Establishing Clinical Networks to Deliver Optimal Care for Children and Young People with Juvenile Idiopathic Arthritis - Guidance for Medical Professionals

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Abstract

Background: Clinical networks are evolving across the United Kingdom (UK), as a means to address inequities in access to specialist care for children and young people with Juvenile Idiopathic Arthritis (JIA). There is recognition that establishing clinical networks, and educating and training health professionals has been challenging. This study therefore explored the experiences of those involved to understand this area further. The aim of this study was to produce an educational framework to guide medical professionals in this process.

Methods: Focus groups and one-to-one interviews were used to explore experiences of health professionals, young people with JIA and their families. Participants were recruited from paediatric and adolescent rheumatology specialist centres, clinical networks and charities across the UK. Data was analysed using coding, memoing and mapping techniques to identify issues and features relating to the support required. The findings provided the content for an educational framework.

Results: Seventy-two participants took part in 9 focus groups and 12 one-to-one interviews. Five tertiary centres and their networks were studied, 4 in England and 1 in Scotland. Networks were constantly evolving and no one network or 'link' within a network was the same. Different network structures gave rise to different roles and responsibilities, educational needs and training opportunities. Crucially professional and organisational boundaries have impeded the effective implementation of organisational change.

Conclusions: This thesis has documented key issues and mapped out the support required for medical professionals establishing and maintaining clinical networks to deliver optimal care for children and young people with JIA. The support required is complex and context specific. There are many questions still to be answered. However, I hope my observations, theories and educational framework development provides the basis for future research and begins to facilitate change to improve care for children and young people with JIA.

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Finally, this thesis is dedicated to Paul. No doubt he will be as pleased as I am to see its completion.

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List of Abbreviations

ARMA	Arthritis and Musculoskeletal Alliance
BPRG	British Paediatric Rheumatology Group
BSPAR	British Society for Paediatric and Adolescent Rheumatology
CPD	Continued Professional Development
DOH	Department of Health
DGH	District General Hospital
FG	Focus Group
GP	General Practice
GMC	General Medical Council
HF	Helen Foster
INT	Interview
JIA	Juvenile Idiopathic Arthritis
MAS	Macrophage Activation Syndrome
MB	Mary Brennan
MCN	Managed Clinical Network
MDT	Multidisciplinary Team
MSK	Musculoskeletal
NHS	National Health Service
NRAS	National Rheumatoid Arthritis Society
RCPCH	Royal College of Paediatrics and Child Health
SOC	Standards of Care
SCN	Strategic Clinical Network
SPIN	Special Interest Modules
UK	United Kingdom
WHO	World Health Organisation

Chapter 1. Introduction

1.1. An Introduction to the Thesis

1.1.1. The Need for this Study

The aim of this study is to develop an educational framework to provide guidance for medical professionals involved in establishing clinical networks to deliver optimal care for children and young people with Juvenile Idiopathic Arthritis (JIA).

I explain in more detail later in this chapter, what *clinical networks* are, but in brief they are linked groups of health professionals from different organisations, working together to ensure equitable provision of high quality clinically effective services (RCPCH, 2012a).

The following statements summarise the drivers that led to the development of this study. They are discussed in detail with reference to the published literature later in this chapter:

- Inequities in access to optimal care for children and young people with JIA are known to exist.
- Clinical networks have been proposed as a mechanism to help address inequities in access to optimal care.
- Clinical networks in paediatric rheumatology are establishing across the United Kingdom, and any health care professional involved in the management of a child or young person with JIA should now be working as part of a clinical network.
- Any health care professional involved in the management of a child or young person with JIA should be appropriately trained to do so and have access to continued professional development.
- Although clinical networks may be of benefit, challenges have been encountered.
- It is unknown how best to support professionals involved in establishing clinical networks to deliver optimal care for children and young people with JIA.

1.1.2 How this Study came about

The study evolved out of a previous project proposal to Arthritis Research UK for a Barbara Ansell Fellowship, investigating ‘what makes a successful clinical network for JIA’. Dr Joyce Davidson, who at the time was the lead clinician of the Scottish

Paediatric and Adolescent Rheumatology Network, conceived the original project idea and with help from the research team from Newcastle University, I developed the project proposal. This project was unsuccessful in attracting funding, and as a result a modified proposal relating to clinical networks was developed, with a particular focus on education. This study was successful in obtaining funding from Arthritis Research UK (ref 20123), and undertaken as part of 2 year full time equivalent Educational Research Fellowship. The timing of this fellowship followed on seamlessly from the completion of my postgraduate training in paediatric rheumatology. It was during my clinical training, whilst working in different locations across the United Kingdom (UK) that I observed different service set-ups for delivering care for children and young people with rheumatological conditions. I witnessed the development of a paediatric rheumatology clinical network, and observed some potential benefits that networks could offer, such as the provision of local specialist expertise. I was also witness to significant challenges encountered by health professionals, for example during attempts to collaborate and 'share' patients. These experiences informed the study development and along with a developing enthusiasm for education, stimulated my interest in how professionals collaborate and work together to deliver care in clinical networks. It is hoped that this study will ultimately facilitate professionals working within clinical networks to deliver optimal care for children and young people with JIA.

