decision Talk is Stage 3 of Elwyn's Shared Decision Making Framework (Elwyn et al 2012).

One health visitor and a parent were able to discuss the parent's concern around attending a parenting group; where the parent disclosed her fear of being judged by other parents at the group if she attended.

I think yeah I think she was frightened of being judged, you know.....we spoke about everybody.....what I probably explained to her as well that everybody is there because they feel the need to be there and reassuring her that, you know.....cause she felt with this being the fourth... fifth child rather, so why did she need now and that was her anxiety, and I says... you know, we talked about different situations, different children, you know, and really about gaining confidence that she'd maybe lost a bit of confidence about parenting and this was really just to give her confidence in her own skills again

(Phase 2 HV 8)

There were some indications of parents showing willingness to change their behaviour as part of the process; however there were also admissions from health visitors that they generally did not explore what participation in the intervention might mean logistically for the parents despite their awareness that parents were often expected to make changes in their behaviour or learn new skills.

INT: I don't know if you ever had any discussion with this particular mum around what she could expect from the dietician?

HV1: No I don't think I have, no, and I guess actually she probably wouldn't know... if I can imagine that conversation, she probably wouldn't actually know what to expect either, cause I don't think it's a service that she's used before.

(Phase 2 HV1)

Although the process of parents being actively involved during the request for assistance process, and completing forms with the health visitor, was felt to initiate a greater participation in the request system, and underlined that parents were giving their consent in an informed way, some health visitors admitted finding it challenging to be able to explain in simple language to parents what the

various terms meant. Two health visitors volunteered that they found it particularly difficult to translate what GIRFEC was, and the language around wellbeing, into something understandable for parents and then apply it to this particular baby or child.

And also the paperwork not being fit for the purpose of that age of child, a SHANARRI is not a baby thing, it's not. It's fine when they get to maybe about three, right okay fair enough, four/five/six school age, absolutely, but it's not for babies and I just don't...it's the parents you're talking about on a baby SHANARRI really more than anything.

(Phase 2 HV 5)

Yeah, we were actually talking about writing up the SHANARRI although to be honest I didn't actually explain the term SHANARRI to mum, cause I felt it was too complicated.

(Phase 2 HV 6)

One health visitor pointed out that she was aware that there may be logistical problems with attending appointments but that financial costs could be covered if the parents were unemployed.

I do think as well on the same hand if you're aware then there is, it's about trying to find a way round the transport issue, especially living here I think as well, you know, if they're out of work then we can access where they get the costs back,

(Phase 2 HV 2)

None of the health visitors were able to say that they specifically asked parents what attending another service would mean to them, before the request for assistance, and explore how they would get there, who would look after other children, or whether they could afford the bus fare, instead expecting the parents to bring these matters up if they were an issue, based on their past discussions. One health visitor explained that she intermittently and routinely checks out parents' opinions by saying *is that okay?*

INT: *D'you remember asking mum at all if she had any kind of worries about this*

HV5: *I think it comes out in general conversation rather than saying d'you have any worries or concerns about that, I don't remember actually saying those words, I might have I don't know, I do tend to say 'is that okay?' 'Is everything okay with that, is there anything you want to ask about that?' that's the way I would kind of do it.*

(Phase 2 HV5)

The parents who were interviewed did not see this lack of direct questioning as a problem as they felt that if they had wanted to ask questions about any aspect of the service or process they knew the health visitors well enough to be able to ask easily, and that they were a good source of information; however these were parents who had volunteered to participate in the research study and clearly had an established relationship with their health visitor who had approached them initially.

So I'd say she just kind of kept everything straight, kept things going, kept me updated and I feel like I can actually talk to her and tell her things, that I do feel like we've got a good relationship and that she's approachable and I don't ever have to feel like if I was to ask her a question or say anything about him, that she would be non-supportive.....

(Phase 2 Parent 2)

INT: *Who d'you tend to go to when you've got things that you want to kind of ask about what happens next or...?*

Parent1: *Well I'll phone (HV) or I'll look it up on Google [laugh]!*

(Phase 2 Parent 1)

Some health visitors felt that the timing of approaching an issue, where a decision was required, was really important and waited sometimes many weeks for the right moment; however on further analysis this delay only happened in relation to situations where health visitors were consciously supporting parents with children with complex needs or disabilities and decisions were required in relation to services which would support them in the future. Issues identified within reviews were addressed immediately in some way – even if the health visitor had to arrange to meet the parents again to provide them with information about other services.

So that was actually, it's not a big form, but it was actually a long process, I left that form with them for three months before and of course they lost it and I had to bring them, but it was just gently always... I had to keep putting it in my own diary to remind me that that was a topic that we had to keep addressing

(Phase 2 HV 3)

8.4.1 Decisions were made

Within the data from this study there was evidence that decisions were made in relation to a range of topics such as participation in:

- Sleep programmes
- Parenting programmes
- Toddler groups and nurseries
- A family centre run by a Third Sector Group

There were also decisions to request assistance from

- Dietetics
- Speech and Language Therapy
- Paediatrics
- Pre 5 Assessment Team
- Pre 5 Education Service
- Multi-Agency Support Group
- General Practitioner

8.5 The Quality of *Relationships* was evident

When exploring the interactions within the encounters; and analysing the nature of the relationships reported within the interviews, this reinforced how important relationships were to health visiting practice and how the quality of relationships was integral to shared decision-making processes.

The Solihull Approach is a framework (2014) which is used widely across health visiting practice in the United Kingdom. It was devised by health visitors and clinical psychologists based on well-established theories from psychology and child psychotherapy. The framework takes into consideration three elements of relationships which overlap in practice: containment, reciprocity and behaviour management. How these components manifested themselves within the health visitor and parent relationships has been used as a way of providing structure to this section.

Containment was first described by Bion around 50 years ago (1959) and is linked closely to theories around empathy. It is defined as:

'When a person receives and understands the emotional communication of another without being overwhelmed by it and communicates this back to the other person. This process is known to restore the ability to think in the other person'

Reciprocity was first described by Brazelton (Lewis and Rosenblum 1974) in the context of adult: infant relationships; however it can be used to describe the interaction which takes place in all relationships. Reciprocity, also known as the '*dance of attunement*', describes the initiation, regulation, and termination of an interaction where both parties are actively engaged in the process.

Behaviour management is based on learning theory and behaviourism described by Pavlov in Skinner (Skinner 1988) and refers to the attention and reward behaviours which one person can use to influence the behaviour of someone else.

The Solihull Approach Model (2014) advocates that all aspects of the model will be evident within positive relationships; but that for behaviour management to be effective this relies on evidence of containment and reciprocity being in place first.

This next section explores the theme of Relationships, and uses the Solihull Approach Model as a framework to structure the data, identified within:

- Phase 1 - Health visitors and parents
- Phase 2 - Health visitors and parents

There was evidence that other relationships also had an impact on shared decision making processes – and these include:

- Phases 1 and 2 - Parents and Others
- Phases 1 and 2 - Health visitors and Others

8.5.1 Phase 1 - Health Visitors and Parents

8.5.1.1 Health visitor contains parent or evidence of empathy

It was evident in one of the cases that the health visitor did not want to give new information to the parent too quickly and overwhelm her; the health visitor was also listening attentively and responding appropriately and although a challenging conversation for both of them there were indications that the health visitor was not overwhelmed by the situation.

HV: The other thing that we've spoken about in the past and I've never really taken cause I just don't want to inundate you cause I feel as though you've been inundated with different things is would you want me to look at referring you for the incredible years?

Parent: E thought that...

HV: What were your thoughts on it?

Parent: Solihull would be better for me, that's the one that she takes.

(Phase 1 HV/P1)

There was an example of a health visitor organising a befriending service which was evidence of empathy, a level of understanding around the mother's lived

experience and there was also sensitivity to the impact of having many people all involved in planning processes not only for the parents but also the child.

Parent: So we've got that organised and apparently she is priority for befriending which will start in September

HV: Right, good, good.

Parent: so September, sorted.

HV: Good, so there's a plan ahead then.

Parent: Yes.

HV: That took a wee while but, you know, we got there in the end.

(Phase 1 HV/P2)

In both cases there was evidence of the health visitors showing their human side, there was real concern about the family situation and acknowledgement about how supports for the mother would impact positively on the children.

In both cases there was evidence of the parent trusting the health visitor.

8.5.1.2 Reciprocity between health visitor and parent

Something evident in both cases, and also identified by the research supervisors, was the apparent informality and the turn taking which took place in the conversations in both recorded encounters. In both cases these were well established mature relationships, where each person knew each other well after years of working together. There was evidence of equality in power, a level of human honesty, and respect for each other.

One health visitor was honest enough to admit that she had forgotten some paperwork back in the office and that she would return with it later in the day.

In both cases humour and laughter were used in a reciprocal way as the patterns of initiation, regulation, and termination of the interaction – where both the health visitor and the parent were actively engaged in the process – was evident.

8.5.1.3 Behaviour management

In both recorded encounters there was evidence of the health visitors providing behaviour management advice ranging from advice on attending a parenting group, to sleep advice, to advice around persuading the child to drink a suggested amount of fluid each day. In these examples each health visitor took control of the conversation, giving relevant information and instruction, and the parents became quieter, in agreement with what was suggested.

HV: And she's drinking plenty during the day?

Parent: She drinks when she wants, I mean, she has to be... you know, you have to give her it, 'have a wee drink', 'no I'm fine', 'no have a wee drink, I'm having a drink', 'oh right okay', so...

HV: Cause we're looking at sort of about 1300/1400mls?

Parent: I know, aye, I know you said that but I've no idea.

HV: The reason for that is that we need to stretch her bladder during the day because bladders that aren't stretched they can be irritated quite easily and it can cause bed wetting.

Parent: Right.

HV: So by pushing the fluid, she can hold a lot more during the day, because her brain is kind of hooked into her bladder saying 'I can cope with this and I can hold onto it', it's kind of training it to be able to hold more.

Parent: Aye.

HV: So we want that capacity because if she isn't drinking enough her bladder shrinks and it becomes irritated.

(Phase 1 HV/P2)

8.5.2 Phase 2 - Health visitors and Parents

8.5.2.1 Health visitor containment or evidence of empathy

Within Phase 2, individual interviews with health visitors and parents, there was evidence of containment. One health visitor demonstrated that she understood what life might be like for a parent with a large number of children in terms of being organised and achieving goals.

I wanted to explore all the options with her because she's got enough appointments to keep and people to see because of the process with child protection, so I didn't want to add to her,

d'you know what I mean, a mum with four children, life's hard enough, you know

(Phase 2 HV1)

This health visitor was also aware that 'containing' parents is what is required of the role when other professionals and agencies have discharged the child from their service for failing to attend.

Yeah I know and it eventually just lands back with us who then we've got to contain them or do something with them which can be quite tricky yeah, definitely.

(Phase 2 HV 1)

There was evidence of another health visitor containing a parent as she worked through her guilt of leaving her toddler with grandparents when her baby was admitted to hospital.

he had dad and he had his maternal grandparents who he knew very well, but it added huge amounts of stress to an already stressful situation because she was feeling very guilty about leaving the toddler and worried about the effects on him, and it made it quite difficult actually afterwards because a lot of what she'd be talking about would be everything that was going on with the new baby and all the guilt that she was feeling over leaving the toddler

(Phase 2 HV3)

There was evidence of empathy and effective listening as another health visitor described her awareness of the impact of living with a new baby – and a baby that was difficult to settle – on her own with adult support at a distance.

Interestingly this was a situation where the health visitor was frustrated because of her inability to initiate support from other agencies and her self-awareness that she had run out of ideas. However, when the mother visited the GP it was the health visitor that she mentioned as being someone that she could talk to easily after only two contacts.

I think yeah, and one of the GPs spoke to me to say that obviously because she was quite teary and things like that, the GP had come in to say that she had been in and she felt, the mum had says to her that she felt that I was somebody that she could speak to and she couldn't speak to everybody

(Phase 2 HV7)

Yeah I've got her mobile number and I've got her office number and she's easy to approach, if you leave a message she'll always answer back, but on that occasion I think I just went up to the surgery and saw her, I remember sitting on the bench at the surgery talking to her, so I think I just popped in to see her and managed to get her that day I was off work.

(Phase 2 Parent 5)

8.5.2.2 Reciprocity

There was one example provided at interview with a health visitor which provided evidence of listening and responding, listening and responding as they worked through different concerns that the parent had. This was the first contact. Each issue that the parent was concerned about was worked through and the health visitor clearly took the issue seriously before the parent addressed the issue that was really upsetting her: her 5 year old child's encopresis. This was an example of trust building through the conversation.

HV6: And then the third one which just came up, partly through sort of going through everything and, you know, 'is everything else okay?' was that he's still soiling when he's not at home.

(Phase 2 HV6)

8.5.2.3 Behaviour management

Many examples of behaviour management techniques were described within the interviews. One health visitor described how to use a controlled crying technique with awareness of what impact controlled crying may have on the parent's lives and so personalising it. This was based on having established a trusting relationship with this family – who had asked for her to be their health visitor when they moved back into the area; there was evidence of containment and reciprocity within this relationship.

So we discussed the controlled crying strategies and how they're going to have to be really patient, can they manage that,..... how are you going to feel,?'

(Phase 2 HV5)

Another health visitor encouraged a mother to attend a Parenting Group but approached this in a very sensitive manner; having identified this mother's low

self-esteem exacerbated by her experience of a sequence of abusive relationships. This example provided evidence that it took a long time for a health visitor to build up trust in a relationship where the parent has difficulties with forming trusting relationships due to their past life experiences.

I have quite a historical contact with this mum because the children at high school, mum arrived... it's been quite a tenuous relationship over the years

(Phase 2 HV8)

8.5.2.4 Trust became a theme within Relationships

It became evident within the data that where containment and reciprocity existed within a relationship, a level of trust was also evident. In trusting relationships the mothers believed that the health visitor had a genuine interest in them at a personal level. This was evident when the health visitor phoned up to find out how things were when the parent was engaging with another agency and also the level of on-going concern.

Yeah absolutely, yeah and I know it's good, I can phone her, I know she'll phone me back and she'll sometimes phone me out the blue just to see how we are and that's a nice... it's nice to have that.

(Phase 2 Parent 3)

However there was evidence that some parents found it easier to respond to trust than others and for many it took time to build up trust – particularly if there was current or historical adversity in their lives. There was one example of parents, where one had been in the Care System and both had experienced poor parenting, where it took time to trust this health visitor. Interestingly it then took joint visits with the health visitor and another agency before parents trusted people from the other agency and would attend on their own without the health visitor.

INT: Yeah.....do they ever do joint visits?

HV5 .I've done a few joint visits with (Third Sector Organisation) to this family

(Phase 2 HV5)

There was an example from a parent who was socially isolated and feeling depressed due to a series of disappointments in her life, where the health visitor supported her to meet with parents in the same area.

we were a little bit worried about whether I was going to end up with postnatal depression so she was very kind of... 'right, there's this group and there's that group, do you want to do them, is there anyone that'll take you?' and she would give me lots of information about different things to do. So not even just for helping out with (Child), she was great

(Phase 2 Parent 2)

Sometimes there are difficulties with building relationships and trust. One health visitor spoke about the challenges which presented when a mother who had just moved into the area failed to engage with her. Due to the level of concern this initiated the need for social work input as there were concerns about the children's safety; which led to child protection processes being implemented and the children's names being placed on the local Child Protection Register. However when another new baby was born into the family the relationship had the opportunity to develop and it was only then that the health visitor felt that a trusting relationship was beginning to form.

HV: And she had a new baby, so in a way it was good.

INT: Right okay, so that was a way in.

HV: Yeah it was, cause they could see that we were there to support them and help them, not just to pick them up or how they may be perceived that we were just there to, you know, pick fault with what they were doing.

(Phase 2 HV 1)

One health visitor spoke about the work and effort involved in building up a relationship with a couple with a new baby, where the mother's older children had been removed when in a previous relationship. Both parents were participating in methadone programmes, both involved in the same accident when 'under the influence' so both had physical needs, but building a relationship and building trust in this situation took time despite the health visitor being very clear and honest about her role and responsibilities and that it was the baby who was

always going to be her focus and that she would always intervene if there were concerns.

INT: How long d'you really think that the kind of process of just getting... building your relationship and actually getting her to kind of come on board with you took?

HV: A good few weeks.

INT: Good few weeks, yeah I'm sure it would do actually.

HV: Yeah a good few weeks, you know, it was just sort of bottom up approach, just assessing them.

(Phase 2 HV 9)

8.5.3 Health visitors and Others

There was evidence that health visitors were not only building up relationships with parents to work collaboratively, make shared decisions and work towards improving outcomes for their babies and children, but to enable this to happen they were also needing to build relationships with others.

8.5.3.1 Relationship with baby or child

A key focus of the role of a health visitor involves observing, weighing and measuring; examining babies and children in relation to their growth and development and assessing their interactions and communication with those around them.

In the early days this focus is a way of building up a relationship with the baby and child and can be particularly helpful if there are any concerns

So I went to her house and I sat with her and we talked all about the behaviour and actually loads came out, you know, he was eating sand, he paces up and down, he's got short attention span,and as I say, his speech was quite delayed, a lot of this pacing, in his own wee world, own agenda, all that kind of thing

(Phase 2 HV 4)

One health visitor was concerned about the child listening to her parents talking about her in a negative way

HV5: Sometimes you think when a child's a certain age they're actually listening in to your conversation a little bit, and sometimes it's difficult

to really get down to the nitty gritty of what the child's behaviour is in a positive way, so the parents are maybe saying 'oh she's a this, that and the next thing' and they're kind of sitting knowing that this child's kind of still there, so I kind of try and say 'well, you know, she's here and what do you think (Child's name)?'

(Phase 2 HV 5)

But despite these occasional references to relationships with babies and children there were indications in the data that there was much less interaction with the baby or child than with the mother.

8.5.3.2 Relationships with other family members

There was evidence that interactions with other family members varies across health visitors and across families.

One health visitor mentioned the child's grandmother, and examples of health visitors meeting the father was specifically mentioned in three cases – one with a child with congenital abnormality, where the father came home from work early in order to meet the health visitor and be part of any decisions

HV3: and dad was there as well, and he would arrange to be home from work when I was coming cause he would have questions he wanted to ask because I'd been through all this, you know, through their last baby with them

(Phase 2 HV3)

and another who had substance misuse issues who was possibly always at home. There was a history of domestic abuse within this family and it is not unusual for health visitors to be aware of the presence of controlling partners at every visit; however a relationship developed with the health visitor in relation to his own needs (as the health visitor became seen as an extension of the GP and Addictions service)

HV9: but I had also asked her permission to contact her (Addiction) worker and also dad's (Addiction) worker; so we'd been having wee conversations, you know, back and forward and about supports for parents and so we kind of moved it forward from there.

(Phase 2 HV9)

From the data it was unusual for the health visitor to meet with fathers and other family members after the first visit.

Some health visitors asked about other family members and the parents' experiences of being parented themselves – but again this was rarely reported unless there were issues

HV5: the dad's got a background in foster care, he's got a stigma with social work, he just can't do it, he wants to be the best dad he can be to his children but he probably has not had the background knowledge and skills

(Phase 2 HV 5)

8.5.3.3 Relationships with other professionals and agencies

The data provided evidence that positive relationships with other agencies and professionals, where there are the same level of concerns about children and families, can create an environment in which professionals working together can support families:

HV I spoke to (another professional), that day I phoned you..... and she was saying we're trying to get a Team Around the Child meeting, cause I wanted to have another meeting to get the health side into that Form

(Phase 1 HV & Parent 2)

On the other hand, if other agencies and professionals do not share the same concern for the baby, child or family, or if communication is difficult, then this can create increased stress and workload for the health visitor, and can also make shared decision making with parents to request assistance from another agency more difficult.

Section 8.4.1 identified the range of different agencies spoken about in this study where decisions were made to request assistance.

There were examples where professionals did not share the same concern. According to health visitors, this was evidenced when professionals created barriers to reappointing children if they have failed to attend their service.

I think the other barrier is the kind of, you know, two strikes and you're off, which I find really frustrating,, the way that services don't always appreciate the complexities of some of the families that we're working with, not that empathetic really, that can be difficult.

(Phase 2 HV 1)

There were a number of examples where health visitors knew people who worked in other agencies well, understood their systems and processes, and trusted them. This sense of trust was interpreted by the parents as efficiency:

It does work and it was fairly quick as well, it wasn't very bureaucratic, so there wasn't months and months of waiting with nothing that you might expect between multi-agencies; they were kind of seamless in their approach

(Phase 2 Parent 7)

Teams around children and networks of support were found to be really successful and supportive to health visitors as they actively contributed to resolving issues with families.

I think that processes have worked, you know, the liaison with everybody that's involved, you know, we have a team around the child, the parents can come to the meetings and so they've seen all the professionals who deal with the child in the community in the one place, and I think the message that that gives the parents as well that nobody's taking decisions in a vacuum, that everybody talks to one another and they can come and talk to everybody at the one time cause I think one of the big things for parents with a child with complex multiple needs is there are so many people involved and things can get lost in translation

(Phase 2 HV 3)

There were positive examples provided in relation to nurseries. One particular parent always liked it when the health visitor was able to attend her child's nursery meetings as she found the health visitor's contribution really supportive.

One third sector agency were reported to meet every four to six weeks with all local health visitors to discuss progress with families, which health visitors found to be very supportive to their practice.

There was a positive example from dietetics where the parent was told about the referral system by the health visitor, which involved:

- health visitor emails dietetics with concern
- dietician reads on the following Monday and phones the parent up as soon as she can afterwards to review the history and the current situation
- dietician then creates a plan and contacts the GP and the HV
- the dietician may or may not see the baby/child - dependent on the plan
- the dietician may or may not invite the parent to a group with other parents with babies with the same symptoms or where there are the same concerns

There were examples of GPs and health visitors having an effective working relationship and its positive impact on the ability to support the mother.

I think she has a very good relationship with the GPs up there, yeah,always feel like if I go to her it'll get sorted or she'll know somebody that I can go to

(Phase 2 Parent 5)

8.5.3.4 Relationships with peers

Some of the interviews outlined the positive support which had been received from other professionals who were working with the same family; this was through positive experience of meeting with the professionals and using a secure email system to email each other back and forth with progress reports to avoid 'over visiting' the family.

Support from peers was valued in an example where a health visitor was really upset, but as this was not child protection no other form of supervision was available.

I remember being quite aghast by the situation and I got a lot of support from my colleagues but I remember at the time being quite significantly upset by what had happened

8.5.4 Parents and Others

Within the encounters and interviews in Phases 1 and 2, there were examples which indicated the nature of the relationships between parents and their children. This section will return to the Solihull Approach Framework to identify evidence of each of the components.

8.5.4.1 Containment

In both examples in Phase 1 the parents described how they contained their children in relation to sleep issues, with the first staying in the room whilst the children went to sleep, and the second getting up and supporting her daughter back to bed when she gets out of bed during the night.

HV: And did the sleeping thing all get sorted out, I mean, obviously other than when you had the blip?

Parent: I'm still in the room.

HV: But you're gradually starting to get out?

Parent: No

(Phase 1 HV/P1)

HV: I mean, a good five out of seven she's up through the night, but she's easy to go put back

(Phase 1 HV/P2)

In another example from Phase 2 the mother was trying to protect her baby from being readmitted to hospital - whatever it took

I'm trying to say 'they're looking at him as a whole child not just in relation to his weight gain', and she said 'I get that but he ended up in hospital before because he didn't put weight on and if that happens againI will be really angry because I'm flagging this up now

(Phase 2 HV 3)

8.5.4.2 Reciprocity

An example was given where a mother relayed a conversation that she had with her child where she rationalised the change of name of the 'night nappies' to 'pyjama pants'.

Exactly, exactly so, I mean, I keep saying that to her because (Dad)'s always saying to her 'you're five, you don't need nappies at bedtime' and she always relays that back to me 'my daddy says I don't need nappies' I said 'well that's good cause you're not in nappies, you're in pyjama pants'.

(Phase 1 HV/P2)

8.5.4.3 Behaviour Management

There were a number of examples where parents were learning Makaton (a visual sign language) in order to improve their child's communication skills – and then they were ensuring that their child was also learning it in order to communicate – and it was possible to understand the nature of their relationship by how they spoke about it.

INT: Yes so it's like a game actually isn't it, when you do that?

RES: Aye, so we're all doing it, like, after we have our dinner we sit here and we'll say, like, your sister and they've got to guess what we're saying, so it's been really good, really good.

(Phase 2 Parent 8)

8.5.4.4 Parents' relationships with each other

There was some mention of the relationships which parents had with each other and its impact on the children.

There is an example of a father questioning the need for his daughter to learn Makaton.

My husband was a bit curious at times because he was like 'why does she have to learn the words if she can say it?' and I says 'well it's bringing her on and it's bringing her onto different words and she's putting them into sentences now.

(Phase 2 Parent 8)

However most of the reference to parental relationships in the interviews related to parents' relationships breaking down or abusive relationships

my first son's father and I separated when he was one and it's never been amicable, it's always been fraught

(Phase 2 Parent 7)

I said that I'm a single parent and during the breakup of my husband and I's marriage it was really... it still is really difficult, and his attitude towards myself's not great and obviously that rubs off on the kids,

(Phase 2 Parent 5)

Parents' relationships with other family members and friends were mentioned – particularly in relation to the mother's mother; but also in relation to in-laws and the influence that they tried to have if they did not think there was anything 'wrong' with the child when parents were trying to pursue some follow up because they had concerns.

Sam's gran and papa, you know, 'what's wrong with the kid?' you know, this kind of attitude

(Phase 2 Parent 6)

8.5.4.5 Parents relationships with other agencies

In the interviews there were examples of parents finding it easy to build positive relationships with some agencies, and coming back to the health visitor to say how things had gone and were progressing.

So when she came back from her speech and language she done a session, I think it's a three month block they do, so she must have completed a blockshe either popped into the clinic or she phoned me, I said 'how did you get on at speech and language?'