1.2 Overview of Chapter

This first chapter provides a critical review of the relevant literature and develops the rationale for this study. The review first describes what constitutes optimal care for JIA and outlines the problem of delays and inequities in access to optimal care. An overview of the current service provision for children and young people with JIA is then provided. In order to fully appreciate the current care provision situation the evolution of the specialty of paediatric rheumatology is described. Finally the concept of clinical networks is explored in detail, with a review of the benefits, challenges and areas of concern that may be created by their establishment.

1.3 'Optimal Care' for JIA

The specialty of paediatric rheumatology covers a wide range of conditions from mechanical aches and pain to complex life threatening multisystem inflammatory disorders (NHS Commissing Board, 2013). For the purposes of this study, I have

focused on the care required for the commonest chronic rheumatic childhood disease seen – namely JIA.

JIA is a term, which includes a heterogeneous group of conditions that affects children and young people before their 16th birthday, where arthritis is the main feature, and is a diagnosis of exclusion (Ravelli and Martini, 2007). JIA affects an estimated 12,000 children and young people in the UK (Symmons *et al.*, 1996), prevalence 1 in 1000 and incidence 1 in 10,000 per year.

The management of JIA has radically changed in recent decades, with 'optimal care' focusing on early diagnosis and aggressive management by specialist paediatric multidisciplinary teams (MDTs) (Davies *et al.*, 2010). This is based on evidence that early intervention with aggressive treatment has been shown to improve clinical outcomes (Ravelli and Martini, 2007; Beresford, 2011; Wallace *et al.*, 2012, 2014).

Throughout my thesis I refer to *'*optimal care' being care that is defined by the British Society for Paediatric and Adolescent Rheumatology (BSPAR)/Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care (SOC) for children and young people with JIA (Davies *et al.*, 2010). These SOC are explained in more detail in section 1.3.2.

1.3.1 Delays and Inequities in Access to Optimal Care

Delays and inequities in access to optimal care (both in the UK, and globally) are known to occur and have been shown to significantly impact on patient outcomes (Manners, 1999; H. Foster and Rapley, 2010; Shiff *et al.*, 2010). For example longer interval from symptom onset to starting methotrexate is associated with lower treatment response (Albers *et al.*, 2009); delay in eye screening risks undetected and therefore untreated uveitis which may result in visual impairment (Chia *et al.*, 2003); the longer a child waits for a steroid joint injection, the higher the risk of functional disability from length discrepancy or muscle wasting (Sherry *et al.*, 1999). Addressing these issues are key to improving clinical outcomes (H. Foster and Rapley, 2010) and is a stated priority within the National Institute for Health Research Clinical Research Network: Children / Arthritis Research UK Paediatric Rheumatology Clinical Studies Group research strategy (2011).

Barriers to optimal care for children and young people are complex (see Figure 1) - the reasons for delays, inequities and suboptimal care are likely to be multifactorial (H. Foster *et al.*, 2010).