(Phase 2 HV4)

It was evident that the Pre-5 Education Service were committed to delivering a stepped approach to parents – by providing a baby and parent group for parents of babies with additional support needs to attend before referral to their service. The only issue was that it was not well advertised.

INT: *did you get information, did you get written information about the mother and baby group from pre-five education?*

HV3: *They sent me out, it's in their information leaflet that they send out, but of course there's so much information in that, that as a parent with all this, you could easily miss it.*

(Phase 2 HV3)

And a parent was very impressed by the service which she received from audiology and speech and language

She said that either/or would be fine, if I could go and see her or if it would be easier she could come and see me

(Phase 2 Parent 4)

However there were examples where parents found the timescale for referral too long.

INT: It was a long time wasn't it?

Parent3: (HV) wasn't happy either and I think that must have been when he was 12 weeks cause that's when we went to see her and she emailed them again and they actually phoned me that afternoon

(Phase 2 Parent 3)

There were instances recalled where parents did not feel confident enough to attend

Yes there was playgroups which I think to start off with she went to and then that sort of fell by the wayside, I think it was a confidence thing for her I think to keep going.

(Phase 2 HV2)

Physical distances between the parents and the resources was a big issue in one area

INT: Yes, so there's a big geography there isn't there?

HV1: Yeah, definitely and like I said we don't always have the resources to support those kind of families.

(Phase 2 HV1)

And other instances where professionals gave mixed messages.

so this other dietician had said to her that it actually looks like more a reflux problem rather than a milk allergy which the other dietician says it sounded more like, would the mum not want to try going back onto standard formula, and when I went up to visit the mum she was no way, she was (HVs name), after having had an unsettled baby for three/four months, there's no way I'm trying that

(Phase 2 HV7)

What follows in this chapter are links between these interpretations from Phases 1 and 2 and how they address Objectives 1 – 3, which relate to what processes currently support shared decision making in health visitor practice.

8.6 Objectives 1 - 3

The study identified three objectives to help address the principal research question. Objectives 1 and 2 related to Phase 1; and objective 3 related to Phase 2.

These objectives will now be summarised in relation to the findings and the themes before moving onto Phase 3, which has a specific focus on the main research question.

8.6.1 Objective 1.

What was happening within health visitor/parent encounters when decision-making was taking place? (Phase 1)

The agreed issues for decision making, in each of the two encounters, by chance both related to a bureaucratic process; however, within each of the conversations, decisions were made in relation to the children's health, development and wellbeing.

Although choice existed, it was not always evident; but in each case the parents had a 'voice', which was encouraged by the health visitors.

In one case the options for parenting programmes existed, but they were quickly reduced to one programme in relation to suitability and accessibility.

One of the prerequisites of decision talk, according to Elwyn et al, (1999b) is that the health visitor spends time sharing their views and the parent shares their views – which they all did at some level informally. However, there was lack of clarity around each stage of the decision making process and no evidence, in either encounter, of parents being specifically invited to share their views.

Within their relationships there was an abundance of evidence of containment, reciprocity and some behaviour management both in terms of the relationships between the health visitors and parents, and between the parents and children.

8.6.2 Objective 2

What were the perspectives of the health visitors and the parents after their encounters – in terms of their perceptions of the process and satisfaction with the final decision? (Phase 1)

Following each encounter in Phase 1, each of the four participants were presented with an OPTIONS questionnaire (Appendices 10 and 11). The range of descriptions of each phase of the process could potentially range from *Strongly agreed* to *Do not agree*.

It was interesting to note, as identified in Table 4, that after each encounter the perception of each participant was *Strongly Agreed* or *Agreed* for all phases; that there was agreement between the two health visitors and the two parents when their results were aggregated, and agreement across the four participants except in relation to decision talk.

Phase 1 Questionnaires	Health Visitors	Parents
The issue was clear	2 x Strongly agreed	2 x Strongly agreed
There was choice	2x Agreed	2 x Agreed
Different options were provided (including doing nothing)	2 x Strongly agreed	2 x Strongly agreed
There were opportunities to ask questions (decision talk)	2 x Agreed	2 x Strongly agreed
A decision was made	2 x Strongly agreed	2 x Strongly agreed

TABLE 4 RESPONSES TO THE OPTIONS QUESTIONNAIRES IN PHASES 1 AND 2

8.6.3 Objective 3.

What evidence was there that decision-making was shared between the parents and the health visitors? (Phase 2)

8.6.3.1 Issues

Although issues were identified where decisions had been made, different levels of concern between parents and health visitors were evident and again there were examples of decisions related to processes which were not always directly related to the current wellbeing of the baby or child.

8.6.3.2 Choice

Choice was not always evident, and whether choice was given was related to the condition and the method of decision making which the health visitor used. True choice was not always possible, either due to the views of others who had influence e.g. partners, other significant family members, or because of the views of health visitor managers around the necessity to refer on swiftly. Choice was also potentially reduced where parents were within child protection systems.

8.6.3.3 Options

Options of the availability of evidence based interventions and the involvement of other services were minimal; the only feasible options were either to request assistance from another service now or to delay and review. Doing nothing was never an option once there was indication of a need. The options available were also related to health visitors having relationships with other services; knowing their systems and processes and their criteria for requesting assistance.

8.6.3.4 Decision Talk

Decision talk relied on health visitors knowing and understanding the child, parent and family. It also required understanding of the current systems and processes

of other agencies, and being able to explain this to parents. Although health visitors felt that they knew families well, and parents interviewed also felt that the health visitors were accessible and interested in their situation, there was no evidence of structure in the conversations which would raise any issues around emotional and physical accessibility to other services.

8.6.3.5 Relationships

The interviews portrayed that strong, established, trusting relationships existed between health visitors and parents; which was understandable in terms of the parents' experiences due to the recruitment processes adopted within this research study. There was also evidence of containment, reciprocity and descriptions of some behaviour management techniques being described – but only once a strong relationship had been established. This was interesting as it transpired that very few of the health visitors interviewed had had the opportunity to participate in Solihull Approach training – which may indicate that this way of working and relationship building is intuitive to health visiting practice. This is discussed further in the next chapter.

A summary of these findings from Phases 1 and 2 were reported back to the three focus groups during Phase 3, and each group of health visitors agreed that this information was credible and related well to health visitor practice. This information then prompted discussion in relation to the implementation of GIRFEC and its potential impact on health visitor practice. The focus groups were recorded, transcribed and analysed in the same way as the data from Phases 1 and 2 in order to address the principal research question; the findings are the subject of the next chapter, before being discussed in the following one.

Chapter 9 - Findings from Phase 3

Within each of the focus groups around 20 minutes was spent relaying back to the participants the findings from the study to date. By that stage the interviews and encounters had been transcribed from Phases 1 and 2 and the majority – though not all – of the analysis had taken place.

The findings were placed in the context of GIRFEC. When fully implemented, as health visitors – and therefore the Named Person – if they become aware that a child's wellbeing is not currently being supported, promoted and safeguarded, the National Practice Model will create a framework for them to assess the child and their environment using the My World Triangle Assessment Tool. Following the assessment and analysis if issues are identified, which are 'getting in the way' of the child's wellbeing, then the health visitor will need to address the issues through planning processes.

The findings, as they were portrayed, were accepted as being realistic to current health visiting practice.

Group 2 with 4 Health Visitor Participants

Res: So does that sound realistic?

Various: Mmmmm Yeah

Group 3 with 2 Health Visitor Participants

Res: Does it feel relevant to the way things are progressing at the moment?

HV 1: I think so – yes

HV2 I think so cause it's all based around GIRFEC...and the language that's used.....it is very relevant and up to the minute

The focus during the following 30 minutes in each group explored what implementing *Getting It Right for Every Child* may mean in practice for health visitors and what processes would be supportive when planning with parents.

Extracts from the discussions related to each of the five themes are identified below.

9.1 Issues

It was apparent that health visitors were currently trying to work in a way consistent with the role of the Named Person. They were creating and managing 'Teams Around Children', but were struggling to offer the level of service to children, parents and families which they wanted to, sometimes due to bureaucratic issues:

because we don't have the process of administration, room availability, whatever, the whole logistical of actually getting a team around the child meeting up and running....everything is in PDF....., you can't update that plan because it's in PDF which is read only

(Gp 2 HV 1)

Although each group relayed how they are currently carrying out this responsibility, there was still concern around the perceived additional responsibilities related to the roles and responsibilities of the Named Person, and what that might mean for health visitors and their practice in the future.

There was a feeling that more would be expected from them than is currently expected, and that more information about children would be forwarded to them once others knew who the Named Person is for each child.

Conversely, they were also concerned that there might be challenges around others *not* knowing the Named Person for each baby and child. There were also concerns about the logistics of ensuring 'cover' when the named person is away, and that other professionals might not understand the role and responsibilities of the Named Person and how it interfaces with their own roles.

I did not mention at this stage the findings from Phases 1 and 2 which indicated that not all *issues*—which were addressed through planning processes in the study—were directly related a child’s wellbeing; as at this stage this was not realised. This was unfortunate as it would have been an ideal opportunity to explore why this might be the case with each of the groups.

There was however a recognition within the groups that in order to work in collaboration with parents through the assessment and planning stages it would be important to engage with the parents in a meaningful way around GIRFEC. This was interpreted by the health visitors as needing to be able to explain the National Practice Model to parents— especially with it being included in the Scottish Women’s Handheld Maternity Record (SWHMR) and the child’s parent held record (the Red Book). Implementing this in practice had presented difficulties to the health visitors who had found that describing the wellbeing indicators and the GIRFEC National Practice Model to parents was a challenge - with a particular concern around being able to explain and apply each of the wellbeing indicators to a baby in a meaningful way.

I think for parents that looks all very mathematical, circles and triangles, you know, and you look at it as a parent and you'd think 'oh...' you know, it's all diagrammaticI don't think it's particularly user friendly, cause we've got a big laminated version of it in the office, you know, and it's hugely complex.

(Gp 2 HV2)

In terms of identifying risk it was acknowledged that the resilience matrix is really helpful with supporting the assessment process; however it was voiced that further training in using the resilience matrix was necessary along with practice at using it.

HV1 *we just need to get a bit more practice at it really and have the tools that support that process as you're saying yourself, the resilience matrix.*

INT: *.....enough training in using the resilience matrix?*

HV1 *No, absolutely not.*

(Gp1 HV1)

In terms of the assessment process, observing a child in different contexts was identified as an important contribution, as it helps to focus on possible issues, particularly seeing the child with other children of the same age.

9.2 Choice

Each of the groups discussed the importance of knowing when a decision is indicated and when choice is appropriate because options are available.

However, in each group the discussion focussed on the lack of options available when planning with parents and the complexity of the request for assistance processes when an option had been chosen.

9.3 Options

The language used within the Request Forms was one of the issues which health visitors found difficult, in terms of being able to explain services to parents and then make progress:

you know, you're teasing that out and doing all that with them and then you start to get, then you look at this paperwork and think 'this is going to put them off'.

(Gp2 HV3)

There were also challenges associated with accessing evidence-based interventions, as well as vulnerable families having to opt in

we've got families that are quite vulnerable and they're being asked to opt into a service sometimes rather than opt out....so you're referring or requesting assistance from a service.....and they've got no money to phone them or they've got no transport to get there

(Gp2 HV4)

9.4 Decision Talk

In terms of the planning processes and discussions with parents through the processes, it was evident that parents were engaged in the processes, were able to express their views to health visitors, and that these views were understood.

I've had that with parent, wee boy's got severe disabilities in relation to a rare condition that he has and from birth I've had to gradually introduce each service one at a time because at certain points in that she would say 'I've reached overload, I can't do anymore of this, I can't have anybody else involved, I'm doing too many appointments, I'm losing the will to live, I can't have anything else!'

(Gp2 HV2)

Paperwork associated with the planning processes at a multi-agency level was challenging.

When the groups were led to think about what supports planning in a collaborative way with parents, the quality of the relationship was given high priority.

9.5 Relationships

Although the quality of the relationships between the health visitors and the parents were valued, once again the discussion moved round to discussions about the need for the health visitor to link effectively with other agencies, the importance of knowing them well, and understanding their systems and processes.

The informal support that health visitors get from each other was acknowledged and valued; however it was felt that there was not enough opportunity for formal clinical supervision necessary to implement this new way of working.

The importance of parents being part of planning processes in multi-agency planning, and in this context the need for admin support if the health visitor is chairing the meeting, were also highlighted.

It was felt that the new programme of contacts will be helpful in terms of creating opportunities to build relationships with parents.

The Child Health Surveillance Programme (CHSP) system also supports the planning and review processes.

In summary, processes to support planning with parents were identified in Phase 3 (Table 5) as:

Assessment Processes	Analysis Processes	Planning Processes
Trusting relationships with parents	Supportive relationships with colleagues and peers Supervision to make sure that approaching analysis correctly	Supportive relationships with other Agencies and efficient and effective parent friendly request for assistance processes
Health visitors able to explain about wellbeing to parents	Health visitors having a good understanding about the National Practice Model and the Resilience Matrix	CHSP for recalls Multi agency planning with the parent present

TABLE 5 PROCESSES WHICH SUPPORTED ASSESSMENT, ANALYSIS AND PLANNING

Chapter 10–Discussion in relation to the Findings

This study aimed to identify what processes support effective shared decision making when health visitors and parents are planning to improve the wellbeing of babies and children within the context of implementing GIRFEC. Current practice in relation to shared decision making was considered at the start of this project, and then this moved towards thinking about the impact of implementing the Named Person Service into health visitor practice as GIRFEC is rolled out across Scotland.

The findings, when exploring current practice, indicated that key elements of shared decision making were missing, for instance the ‘issue’ was not always clearly understood in the same way by the health visitor and the parent, or triggered the same level of concern. ‘Choice’ was not always possible or clear because the ‘options’ available were limited and sometimes there were no suitable options of evidence-based interventions designed to improve the wellbeing of children. Although ‘decision talk’ clearly took place, there was not the evidence to show that it took place at the depth required to establish the impact of each of the possible options on the child or family – where options were available. This is similar to Towle et al’s (2006) experience, where the participants thought that they were offering shared decision making but the transcripts indicated that this was only taking place in a limited way.

This final chapter will reflect on findings from the data. Through continuing to use each stage of Elwyn’s Framework as a structure (Choice, Options, Decision Talk), along with the additional themes of ‘Issues’ and ‘Relationships’ which were identified within the study, the discussion will reflect on the research question and develop theory around health visiting practice in the context of shared decision making.

10.1 Issue

Although analysis of the encounters in phase 1, and interviews with the parent participants within phase 2, did demonstrate that issues which required decisions were clear, when the health visitor participants were interviewed in Phase 2 they described encounters which they had been involved in where there was some lack of clarity around the nature of the issue. Sometimes this was due to a number of issues merging, lack of agreement about what the issue was, or differences in levels of concern around the issue between the parent and the health visitor.

As one of the main ambitions of implementing GIRFEC is to give every child in Scotland 'the best possible start', there is a focus on improving outcomes for children when planning which interventions are required with parents. However even when the issue was defined clearly in the study, there were times when the issue discussed was not directly related to improving outcomes for the child, but was more focused on bureaucratic processes which, it could be argued, may have got 'in the way' of the real issues.

Within GIRFEC, the expectation is that many of the issues which will need to be addressed will be identified as a result of using the National Practice Model as a structured framework – which in essence aims to support the use of rational, logical, systematic (system 2) thinking and decision making. Evidence shows that this slower more methodical type of decision making is less likely to be affected by cognitive bias than a more intuitive, fast approach (Baron 1997). In rational decision making, information is gathered in a structured and systematic way, using tools and frameworks to support the gathering of facts, data, and observations, which then supports analysis.

Some of the examples which were described demonstrated a lack of the health visitor's understanding about the nature of shared decision making in the context

of using the National Practice Model during assessments – as sometimes what was described was a situation where the parent presented with an issue or concern, looked to the health professional for advice and then agreed with what the health professional suggested; which was more akin to a traditional paternalistic approach (Upton et al 2011). This is not to say that the decision making processes which these health visitors chose were inappropriate for the context but rather that there was evidence of using fast, intuitive, (system 1), decision making in these cases. This uses heuristics, or 'rules of thumb', and although the right decisions are made frequently in these situations when there is a level of expertise in general these decisions are prone to the influence of cognitive biases when they use this approach and tend not to be able to take another person through the decision making process; which reduces the likelihood of it being shared.

Although health visitors in the West of Scotland (in five Health Board Areas) have used the 'My World Triangle Assessment Tool' since 2006 for routine assessments of all children on their caseloads, audits of records across Scotland, including by the Care Inspectorate (2014; 2013) have indicated examples of a disconnect between the information gathered, analysis and what is planned for the child. This could indicate that health visitors in practice are tending to respond to what they are presented with and applying heuristics, through learnt behaviour, which speeds up the decision making processes (Baron 1997), and as this intuitive decision making approach does not require conscious analysis this may be why the analysis has tended to be missing from the child's records.

It was also interesting to note how, within Phase 3, there was a tendency in each of the groups of health visitors to veer away from any discussions which spent time contemplating decision making processes with the parent. This may suggest

a lack of insight into the processes which the health visitors were undertaking at the time or a lack of understanding that shared planning is the ideal.

It is possible to support aspects of these findings with two prominent decision making theories; Dual Process (Kahneman, 2011) and Cognitive Continuum (Hammond 1986). Dual Process Theory (Kahneman, 2011) suggests that humans use two systems of thinking (System 1 and System 2) and incorporates recent work from social psychology and neuroscience (Kahneman 2011). Within this theory both System 1 (using the intuitive part of the brain) and System 2 (using the cognitive more rational part of the brain) are acting simultaneously whilst continually interacting and influencing each other. According to this theory the output depends on the context, the decision maker's personal insight and their intellectual capacity and capability.

Cognitive Continuum Theory (Hammond 1986) has often been applied to nursing research; it shares similarities with Dual Process Theory and can also offer a level of insight into what appeared to be happening in practice within the study. Cognitive Continuum Theory, as described by Thompson and Dowding (2009), suggests that decision-making in practice does not often fit neatly into either intuitive decision making (at one end of a spectrum) or analytical decision making (at the other) but instead takes place somewhere between these two extremes – termed quasi rationality, it is dependant on factors related to the task such as the amount of time available, the number and nature of cues evident, and the level of uncertainty within the context.

Thompson and Dowding (2002) suggest that in reality practitioners operate nearer the intuitive mode most of the time rather than within the analytical mode because time is often limited, there are multiple cues (some with limited salience) which create complexity leading to high levels of uncertainty. In addition for many years there has been no need to justify the decisions on paper which have

been made in practice. This overriding tendency to use intuition in practice is also recognised within Dual Process Theory and is explained in relation to the natural dominance of the part of the brain which makes quick decisions with minimum emotional and intellectual effort. This fast thinking is essential within many aspects of life, for instance to preserve personal safety, and it is crucial within many areas of healthcare to respond quickly where time is of the essence and clinical deterioration may occur if there is a delay. Consistent with Cognitive Continuum Theory Kahneman (2011) also suggests that a more rational way of thinking is most likely to dominate when there is thinking space, low levels of anxiety, emotional well-being, and where the decision maker understands that there is always a tendency to veer towards System 1 thinking when, in many cases, System 2 produces more reliable results.

When applying the ideas from these two theories to this study it is possible to identify cases where there are multiple cues and complexity, both of which are triggers for using intuition in decision making. The difficulties described by some health visitors in defining the issue and processes may have been linked to a lack of personal insight into decision making processes in addition to a lack in understanding around wellbeing indicators and corresponding outcomes.

The implication for health visitor practice is that when there is evidence that the optimum outcome from a decision will be achieved through rational, analytical thinking, in collaboration with a parent, this is more likely to be achieved when the health visitor has personal insight into their decision making tendencies, has time for deliberation, is emotionally well and is able to define the issue to be addressed with the parent with clarity and share an understanding of the impact of the issue on the baby or child..

10.2 Choice

To be able to make a choice there needs to be at least two options which are described and then offered. There were a number of examples where choice was not offered, but health visitors made the decisions and parents agreed; which means that these were not shared decisions. There were times when this was entirely appropriate; such as a child with a rash, or in instances where lack of weight gain in a baby was the issue.

On one occasion choice was given between progressing with requesting assistance to speech and language therapy or delaying the request whilst the parent increased their activities with their child, such as reading and talking directly to them face to face. The child's development was to be reassessed at a future date by the health visitor. It was acknowledged that, in these instances, having an evidence based tool to assess or screen a child's development and then to reassess this was valuable, as was having a system in place to recall the child back to the health visitor's attention (through the National Child Health Surveillance Programme).

It was noted, however, that this type of choice was not always offered to all parents. Examples in the study where choice to delay requesting assistance was provided was more apparent where the health visitor appeared to trust the parent to implement an intervention. It could be argued that these were articulate, intelligent parents who understood what was expected at a sophisticated level because they were used to making conscious choices in their lives. There is evidence to show that to be able to make these rational choices in life a person needs high self-esteem, a sense of purpose, and self-efficacy. From my experience in practice it is evident that a significant number of parents have not themselves been parented in such a way which will provide them with what Antonovsky (1987) calls, a 'sense of coherence', and the knowledge and skills to

make rational choices with a positive sense of purpose(Eriksson and Lindsrom 2006). These theories can be integrated into theories around parental capacity (Cleaver et al 2011).

There is also knowledge from practice, identified through practice wisdom (Dybicz 2004), that many parents are distracted from putting a child's needs before their own needs because their lives are complex and their own basic needs are not being met, for instance due to levels of deprivation, a drug dependence, or through fear of emotional or physical harm to themselves or their child(Wilson et al 2011). In this environment, parents find it challenging to make rational decisions, as they are frequently responding to what is within their chaotic environment by using reflexive, intuitive, fast, (system 1) type of thinking (Baron 1997).

It would be no surprise then if health visitors had a tendency to be directive with parents who are struggling, rather than providing them with a choice. It could be argued that this a missed opportunity for health visitors to support parents in their personal development, and expose them to a kind of decision making which is based on choice, as long as the child is safe. Perhaps there is the potential to be able to build a trusting relationship through this approach, and also to increase a sense of self-worth in the parent. It should be recognised that this approach may be more time consuming, and hold an element of risk due to the uncertainty.

However, Adams and Grieder (2014) promote the concept of supporting decision making when planning with clients who misuse substances, as they believe it is an effective way to recovery, despite these being some of the most challenging people to work with due to the high prevalence of mental ill health inthese clients.

Another reason why a parent's ability to make choice may be limited is because they are not in control of their own destiny but rather there are others within their family and associates who have power and control over them. An example was

given within the interviews where a mother's decisions were overruled by her abusive partner. This prompts the question of how much cognisance health visitors give to others' opinion when offering choice, particularly when those other people are not visible to the health visitor. Fear also triggers basic reactions in people, which reduces their ability to be rational (Humphries and Stanley 2006).

10.3 Options

A great deal of the discussions within Phase 3 revolved around the challenges which were faced by health visitors in relation to lack of options, and the quality of the options which were available to provide evidence based interventions. Health visitors were aware that how the options were presented was very important.

As already indicated, to make a choice there needs to be at least two options; and in this context there would need to be evidence that each of the options can provide evidence that the output will lead to the support, promotion and safeguarding of the child's wellbeing. This could explain why it was entirely appropriate that 'doing nothing' was never an option offered by health visitors within this study; whereas Elwyn always includes 'doing nothing' is an option in the framework and the literature (Elwyn et al 1999a).

Readily available information about other services in a variety of formats is a pre-requisite of providing a fair and equitable service, as identified within The Equality Act (2010), and there was evidence of health visitors finding it difficult to access information about services in a way which would support their discussions and decision making. If health visitors want to reduce the influence of evaluative bias it is important that appropriate information is provided at the time of the discussion (Elwyn et al 2012). However even if information had been recorded as being able to be given in relation to the options, at the time of establishing choice there is still evidence which shows that patients, or parents, when given choice in this way, and encouraged to use a rational approach, are still more likely to use

heuristics, as it is easier, uses less cognitive capacity and is more familiar. The impact this has is that parents will respond to what appears naturally most appealing rather than what is best for their child. They will respond to whether they like the person who tells them about the options and how it is delivered, rather than the content and its potential impact on their child. This cognitive bias has significance for health visitor practice.

10.4 Decision Talk

When parents failed to attend appointments for other services it would have been tempting for the health visitors to assume that the parents had little concern for the issue which was being addressed – but this was not the case in this study – as health visitors did show concern and understanding around the context that the parents were living within and provided evidence of compassion. However there was little evidence that the health visitors were engaging in enquiry *before* the parents received their appointments, in relation to what other factors might impact on their ability to attend another service.

Work which is currently on-going in relation to person centred care focuses on compassion, but Dewar et al (2013) also use phrases like ‘being curious’, ‘being courageous’ and values ‘connecting with people’ at an emotional level. This thinking implies it is appropriate to use enquiry to find out what really matters to parents, and what they wish for their child as they grow up and develop. This is an approach which the Family Nurse Partnership takes, but it is dependent on a commitment and ability, in both parties, to building a relationship (Scottish Government 2013). ‘Compassionate connections’, a programme used within maternity services, also promotes these effective conversations (NHS Education Scotland 2013).

Although the quality of relationships between the health visitors and parents were valued within the parent participant interviews, and the importance of building

'trusting' relationships was mentioned a number of times, it is still valuable to break this down into what made the health visitor relationships with the parent participants so effective?

10.5 Relationships

There were numerous examples, across all the Phases, of health visitors emotionally containing parents within the study. There were also examples of health visitors being empathetic and developing reciprocal relationships with the parents; even sharing a joke. There were examples of instances where health visitors described behaviour management interventions to parents. One health visitor indicated, from her language, that she understood the Solihull Approach (2014); which provides insight into what supports effective communication between two people, adults and babies/children. An awareness of the theories which support containment and reciprocal relationships, which are identified in the Solihull Approach, enables health visitors to consciously role model reciprocity and containment within their interactions with the parents. The Solihull Approach's theoretical framework, which is based on theories from psychology, identifies that if parents are encouraged to emotionally and physically contain their child, and develop a reciprocal relationship, then this creates the context where a child will increase their ability to self-regulate and to become resilient as they grow and develop (Daniel et al 2010). It was evident, however, that some health visitors had not had this training opportunity, and although they were intuitively compassionate and warm, when they were describing behaviour management interventions to parents there was a lack of evidence of reciprocity and checking out at each stage how the suggestions sounded and establishing the views of the parents.