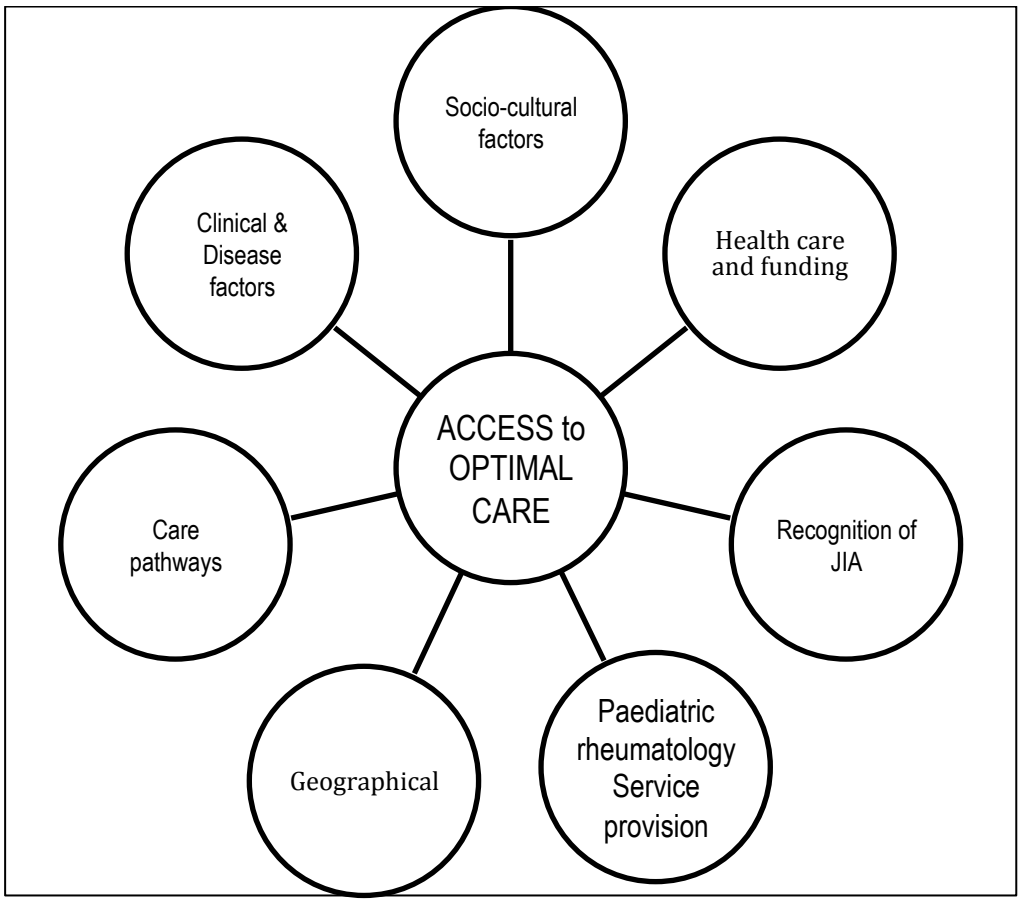

Figure 1 Barriers to Optimal Care in JIA[1]

In the UK strategies to address the barriers and inequities in access to optimal care are developing and include the publication of standards of care for JIA, educational awareness about JIA and the establishment of clinical networks. As this thesis will reveal in the later chapters, these three strategies are all interrelated. I discuss these three strategies in the next section.

1.3.2 Standards of Care for JIA

The BSPAR/ ARMA SOC for JIA (Davies *et al.*, 2010) have been devised in accordance with the Department of Health's (2004b) Children's National Service Framework. The SOC bring together models of best clinical practice based on the evidence and the expertise of clinicians with an understanding of the problems experienced by children, young people with JIA and their families. They describe the optimal clinical care to be expected by all patients irrespective of their geographical location, which includes care that is delivered by experienced clinicians with

[1]Slide from Prof. Helen Foster, used with permission

appropriate training. They include 44 statements detailing a range of domains and have been set to improve

- Access to early diagnosis and treatment
- Access to information and support
- Access to on going responsiveness to treatment and support
- Maximizing independence, inclusion and quality of life
- Transitional care
- The development of services for JIA

The SOC built on a BSPAR Position Statement (Baildam and Davidson, 2008), which defined what constituted a paediatric rheumatology specialist MDT (Table 1) and recommended that all professionals working with children in paediatric rheumatology needed to demonstrate that they had the required skills, knowledge and experience for this type of work.

• Consultant paediatric rheumatologists
• Specialist nurses
• Physiotherapist(s)
• Occupational therapist(s)
• Ophthalmologist
• Pharmacist
• Podiatrist
• Orthotics
• And access to dentist / orthodontist, dietician, clinical psychologist / psychiatrist, pain team and hospital play specialist, teacher, social worker and administrative support with close links with adult rheumatology teams for transitional care.

Table 1 List of Professionals in the Multidisciplinary Team

The SOC has been a useful benchmark on which to audit current services; two recent audits identified that access to specialist MDTs still remains variable across many parts of the UK (Bale *et al.*, 2012; Kavirayani *et al.*, 2013).

1.3.3 Educational Awareness

In order for early diagnosis and treatment of JIA, recognition of the condition is key. Children and young people with JIA may present to a number of health care professionals who may not have any expertise in paediatric rheumatology, and it is recognised that medical professionals have low confidence in musculoskeletal

assessment (Jandial *et al.*, 2009). Educating all professionals who may come in contact with a child who may present with signs or symptoms of JIA is therefore a fundamental strategy. This firstly involves raising awareness about the condition, and secondly getting the message across that if referred early to a team with expertise in paediatric rheumatology, treatment can be commenced early in the course of the disease, and outcome may be improved (H. Foster and Rapley, 2010).

Educational resources and strategies have been developed in response to the unmet need in paediatric musculoskeletal (MSK) education at undergraduate and postgraduate level (Kay *et al.*, 2003; Jandial *et al.*, 2009). These include pGALS, a musculoskeletal screening examination (H.E. Foster *et al.*, 2006; H.E. Foster and Jandial, 2013), which is now taught in many UK medical schools; pREMS, a more detailed regional examination, which is aimed at postgraduate trainees (H. Foster *et al.*, 2011a); and pMM (Smith *et al.*, 2016), an evidence-based free online resource, to enable a wide range of health professionals to learn more about paediatric musculoskeletal problems, and which aims to raise awareness, knowledge and skills to facilitate early diagnosis and referral to specialist care when needed. The Royal College of Paediatric and Child Health (RCPCH) general paediatric framework curriculum now contains paediatric MSK themes, and specific MSK competencies including clinical examination skills, knowledge and red flags.