This ability to 'check out' is the same approach to enquiry which is required to establish shared understanding about the issue, to find out what choice means to

the parent, and who else they may want to include in the decision-making.

Enquiry about the potential impact on the child, parent and family of each available option uses the same approach through 'decision talk' and supports effective planning. The next chapter will address the main research question.

Chapter 11 - Addressing the main research question

11.1 Processes which support effective Shared Decision Making

Within this study, the processes which were evident which will support effective shared decision making when health visitors and parents are planning to improve the wellbeing of babies and children – within the context of implementing the Getting It Right For Every Child (GIRFEC) Policy Framework are:

- Health visitors understanding decision making theory, so that they generate the knowledge and skills to know what types of decision making tend to be used in practice at what point, in order that they can reflect on the appropriateness of their approach to different situations
- Health visitors consciously using rational decision making (System 2) when applying the National Practice Model to support gathering and analysing information over time
- Health visitors having the skills and resources to be able to use evidence based tools to assess and reassess a child's development – and to be supported with a recall and review system
- Health visitors being able to describe the assessment process to parents in an understandable way; which will support clarity around the Issue, and support shared understanding and structured planning
- Health visitors understanding what cognitive and social factors impact on a parent's ability to make choices in life, and to have the knowledge and skills to be able to support them with decision making and to support development in parents' self-efficacy
- Health visitors being aware of, but also critical of, what options are available to ensure that interventions will lead to the outcomes which are required for a particular baby or child

- Local authorities, voluntary agencies, and other health services supporting health visitors with a range of information about their services, and being clear about their systems and processes and how they communicate with health visitors in relation to how parents are progressing and if outcomes are being met
- Health visitors taking a person centred approach to decision talk, where there is curiosity, enquiry and identification of what matters, and understanding develops in relation to what a request for assistance will really mean to the parent and their child/family, whilst also being very aware of the impact that other people with power and influence within the family can have on decision making processes

11.2 Recommendations for practice development

From evidence in this study it is recommended that health visitors routinely receive training in decision making, and are supported in practice to develop relevant skills, as it will:

- support them to have insight into their own decision making and behaviours within specific contexts
- help them to understand what influences parents' decision making when they are making choices
- support implementation of the National Practice Model as an assessment tool and the generation of analyses within records
- generate an understanding of the value of enquiry to establish parents' views; this in turn will create understanding about how the options are being interpreted by the parents and create opportunities to influence their decision making

Health visitors may also require training in communication and relationships, with the purpose of having the knowledge and skills to support parents to make

decisions, and to establish their views (essentially training in the application of Person-Centred Care in this context).

11.3 Was Elwyn's model a useful tool to use as a framework?

Using Elwyn's model of shared decision making was helpful as it provided structure to the research process; it also raised many issues where there is the potential for practice to be improved if health visitors are to work in partnership with parents (Elwyn et al 2013). It could be argued that this framework may have limitations if used in health visitor practice to support shared decision making because decision making is rarely a 'one off' occurrence in relation to one decision being made at a time. In practice, health visitors can work over many years with parents, who are sometimes making a number of decisions at the same time, over time. However perhaps a version of a Shared Decision Making Tool could be available within a toolkit to provide health visitors with a structure for the decision making encounter and to increase parent participation.

11.4 Limitations of the study

This was a small study, with a small sample, which was designed to describe what was occurring when parents and health visitors were planning to improve outcomes for babies and children. The topic was chosen as there was no evidence of any research study in Scotland which had explored shared decision making within health visitor practice. The study was conducted within a very short timeframe due to constraints around it being an academic piece of work and in the context of the challenges associated with obtaining ethical approval and slow recruitment. Although the findings, using this approach, should not be generalised it may be that these findings will inspire the need to undertake further research and inform practice.

11.5 Recommendations for further research

Following the findings of this study there are a number of areas for further research which could potentially have a positive impact on health visitor practice and the wellbeing of children including:

11.5.1

An evaluation of the impact of health visitor training, with practice development support, which focuses on theories and behaviours related to decision making and specifically 'shared decision making'. This study could determine which of a number of approaches to teaching and learning has the most positive impact on health visitors' learning, self-awareness and decision making behaviours when assessing and analysing information in relation to children in their caseloads. Impact measures could include the quality of the analysis in the record, the quality and the extent of implementation of the child's plan, and the impact of the decisions on the wellbeing of the child.

11.5.2

An evaluation of the impact of 'caring communication training to health visitors', on the quality of the shared decision making processes with parents. Impact measures could include the extent to which parents felt included and involved in the processes (whether decisions were truly shared), the extent to which other family members were able to engage in the decision making processes, and the level of parents' understanding around the impact that the identified issue may have on their child's wellbeing if not addressed.

11.5.3

Currently there is evidence that a range of different assessment tools are being used across Scotland to assess children's development and to inform decision making. In relation to the findings different interventions may or may not then be available, or accessible, to parents.

A mixed methods research study could identify the minimum, and ideally the optimum, information which needs to be gathered from each of the assessment tools, which will inform the range of evidence based interventions required to support improvements for children in relation to the most common issues which may arise. The development of a matrix of options, which could replicate the format of decision aids, could then be developed, with the support of the agencies involved, in order to support shared decision making processes with parents.

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Appendices

Appendix 1 - Health Visitor Information Sheet

Appendix 1 (version 1 – 27.7.13)



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AND HEALTH

Health Visitor Information Sheet

Date

01324 815105/ 07825 823 587

Bonnybridge Health Centre
Larbert Road
Bonnybridge
FK4 1ED

Dear health visitor

You are invited to take part in a study which explores:

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

Before you decide whether or not to take part, it is important that you understand why this research study is being done and what it will involve. Please take a few minutes to read the following information and discuss it with others if you wish, and feel free to ask me if there is anything that is not clear or if you would like more information.

Why is this research study being carried out?

As you know Getting it Right for Every Child (GIRFEC) is being implemented across Scotland and this gives us as health visitors a key role in supporting processes to meet the unmet needs of babies and pre-school children on our caseloads. An important part of this process is joint planning with children, parents and families. We know that health visitors, to a greater or lesser extent, already involve parents in decision-making when planning but little is known currently about how they achieve this.

Why have you been invited to take part?

Your Director of Nursing and Managers have agreed that this is a worthwhile study and have given me permission to approach you and for my contacts with you to be during working hours.

Who has reviewed the study?

This study has received favourable ethical opinions from the School of Nursing, Midwifery and Health Research Ethics Committee, University of Stirling, and the East of Scotland NHS Research Ethics Committee.

Do you have to take part?

There is no pressure to take part in the study and you are completely free to decide whether or not you want to. If you do decide to take part, you will be asked to sign a consent form. However, you are free to then decide to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your work or working conditions.

What will taking part involve?

There will be three parts to this study, you may take part in one or two parts only

For Phase 1 - I am looking to recruit 5 health visitors who are prepared to audio record a conversation with a parent (who has also agreed to participate) where decisions are being made to find ways to support the family in order to improve the well-being of the baby or child. No-one else will be in the room whilst the conversation is taking place; it is likely to take anywhere between 10 and 50 minutes and will be a conversation which will be taking

place as part of routine care. Afterwards the health visitor and the parent will be asked to complete a confidential questionnaire which will help to identify the nature of the decision-making; this will take around 5 – 10 minutes

For *Phase 2* – I am looking for 10 other health visitors and 10 other parents who will agree to being interviewed individually about their recent experiences of working with parents or health visitors in order to decide the most suitable plan for a baby or child. This interview will take 30 - 45 minutes and will be held at a convenient location close to where the participant lives or works.

After the conversations and interviews have been analysed any of the health visitors who have been involved already will be free to participate in *Phase 3*, where the findings from the study will be presented to a Focus Group (in a way which removes any chance of identifying what individual health visitors or parents have said). The facilitated discussion which follows will explore what processes support shared decision-making in health visitor: parent encounters and will then focus on a consensus as to how this new knowledge might impact on practice when creating a Child's Plan in the context of GIRFEC. To enable accurate recording of the content and process the data will be gathered using flip charts and an audio recorder during the discussion.

What are the possible disadvantages of taking part?

Although I have permission for you to participate in this study during work time I'm afraid that I do not have the ability to provide support to make up for your time out of practice. As far as practically possible I will always arrange to meet you at a time which suits you and at your base to minimise travel time and expenses.

What are the possible benefits of taking part?

During the course of the study there will be the opportunity to reflect on your personal practice in relation to how you involve parents in decision-making. There will also be the opportunity of being actively involved in a research study, which may include the opportunity to present the findings to colleagues, along with myself and other participants, at local and national meetings if you want to.

Anonymity and confidentiality

The content of the conversations with parents, interviews, and discussions will be analysed by me and my two research supervisors. Any identifying features will first be removed by me from the analysis so that no ideas can be attributed to one individual. All the information will be treated in the strictest confidence and will be stored in a locked cabinet in a locked office in the Health Centre where I work - or on an electronic device or computer which is password protected.

All data from the study will be confidentially destroyed ten years after the end of the study or after publication of the results of the study, whichever is later. The provisions of the Data Protection Act 1998 will be adhered to. The final thesis which will be generated out of the study will be held by the University of Stirling.

In the unlikely event that during the process causes for concern are identified – for example in relation to child protection or poor practice – it has been agreed that I will discuss this with *(name of a local manager)* and proceed accordingly.

What to do now

If you would like more information before you decide whether or not to take part, please contact me by email or telephone - the contact details are below. If you decide that you would like to take part, a volunteer form is attached. If you complete this I will phone you within one week of receiving it to discuss the study further, to answer any questions that you may have and to discuss your preference for being involved in Phase 1 or Phase 2 and also whether you might be interested in participating in Phase 3. If I receive more than the required number of volunteers I will select health visitors by the demographics of the areas that they work in so that I get a mixture of social areas represented; this may mean that some offers to participate may not be required. If you make a decision to participate in this study I will arrange to meet you to ensure that you have understood what will be involved - and for you to sign a Consent Form before the recorded conversation with a parent or before being interviewed.

Kindest regards

Ruth A Astbury (RGN, SCM, RPHN (HV), RPHN (Schools), MSc (Nurs), PGCert(PE))

My contact details are:

Ruth Astbury
Bonnybridge Health Centre
Larbert Road
Bonnybridge FK4 1ED
Tel: 01324-815105/ 07825823587
Email: ruthastbury@nhs.net

For further information you can also contact my research supervisor:

Dr Ashley Shepherd
School of Nursing, Midwifery and Health
University of Stirling STIRLING FK9 4LA
Tel: 01786 466334
Email: ashley.shepherd@stir.ac.uk

If you would like to speak to someone who knows about this study but who is an independent advisor, please contact:

Professor William Lauder
School of Nursing, Midwifery and Health
University of Stirling STIRLING FK9 4LA
Tel: 01786 466345
Email: william.lauder@stir.ac.uk

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?



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Volunteer form for health visitors

Thank you for reading the information sheet. If you are interested in taking part in this research study could you please complete the following details? Once I have received this I will contact you again within 1 week.

Before we begin I will provide a second copy of the information sheet and check to make sure that you are happy to proceed. I will then ask you to sign a consent form.

Name (capitals please).....

Work base

Contact telephone number at work

Mobile if you prefer

Best time of day to contact you

Work e-mail address if you would prefer me to contact you this way

Do you work in an area that is affluent, or deprived or mixed? (Please circle)

Are you most interested in participating in: (Please tick)

☐

Phase 1 - with one of your clients/parents

☐

Phase 2 – an individual interview

☐

Phase 3 – a focus group

Please return this form to me at

Ruth Astbury

Bonnybridge Health Centre

Larbert Road

Bonnybridge FK4 1ED

Tel: 01324-815105/ 07825823587

Email: ruthastbury@nhs.net

Thank you

Ruth A Astbury (RGN, SCM, RPHN (HV), RPHN (Schools), MSc (Nurs), PGCert(PE))

Appendix 2 – Consent Form for Health Visitor Participants

Appendix 2 (version 1 – 27.7.13)

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?



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Consent form for Health Visitor Participation

Please initial in box

I confirm that I have read and understand the information sheet dated () Version ()
for the above study.

☐

I have had the opportunity to consider the information, ask questions, and have had
these answered satisfactorily

☐

I am aware that, as part of the study, the conversations will be digitally audio
recorded however if any of this information is presented as part of the study findings
it will be done in a way which will protect my identity

☐

I understand that my participation is voluntary and that I am free to withdraw at any
time without giving any reason, without my legal rights being affected, and that any
information that I have provided as an individual, up to that point in time, will also be
withdrawn

☐

I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of Researcher

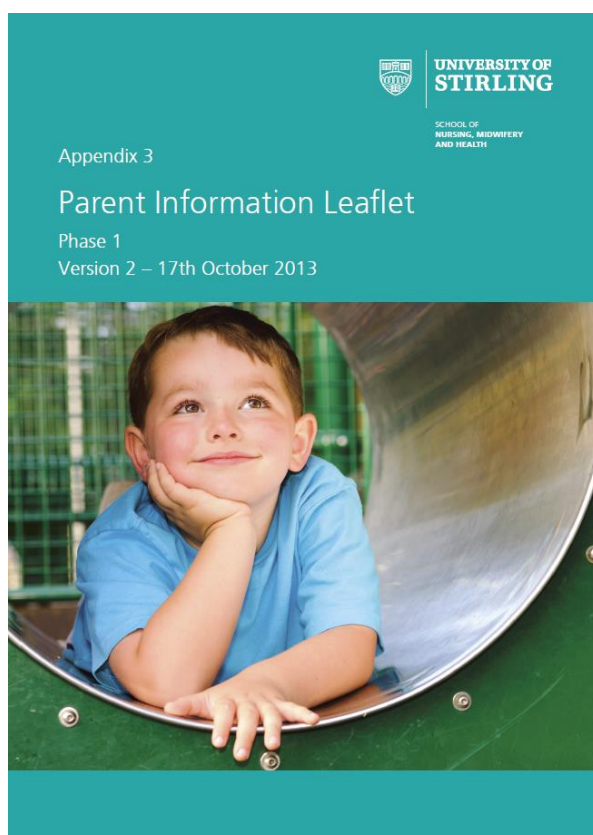
Date

Signature

1 copy for participant

1 copy for researcher

Appendix 3 – Parent Information Leaflet – Phase 1



What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

My name is Ruth Astbury and I need to undertake a project as part of my Clinical Doctorate Programme; I am therefore inviting you to take part in this study.

Before you decide whether to be involved or not I need to be sure that you understand firstly why I am doing the study, and secondly what it will involve if you agree to take part. I am therefore providing you with the following information.

Please read it carefully and be sure to ask any questions you might have and, if you want to, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

WHY is there a need for a Study?

For many years now in the health service we have known how important it is to involve people in their care and the care of their children – because if they are involved it is more likely to be:

The Right Care which is given

- At the **Right Time**
- In the **Right Place**
- In the **Right Way**
- By the **Right Person**

If you have a baby, toddler or pre-school child your Health Visitor will want to make sure that you are getting all the support that you need.

This is not always easy because sometimes the support that families need is from other services and not just the Health Service. However now that the Health Service, Councils, the Third Sector and Voluntary Agencies are working together more closely this should help families.

Health Visitors are being asked to involve parents when deciding who to approach for help locally; however, up until now there has never been any way of showing Health Visitors the best way of involving parents when making these decisions.

Finding ways is the focus of this study.

So HOW can you help?

If you currently need either a bit, or perhaps a lot, of extra support for your child, and you are currently having discussions about this with your Health Visitor I would really like to hear from you.

With your permission I would like to arrange for one conversation that you have with your Health Visitor to be audio recorded. This will take between 10 and 50 minutes.

Once the recording has taken place the only people who will listen to it will be those directly involved in the research at the University, and I will personally analyse the transcripts once names, or anything else that will let others know who the information has come from, have been removed.

The final report will be made up of views collected from a number of parents with no one parent's views being able to be identified. After recording a conversation with your Health Visitor (which you will be having anyway) there will be an additional short confidential questionnaire to complete which will give an idea of how helpful you found the conversation and how involved you felt. It will take about 5–10 minutes to complete and your Health Visitor will not find out what you write here.

What will it mean for YOU?

Through letting us know what things are really important to you in turn you will be helping to improve the way that Health Visitors support parents. For many parents helping in this way is satisfying.

WHO has reviewed this study?

This study has received a favourable ethical opinion from the School of Nursing, Midwifery and Health Research Ethics Committee, University of Stirling. The East of Scotland Research Ethics Committee REC1, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that any relevant records are made available for scrutiny by monitors from the University of Stirling and NHS Forth Valley, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

I also have permission to speak with you from Managers in your Health Board area.

What if I want to complain about my experience of taking part in this study?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through University of Stirling – who are acting as the research sponsor. Details about the process are available from the Research Team (details below). Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS processes. To do so, you can submit a written complaint to:

NHS Forth Valley Patient Relations and Complaints Service
Forth Valley Royal Hospital
Stirling Road, Larbert. FK5 4WR
Tel 01324 566660
Email fv-uhb.complaints@nhs.net

Note that the NHS has no legal liability for non-negligent harm. However if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Forth Valley but you may have to pay your legal costs.

What if NEW information about a child or parent at risk of harm is disclosed during the study?

In the unlikely case that **new** information about children or adults being harmed or at risk comes up during the conversation, or if any Health Visitor doesn't seem to be working in the way that they should, I have arranged to discuss this with one of the Health Visitor Managers in NHS Forth Valley – as it is important that all children and adults are protected and that Health Visitors always deliver a good service.

Do I NEED to take part?

Deciding whether or not to take part is completely your choice; however if you are interested in finding out more please complete the section at the end of this leaflet and pass it to your Health Visitor or post it to:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling STIRLING FK9 4LA

Tel: 07889 858 269

Email: ruthastbury@nhs.net

In a pre-paid envelope provided

So WHAT NOW? Still interested?

As soon as I receive your details I will phone you, or email you if you prefer, and we can chat about it further before you decide if this is something that you definitely want to do.

If you do decide that you want to take part in this study I will ask you to fill in a Consent Form when I meet you with your Health Visitor – which says that at any stage you are free to change your mind. And please note that whether you do or don't choose to participate will make no difference to the care that you receive from your Health Visitor.

Contact Details

Thank you for taking the time to read this Information Sheet and for considering to take part in this study. I am hoping that this Sheet has set out clearly **why** I am doing this study and how you can help. However if there is anything that you don't understand, or want to ask questions about, please phone or email me directly at:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

For further information you can also contact my research supervisor:

Dr Ashley Shepherd

School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 01786 466334
Email: ashley.shepherd@stir.ac.uk

If you have any worries about any aspects of this study you can contact:

Professor William Lauder

School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 01786 466345
Email: william.lauder@stir.ac.uk

For more information

(or if you want to take part) please complete this section and send it to:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

In a pre-paid envelope provided

Name (capitals please)	
Address	
Telephone number (Landline or Mobile)	
The best time of day or evening to phone you	
An e-mail address if you would prefer me to contact you in this way	

Thank you

Ruth A Astbury MSc (Nursing) RGN, SCM, RHV

Appendix 4 – Parent Information Leaflet – Phase 2



What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

My name is Ruth Astbury and I need to undertake a project as part of my Clinical Doctorate Programme; I am therefore inviting you to take part in this study.

Before you decide whether to be involved or not I need to be sure that you understand firstly why I am doing the study, and secondly what it will involve if you agree to take part. I am therefore providing you with the following information.

Please read it carefully and be sure to ask any questions you might have and, if you want to, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

WHY is there a need for a Study?

For many years now in the health service we have known how important it is to involve people in their care and the care of their children – because if they are involved it is more likely to be:

The Right Care which is given

- At the **Right Time**
- In the **Right Place**
- In the **Right Way**
- By the **Right Person**

If you have a baby, toddler or pre-school child your Health Visitor will want to make sure that you are getting all the support that you need.

This is not always easy because sometimes the support that families need is from other services and not just the Health Service. However now that the Health Service, Councils, the Third Sector and Voluntary Agencies are working together more closely this should help families.

Health Visitors are being asked to involve parents when deciding who to approach for help locally; however, up until now there has never been any way of showing Health Visitors the best way of involving parents when making these decisions.

Finding ways is the focus of this study.

So HOW can you help?

If you have needed either a bit, or perhaps a lot, of extra support for your child over the last 6 months, and you have had discussions about this with your Health Visitor I would really like to hear from you.

I am interested in having a discussion with you about what you found, or would have found, helpful. I can arrange to meet you at a convenient time, in a place which suits us both, and talk for 30 – 45 minutes whilst audio recording our conversation.

Once the recording has taken place the only people who will listen to it will be those directly involved in the research at the University, and I will personally analyse the transcripts once names, or anything else that will let others know who the information has come from, have been removed.

The final report will be made up of views collected from a number of parents with no one parent's views being able to be identified. Although your health visitor will be informed that I am meeting with you (with your permission) , this will happen before we meet and so she will not know what we discuss – unless you choose to tell her afterwards.

What will it mean for YOU?

Through letting us know what things are really important to you in turn you will be helping to improve the way that Health Visitors support parents. For many parents helping in this way is satisfying.

WHO has reviewed this study?

This study has received a favourable ethical opinion from the School of Nursing, Midwifery and Health Research Ethics Committee, University of Stirling. The East of Scotland Research Ethics Committee REC1, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that any relevant records are made available for scrutiny by monitors from the University of Stirling and NHS Forth Valley whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

I also have permission to speak with you from Managers in your Health Board area.

What if I want to complain about my experience of taking part in this study?

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through University of Stirling – who are acting as the research sponsor. Details about the process are available from the Research Team (details below). Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS processes. To do so, you can submit a written complaint to:

NHS Forth Valley Patient Relations and Complaints Service
Forth Valley Royal Hospital
Stirling Road, Larbert. FK5 4WR
Tel 01324 566660
Email fv-uhb.complaints@nhs.net

Note that the NHS has no legal liability for non-negligent harm. However if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Forth Valley but you may have to pay your legal costs.

What if NEW information about a child or parent at risk of harm is disclosed during the study?

In the unlikely case that **new** information about children or adults being harmed or at risk comes up during the conversation, or if any Health Visitor doesn't seem to be working in the way that they should, I have arranged to discuss this with one of the Health Visitor Managers in NHS Forth Valley – as it is important that all children and adults are protected and that Health Visitors always deliver a good service.

Do I NEED to take part?

Deciding whether or not to take part is completely your choice; however if you are interested in finding out more please complete the section at the end of this leaflet and send it in a prepaid envelope provided to:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

So WHAT NOW? Still interested?

As soon as I receive your details I will phone you, or email you if you prefer, and we can chat about it further before you decide if this is something that you definitely want to do.

If you do decide that you want to take part in this study I will ask you to fill in a Consent Form when we meet – which says that at any stage you are free to change your mind. And please note that whether you do or don't choose to meet with me will make no difference to the care that you receive from your Health Visitor.

Contact Details

Thank you for taking the time to read this Information Sheet and for considering to take part in this study. I am hoping that this Sheet has set out clearly **why** I am doing this study and how you can help. However if there is anything that you don't understand, or want to ask questions about, please phone or email me directly at:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

For further information you can also contact my research supervisor:

Dr Ashley Shepherd

School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 01786 466334
Email: ashley.shepherd@stir.ac.uk

If you have any worries about any aspects of this study you can contact:

Professor William Lauder

School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 01786 466345
Email: william.lauder@stir.ac.uk

For more information

(or if you want to take part) please complete this section and send it to:

Ruth Astbury

Clinical Doctorate Student
c/o School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

In a pre-paid envelope provided

Name (capitals please)	
Address	
Telephone number (Landline or Mobile)	
The best time of day or evening to phone you	
An e-mail address if you would prefer me to contact you in this way	

Thank you

Ruth A Astbury MSc (Nursing) RGN, SCM, RHV

Appendix 5 –Consent Form for Parent - Phase 1

Appendix 5 (version 1 – 27.7.13) – Phase 1

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?



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AND HEALTH

Consent form for Parents

Please initial in box

I confirm that I have read and understand the information sheet dated () Version () for the above study.

☐

I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily

☐

I am aware that, as part of the study, information that I provide will be collected in written form and using a digital recorder but will be presented in the study findings in a way which will protect my identity and that of my child/children

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or the care I receive being affected, and that any information that I have provided up to that point in time will also be withdrawn

☐

I agree to take part in the above study.

☐

Name of Parent

Date

Signature

Name of Researcher

Date

Signature

1 copy for parent

1 copy for researcher

1 copy for health records

Appendix 6 – Consent Form for Parent – Phase 2

Appendix 6 (version 2 – 17.10.2013) Phase 2

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?



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SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

Consent form for Parents

Please initial in box

I confirm that I have read and understand the information sheet dated 17th Oct 2013 (Version 2) for the above study

☐

I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily

☐

I am aware that, as part of the study, information that I provide will be collected in written form and using a digital recorder but will be presented in the study findings in a way which will protect my identity and that of my child/children

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or the care I receive being affected, and that any information that I have provided up to that point in time will also be withdrawn

☐

I agree to the Researcher informing my Health Visitor that I am involved in this study and understand that the Researcher will not discuss the content of the interview with my Health Visitor

☐

I understand that relevant sections of Health Visitor records related to me, and data collected during the study may be looked at by individuals from University of Stirling, or from NHS Dumfries and Galloway, where it is relevant to my taking part in this research. I give permission for these individuals to access to my records.

☐

I agree to take part in the above study.

☐

Name of Parent

Date

Signature

Name of Researcher

Date

Signature

1 copy for parent; 1 copy for researcher; 1 copy for health records

Appendix 7 – Letter to Parent Participant's Health Visitor

Appendix 7 (version 2 – 22nd Oct 2013)



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

c/o Postgraduate Mailbox
School of Nursing, Midwifery and Health
University of Stirling
STIRLING FK9 4LA
Tel: 07889 858 269
Email: ruthastbury@nhs.net

(Name of Health Visitor and Work Address)

Date

Dear (name of health visitor)

I am a Health Visitor - Practice Development Nurse and currently undertaking a research study which is exploring:

What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

The East of Scotland NHS Research Ethics Committee has given this study a favourable opinion, and it has been approved by the School of Nursing, Midwifery and Health Research Ethics Committee, University of Stirling. Your local Research and Development Department (name to be added) have given permission for this research to take place within (Name) Health Board and I also have the support of (name of Director of Nursing) and your Managers.

I am writing to you because one of the parents on your caseload (name of parent) who has a child called (name of child) has kindly volunteered to be interviewed to allow me to find out about their experience of planning with their health visitor. The conversation may relate to a time when you have been working with them, or, if they have recently transferred into your caseload, this may refer to another time with another health visitor.

There are two reasons why I am writing to you just now - the first is by way of courtesy so that you are aware that I will be interviewing (name of parent) as they may choose to mention this to you. (Name of parent) has agreed to me being in contact with you in relation to this study. The second reason is to ask that you inform me if you are aware of any known risks associated with visiting (name of parent) at home as I have no right to access their patient records at any stage and therefore I have no background information.

I will be following (name Health Board's) Lone Worker Policy and if you do have any information and want to discuss anything in relation to potential risks to my safety I ask that you please phone me on 07889 858 269 or email me on ruthastbury@nhs.net.

Please also feel free to contact me if you would like further information about this research study.

With grateful thanks for your help in this matter.

Kindest regards

Ruth A Astbury RGN, SCM, RPHN (HV), RPHN (Schools), MSc (Nurs), PGCert (PE)

Appendix 8 – Parent's Interview Schedule

Appendix 8 (version 1 – 27.7.13)

Parents' Interview Schedule



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AND HEALTH

How do Health Visitors involve parents in decision-making?

Thank you for offering to spend some time with me today telling me about your experience of planning for your child (name) with your Health Visitor.

As I explained before I am going to be recording our conversation today so that I can remember what we talked about – is that OK with you? As you know I will keep the recording very safe and destroy it as soon as I have finished with it.

If you want us to stop at any time please let me know – that's not a problem.

This conversation will probably take around ½ hour – is that OK?

Before we start do you have any questions?

Introduction

1. So to start with – can you please tell me a bit about yourself and your family – how many children do you have? How old are they? Do they keep well?
2. And you have been having conversations with your health visitor about (child's name?) Can you tell me a bit about how you came to be talking with your health visitor about him/her? Did you have problems – or did your health visitor ask to see you both?
3. How long ago was that?
4. Was there anything helpful in the way that she approached you?
5. **Or** was there anything helpful in the way that she responded to your request for help?
6. Would you mind telling me about what happened next please?

(1) The clinician identifies a problem(s) needing a decision making process

7. So can you please tell me a bit more about.....?
8. **Or** can you explain please a bit more about....?
9. Did you agree with your Health Visitor that there was a problem?
10. And – just so that I am clear – what did **you** think the problem was?

(2) The clinician states that there is more than one way to deal with an identified problem ("equipose")

11. So to help with this problem – do you remember ever discussing all the different options?
12. If yes- how did it make you feel?
13. If no – is that because there weren't many options?

(3) The clinician lists "options" including the choice of "no action" if feasible

14. Do you remember ever discussing what might happen if you did 'nothing'?

(4) The clinician explains the pros and cons of options to the patient (taking “no action” is an option)

15. So of all the things that anyone could do to help – did you go through each thing and think about what would be positive about doing this – but also what might be difficult or negative about making this choice? (E.g. your time off work to attend clinics? Transport to the Clinic?)

(5) The clinician checks the patient’s preferred information format (words/numbers/visual display)

16. What do you remember about the information that you were given? What was it? Was it easy to read? Did you understand it? Did it make sense? Was it appropriate? Did your Health Visitor write anything down for you? If so where??

(6) The clinician explores the patient’s expectations (or ideas) about how the problem(s) are to be managed

17. Do you remember if your health visitor asked your opinion about what you were hoping to gain for ... (child’s name)?
18. Did your health visitor ever ask you for your ideas about what would be the best thing to do next?

(7) The clinician explores the patient’s concerns (fears) about how problem(s) are to be managed

19. Do you remember having any worries about what was going to happen next?
20. Do you remember discussing any of your worries with your Health Visitor?

(8) The clinician checks that the patient has understood the information

21. Do you think you really understood all that you were discussing with your health visitor and all the various options that were open to you?
22. Do you remember being asked if you understood everything that was being discussed?

(9) The clinician provides opportunities for the patient to ask questions

23. Do you remember if you were able to ask questions about the options?

(10) The clinician asks for the patient’s preferred level of involvement in decision making

24. And did you get the impression that you had a choice?
25. Who else is about to help you with (child’s name)?
26. **If Yes** - Do you think they had an opinion about what was to happen next? Did you know what their opinion was at the time? Were you able to explain what the Health Visitor had told you easily?

(11) An opportunity for deferring a decision is provided

- 27. Did you feel under pressure to make a decision there and then?
- 28. **If so** – how did it make you feel?
- 29. Was it the right decision do you think?
- 30. What could have been done better?
- 31. **If not** – did you make a decision at the time?
- 32. **If so** - Was it the right decision do you think?
- 33. What could have been done better?
- 34. If not – When did you make your decision?
- 35. Was it the right decision do you think?
- 36. Is there anything that could have been done better?

(12) Arrangements are made to review the decision (or the deferment)

- 37. So what happened next??
- 38. Did you and your Health Visitor ever meet again to discuss what was happening with (child's name) and if everything was getting better?

Summary

- 39. How do you feel now about the decisions you made?
- 40. How satisfied do you feel about the process?
- 41. What went well?
- 42. What could have been better?
- 43. What would have made it better?

Closure

- 44. I am just about finished now – but before we do – and I switch the recorder off – is there anything else that you would like to add about meeting up with your Health Visitor and trying to sort things out for you and your children?
- 45. Thank you so much for your time – I really appreciate it – I am really grateful to you for being so willing to help us make things better for parents and Health Visitors too

Appendix 9 –Health Visitor’s Interview Schedule

Appendix 9 (version 1 – 27.7.13)

Health Visitor’s Interview Schedule



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

‘How do Health Visitors involve parents in decision-making?’

Thank you for offering to spend some time with me today telling me about your experience of finding ways to involve parents when you are planning together – when, in your view, something needs to be done to help the child.

As I explained before I am going to be recording our conversation today so that I can remember what we talked about – is that OK with you? As you know I will keep the recording very safe and destroy it as soon as I have finished with it.

If you want us to stop at any time please let me know – that’s not a problem.

This conversation will probably take around ½ hour – is that OK?

Before we start do you have any questions?

Introduction

1. So to start with – can you please tell me a bit about yourself and your caseload?
2. How long have you worked as Health Visitor?
3. What do you enjoy most about working as a health visitor??
4. From time to time you will see parents where you identify problem when you see them? Perhaps at a review? Or a parent will contact you because they have a problem
5. It would be good if you could think of a time – fairly recently when you have noticed something and you are keen to refer a wee one to say Speech and language Therapy – or a Mum to a Parenting Group?? Can you think of a case just now please?
6. How old was the child?
7. Why were you seeing him/her?

(1) The clinician identifies a problem(s) needing a decision making process

8. What did you notice?
9. What do you think you said? Was it easy??
10. So can you please tell me a bit more about.....?
11. **Or** can you explain please a bit more about....?
12. Did the parent think that there was a problem too?
13. Did they react as you would have expected?
14. What did you do?

(2) The clinician states that there is more than one way to deal with an identified problem (“equipoise”)

15. So to help with this problem – do you remember ever discussing all the different options?
16. If yes- what was the reaction??
17. If no – is that because there weren't many options?

(3) The clinician lists “options” including the choice of “no action” if feasible

18. Do you remember ever discussing what might happen if you did ‘nothing’?

(4) The clinician explains the pros and cons of options to the patient (taking “no action” is an option)

19. So of all the things that anyone could do to help – did you go through each thing and think about what would be positive about doing this – but also what might be difficult or negative about making this choice? (E.g. your time off work to attend clinics? Transport to the Clinic?)

(5) The clinician checks the patient’s preferred information format (words/numbers/visual display)

20. What do you remember about the information that you gave? What was it? Was it easy to read? Was it easy to understand? Did it make sense? Was it appropriate or just what you had available? Did you write anything down? If so where??

(6) The clinician explores the patient’s expectations (or ideas) about how the problem(s) are to be managed

21. Do you remember specifically asking the parent what they were hoping to gain for their child?
22. Do you remember asking what they thought the best thing to do next would be?

(7) The clinician explores the patient’s concerns (fears) about how problem(s) are to be managed

23. Do you remember asking if they had any worries about what was going to happen next? (Such as time off work to get to the Clinic? Finding the bus fare?)
24. I would say from what I have read and what I have done in practice that as health visitors we rarely probe very far – and often make assumptions – thinking that if there are problems we know the parent well enough and they will tell us – but do you think that is always true?
25. In what ways could we make it better? (And I’m asking myself this too?) What would have to be in place? What would you need? What skills would you need? What skills would the parent need?

(8) The clinician checks that the patient has understood the information

- 26. Did you ask this parent what they understood about your discussion – and ask them to describe your discussions and what the choices were??
- 27. If not what made you think that they understood what you were talking about?

(9) The clinician provides opportunities for the patient to ask questions

- 28. Do you routinely ask parents throughout a consultation if they have any questions?
- 29. Do you remember if in this case they were able to ask questions about the options?

(10) The clinician asks for the patient's preferred level of involvement in decision making

- 30. Did you give the impression that they had a choice?
- 31. Or did you feel that they didn't have a choice for the health and well-being of the child?
- 32. Do you know who else supports this parent? Have you met them?
- 33. Do you think they would have had an opinion – and tried to influence the parent you met with?

(11) An opportunity for deferring a decision is provided

- 34. Did you give the impression that they could go and discuss the options and you would meet again at a later date to decide on what you were going to do?
- 35. **If so** – how did it make you feel?
- 36. Was it the right decision do you think?
- 37. What could have been done better?
- 38. **If not** – did they make a decision at the time?
- 39. **If so** - Was it the right decision do you think?
- 40. What could have been done better?
- 41. If not – When did you make the decision?
- 42. Was it the right decision do you think?
- 43. Is there anything that could have been done better?

(12) Arrangements are made to review the decision (or the deferment)

- 44. So what happened next??
- 45. Did you and this parent ever meet again to discuss what was happening with (child's name) and if everything was getting better?
- 46. If yes – how were things going?
- 47. If not – why not?

Summary

- 48. How do you feel now about the decisions that you make with parents?
- 49. How satisfied do you feel about the processes?
- 50. What goes well?
- 51. What could be better?
- 52. What needs to be in place to make things better?

Closure

53. I am just about finished now – but before we do – and I switch the recorder off – is there anything else that you would like to add about meeting up with parents and trying to sort things out for them and their children? Do you think it is easy to share your decision - making?
54. Thank you so much for your time – I really appreciate it – I am really grateful to you for being so willing to help us make things better for Mums and for Health Visiting practice too

Appendix 10 – OPTIONS Questionnaire for Health Visitors

Appendix 10 (version 1 – 27.7.13)

Health Visitor Questionnaire



What was the main problem you talked about?					
Please describe it in a few words		Strongly agree	Agree	Disagree	Strongly disagree
1	A problem was identified where it was clear that a decision was needed	Strongly agree	Agree	Disagree	Strongly disagree
2	More than one way to manage the problem was described	Strongly agree	Agree	Disagree	Strongly disagree
3	Different sources of information to help make the decision were offered (e.g. leaflets, websites, contact with other people)	Strongly agree	Agree	Disagree	Strongly disagree
4	Different options (including doing nothing) were discussed	Strongly agree	Agree	Disagree	Strongly disagree
5	The advantages, disadvantages and possible outcomes of options were discussed	Strongly agree	Agree	Disagree	Strongly disagree
6	Ideas or expectations about managing the problem were discussed	Strongly agree	Agree	Disagree	Strongly disagree
7	Concerns or worries about managing the problem were discussed	Strongly agree	Agree	Disagree	Strongly disagree
8	It was made sure that information had been understood	Strongly agree	Agree	Disagree	Strongly disagree
9	There were opportunities to ask questions	Strongly agree	Agree	Disagree	Strongly disagree
10	The preference to take part in the decision was respected	Strongly agree	Agree	Disagree	Strongly disagree
11	During the meeting a decision was made; or there was an agreement to postpone making the decision	Strongly agree	Agree	Disagree	Strongly disagree
12	The possibility of coming back to the decision was discussed	Strongly agree	Agree	Disagree	Strongly disagree

Based on the discussion that you have just had with the parent today – please complete this questionnaire by drawing a circle round your level of agreement or disagreement against each of the statements.

Please remember that there are no right or wrong answers and that this study is based on the aim that health visitors and parents try together to find ways to improve how Health Visitors support parents when planning for their children.

Based on the dyadic OPTION instrument by Elwyn et al (2008) *Developing a dyadic OPTION scale to measure perceptions of shared decision making Patient Education and Counseling* 78(2010)177-183

Appendix 11 – OPTIONS Questionnaire for Parents

Appendix 11 (version 1 – 27.7.13)

Parent Questionnaire



What was the main problem you talked about? Please describe it in a few words					
1	A problem was identified where it was clear that a decision was needed	Strongly agree	Agree	Disagree	Strongly disagree
2	More than one way to manage the problem was described	Strongly agree	Agree	Disagree	Strongly disagree
3	Different sources of information to help make the decision were offered (e.g. leaflets, websites, contact with other people)	Strongly agree	Agree	Disagree	Strongly disagree
4	Different options (including doing nothing) were discussed	Strongly agree	Agree	Disagree	Strongly disagree
5	The advantages, disadvantages and possible outcomes of options were discussed	Strongly agree	Agree	Disagree	Strongly disagree
6	Ideas or expectations about managing the problem were discussed	Strongly agree	Agree	Disagree	Strongly disagree
7	Concerns or worries about managing the problem were discussed	Strongly agree	Agree	Disagree	Strongly disagree
8	It was made sure that information had been understood	Strongly agree	Agree	Disagree	Strongly disagree
9	There were opportunities to ask questions	Strongly agree	Agree	Disagree	Strongly disagree
10	The preference to take part in the decision was respected	Strongly agree	Agree	Disagree	Strongly disagree
11	During the meeting a decision was made; or there was an agreement to postpone making the decision	Strongly agree	Agree	Disagree	Strongly disagree
12	The possibility of coming back to the decision was discussed	Strongly agree	Agree	Disagree	Strongly disagree

Based on the discussion that you have just had with your Health Visitor today – please complete this questionnaire by drawing a circle round your level of agreement or disagreement against each of the statements.

Please remember that there are no right or wrong answers and that this study is based on the aim that health visitors and parents try together to find ways to improve how Health Visitors support parents when planning for their children.

Based on the dyadic OPTION instrument by Elwyn et al (2008) *Developing a dyadic OPTION scale to measure perceptions of shared decision making* Patient Education and Counselling 78(2010)177-183

Appendix 12 – Approval from University of Stirling School of Nursing, Midwifery and Health

JP/SG

21 May 2013

Ruth Astbury
8 Auchinlay Holding
Auchinlay
Dunblane
FK15 9NA



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

Email: nursingmidwifery@stir.ac.uk
Web: www.nm.stir.ac.uk

John Paley
Chair
School Research Ethics Committee

School of Nursing, Midwifery and Health
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 466399
Fax: +44 (0) 1786 466333
Email: john.paley@stir.ac.uk

Dear Ruth

What processes will support effective shared decision making when health visitors and parents are creating a Child's Plan – within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme

Thank you for submitting your proposal to SREC on 13 March 2013 and responding to queries and clarifications.

I can now confirm the study has now been approved and you can now move on to the IRAS stage.

May I take this opportunity to remind you that a site-file of *all* documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website. Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

Yours sincerely

John Paley
(Chair)
School of Nursing, Midwifery and Health Research Ethics Committee

Highland Campus:
Centre for Health Science
Old Perth Road
Inverness IV2 3JH

Tel: +44 (0) 1463 255655
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Stirling Campus:
Stirling
FK9 4LA

Tel: +44 (0) 1786 466340
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Western Isles Campus:
Western Isles Hospital
MacAulay Road
Stornoway Isle of Lewis HS1 2AF

Tel: +44 (0) 1851 708243
Fax: +44 (0) 1851 706070

The University of Stirling is recognised as a Scottish Charity with number SC 011159

Appendix 13 – Evidence of Indemnity Insurance



**UNIVERSITY OF
STIRLING**

STIRLING FK9 4LA SCOTLAND

Heather Allan
Research Funding Officer
RESEARCH & ENTERPRISE OFFICE
Tel: 01786 466438
Fax: 01786 466688
E-mail: heather.allan@stir.ac.uk

18 October 2013

To Whom It May Concern

Research Study: What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan – within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

This study is included in the following cover put in place by Aon Ltd. These policies are renewed annually and the current period of insurance is 1 August 2013 – 31 July 2014.

I confirm that the following cover is in place:

Professional Indemnity policy provides indemnity for legal liability to third parties arising from breach of professional duty, neglect, error or omission in the course of the business of the University of Stirling. The limit of the Professional Indemnity cover is £5,000,000 for any one event and in aggregate in any one period of insurance.

Combined Liability Insurance - Employers Liability cover is provided for legal liability to employers for death, injury, illness and disease arising out of the business of the University of Stirling. Public/Products Liability is provided for legal liability for accidental loss of or damage to Third Party property or for death, injury, illness or disease arising out of the business of The University of Stirling including liability arising from goods sold or supplied. Indemnity Limit for each is £10,000,000.

Combined Excess Liability Insurance for Employers Liability & Public/Products Liability. Cover limit is £10,000,000 in excess of £10,000,000 with a total limit of indemnity in respect of Employers Liability of £20,000,000.

I trust that this is sufficient for your requirements. Please however do not hesitate to get in touch with me should you have any queries.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Heather Allan'.

Heather Allan
Research Funding Officer

Appendix 14 – Evidence of Sponsorship



**UNIVERSITY OF
STIRLING**

STIRLING FK9 4LA SCOTLAND

Heather Allan
Research Funding Officer
RESEARCH & ENTERPRISE OFFICE
Tel: 01786 466438
Fax: 01786 466688
E-mail: heather.allan@stir.ac.uk

18 October 2013

To Whom It May Concern

Research Study: What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan – within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

This study is included in the following cover put in place by Aon Ltd. These policies are renewed annually and the current period of insurance is 1 August 2013 – 31 July 2014.

I confirm that the following cover is in place:

Professional Indemnity policy provides indemnity for legal liability to third parties arising from breach of professional duty, neglect, error or omission in the course of the business of the University of Stirling. The limit of the Professional Indemnity cover is £5,000,000 for any one event and in aggregate in any one period of insurance.

Combined Liability Insurance - Employers Liability cover is provided for legal liability to employers for death, injury, illness and disease arising out of the business of the University of Stirling. Public/Products Liability is provided for legal liability for accidental loss of or damage to Third Party property or for death, injury, illness or disease arising out of the business of The University of Stirling including liability arising from goods sold or supplied. Indemnity Limit for each is £10,000,000.

Combined Excess Liability Insurance for Employers Liability & Public/Products Liability. Cover limit is £10,000,000 in excess of £10,000,000 with a total limit of indemnity in respect of Employers Liability of £20,000,000.

I trust that this is sufficient for your requirements. Please however do not hesitate to get in touch with me should you have any queries.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Heather Allan'.

Heather Allan
Research Funding Officer

Appendix 15 – Favourable opinion from EoSRES with conditions met

EoSRES



East of Scotland Research Ethics Service (EoSRES) REC 1

Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Mrs Ruth Astbury
Clinical Doctorate Student
NHS Forth Valley
Bonnybridge Health Centre
Larbert Road
Bonnybridge
FK4 1ED

Date: 24 October 2013
Your Ref:
Our Ref: LR/13/ES/0107
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Mrs Astbury

Study title: What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?

REC reference: 13/ES/0107
IRAS project ID: 123475

Thank you for your letter of 17 October 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 24 September 2013

Documents received

The documents received were as follows:

Document	Version	Date
Evidence of insurance or indemnity		18 October 2013
Participant Consent Form: Parent	2	17 October 2013
Participant Information Sheet: HV Information Sheet and Indication of Interest Form	2	02 October 2013
Participant Information Sheet: Parent Information Leaflet for Phase 1	2	17 October 2013
Participant Information Sheet: Parent Information Leaflet for Phase 2	2	17 October 2013
Response to Request for Further Information		17 October 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:



Document	Version	Date
Evidence of insurance or indemnity		18 October 2013
Interview Schedules/Topic Guides – Health Visitor	1	27 July 2013
Interview Schedules/Topic Guides – Patient	1	27 July 2013
Investigator CV – Mrs Astbury		27 July 2013
Investigator CV – Dr Shepherd		05 August 2013
Letter from Sponsor		12 August 2013
Other: Approval Letter from NMH		21 May 2013
Other: Letter of thanks to Health Visitors	1	27 July 2013
Other: Letter of thanks to Parents	1	27 July 2013
Other: letter to director Nursing	1	27 July 2013
Participant Consent Form: Health Visitor	1	27 July 2013
Participant Consent Form: Parent Consent Form Phase 1	1	27 July 2013
Participant Consent Form: Parent	2	17 October 2013
Participant Information Sheet: Health Visitor Information Sheet and Indication of Interest Form	2	02 October 2013
Participant Information Sheet: Parent Information Leaflet for Phase 1	2	17 October 2013
Participant Information Sheet: Parent Information Leaflet for Phase 2	2	17 October 2013
Protocol	1	27 July 2013
Questionnaire: Health Visitor	1	27 July 2013
Questionnaire: parent	1	27 July 2013
REC application		30 August 2013
Response to Request for Further Information		17 October 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/ES/0107:	<i>Please quote this number on all correspondence</i>
--------------------	--

Yours sincerely



Mrs Lorraine Reilly
Senior REC Co-ordinator

eosres.tayside@nhs.net

Copy to: Heather Allan, University of Stirling
Dr Gwen Baxter, NHS Dumfries and Galloway



Appendix 16–Local Research and Development Approval



Date: 27 May 2014
Your Ref:
Our Ref:
Direct Line: 01324 677564
Email: rosemarywilson@nhs.net
R&D ref: FV 783

Mrs Ruth Astbury
Practice Development Nurse
Children and Families Teams
NW Sector - Glasgow City CHP
Drumchapel Health Centre
80/90 Kinfauns Drive
Glasgow G15 7TS

Dear Mrs Astbury

Study title: What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?
REC reference: 13/ES/0107

Following the favourable opinion from the East of Scotland Research Ethics Service (EoSRES) REC 1 on 24 September 2013, I am pleased to confirm that I formally gave Management Approval to the study above on 27 May 2014.

This approval is granted subject to your compliance with the following:

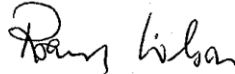
1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and ICH-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at: <http://www.cso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf> and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>
4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.
5. You or the local Principal Investigator will be required to provide the following reports and information during the course of your study:
 - A progress report **annually**

V:\Research And Development\ALL PROJECT FOLDERS\Pipeline\FV783 Decision making in child plan.
Astbury\FV783 approval.doc

- Recruitment numbers on a **monthly** basis (if your study should be added to the NIHR research Portfolio you will receive a separate letter from the R&D Office detailing the steps to be taken)
- Report on SAEs and SUSARs if your study is a Clinical Trial of an Investigational Medicinal Product
- Any information required for the purpose of internal or external audit and monitoring
- Copies of any external monitoring reports
- Notification of the end of recruitment and the end of the study
- A copy of the final report, when available.
- Copies of or full citations for any publications or abstracts

The appropriate forms will be provided to you by the Research and Development office when they are needed. Other information may be required from time to time.

Yours sincerely



PP

DR. PETER MURDOCH
Interim Medical Director

CC: ashley.shepherd@stir.ac.uk
nhsq.NRSPCC@nhs.net

Appendix 17 – End of Study Declaration



Health Research Authority

DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination.

For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	Ruth A. Astbury
Address:	8 Auchinlay Holding, Auchinlay, Dunblane FK15 9NA
Telephone:	07889 858 269
Email:	ruthastbury@nhs.net
Fax:	

2. Details of study

Full title of study:	What processes will support effective shared decision-making when health visitors and parents are creating a Child's Plan - within the context of implementing the Getting it Right for Every Child (GIRFEC) Programme?
Research sponsor:	Heather Allan – University of Stirling
Name of REC:	East of Scotland Research Ethics Committee
REC reference number:	13/ES/0107

3. Study duration

Date study commenced:	1st December 2013
Date study ended:	2nd October 2014
Did this study terminate prematurely?	No <i>If yes, please complete sections 4, 5, 6, & 7. If no, please go direct to section 8.</i>

4. Recruitment

Number of participants recruited	
Proposed number of participants to be recruited at	

Declaration of end of study (non-CTIMP), version 1.3, August 2014

the start of the study	
If different, please state the reason or this	

5. Circumstances of early termination

What is the justification for this early termination?	
---	--

6. Temporary halt

Is this a temporary halt to the study?	Yes / No
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	<i>e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.</i>

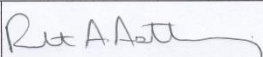
7. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	
--	--

8. Final report on the research

Is a summary of the final report on the research enclosed with this form?	No <i>If no, please forward within 12 months of the end of the study.</i>
---	---

9. Declaration

Signature of Chief Investigator:	
Print name:	Ruth A Astbury
Date of submission:	17th November 2014

Appendix 18 – A paper prepared for submission to a peer reviewed journal