There are currently no published resources relating to educational needs of professionals working within clinical networks.

1.3.4 Paediatric Rheumatology Clinical Networks

Clinical networks have been proposed to address inequities in access to specialist clinical care within the UK (RCPCH, 2006) and this model of working is endorsed by professional bodies as well as patient groups (Davies *et al.*, 2010; RCPCH, 2012a), and is integral to the National Health Service (NHS) commissioning process (NHS England). ‘Bringing Networks to Life’, the latest of a series of improving child health policy documents from the RCPCH (2012a) made the case for the development and maintenance of formal and informal paediatric sub-specialty networks across UK. As recommended within the SOC, any professional involved in the management of child or young person with JIA should now be working as part of an identifiable clinical network, be appropriately trained and have access to continued professional development (Davies *et al.*, 2010). Although robust evidence is lacking, there is suggestion that with appropriate coordinated networks of care, children and young

people with JIA, wherever they live, can have the required support for them to be able to manage their condition to achieve a better quality of life. A number of paediatric rheumatology clinical networks have now developed across the UK, each at various stages of development - some well established and others in the process of establishing links between professionals and their organisations (Kavirayani *et al.*, 2013).

1.4 Current Provision of Services for JIA

The National Rheumatoid Arthritis Society (NRAS) undertook a survey of services for JIA across the UK, whilst this study was being designed (2014). They identified that 5 different service set-ups or models of care provision existed for children and young people with JIA. Their list included:

- Paediatric rheumatology specialist teams working in specialist (tertiary) centres
- Paediatricians working with an interest in district general hospitals
- General paediatricians covering the service but as part of a significant portfolio of additional responsibilities working in district general hospitals
- Adult rheumatologists working alongside a general paediatrician in district general hospitals
- Adult rheumatologists working alone but with good communication with local paediatricians.

The results of their survey should be interpreted with caution, as there was no explanation of the process used to identify the different models of care provision. However, what it does provide is evidence that children and young people with rheumatological conditions are currently being managed by a number of professionals from different backgrounds, in different levels of a healthcare organisation. A criticism of their list of care models is that it does not include service provision provided by clinical networks. They do however mention ‘specialist teams attending outreach clinics’, ‘network clinics’ and ‘shared care arrangements’ in their diagrams where they geographically mapped service provision across the country. These diagrams showed that network/outreach/shared care activities were not a universal process. The conclusion of their survey was in keeping with what was already known – that there is significant variability and inequities of service provision for JIA across the UK (H. Foster and Rapley, 2010).

In the UK, specialist services for paediatric rheumatology tend to be located in tertiary hospitals. There are 10 approved training centres (known as national grid centres), located in tertiary hospitals, and it is widely accepted that these are viewed as specialist centres (see Chapter 3, Figure 5 page 35). To be accredited as a grid centre the RCPCH has stipulated a number of service (and training) requirements have to be met, including the presence of at least two paediatric rheumatology consultants and a full complement of a specialist MDT (Table 1). There are also a number of other tertiary hospitals that provide specialist services for paediatric rheumatology (non-grid centres). These centres tend to be slightly smaller (often with only one paediatric rheumatologist), and/or more recently established. Outwith these centres, children and young people with JIA are also being managed in 'other' hospitals. These other hospitals include smaller district general hospitals, generally located geographically more local to where a patient lives. It is known that these children are managed by a variety of professionals from different clinical backgrounds including paediatric rheumatologists, paediatricians with an interest in rheumatology, general paediatricians and adult rheumatologists. Some of these professionals from 'other hospitals' are working as part of a 'network' of care or have 'links' with their nearest specialist centre. However this currently is not yet common practice, and it is well recognised that across different geographical region there is variable access to specialist services for JIA.

Throughout my thesis I refer to paediatric rheumatology services located in tertiary hospital being *specialist centres* and refer to other models of service provision for JIA, located in the smaller district hospitals, which are generally closer to a patient's home as *local centres.*

Foster et al. (2011b) have previously described the contribution by adult rheumatologists to the clinical care for children with rheumatological conditions. They reported a survey, undertaken in 2007, which revealed that at that time at least 20% of the adult rheumatology consultant workforce were involved in the management of children and young people with rheumatological conditions. Concern was raised by a number of findings from the survey. Firstly, fewer than half were seeing children as part a clinical network. Secondly, although a minority, a few adult rheumatologists (5%) were reported to see children without any other paediatric health professional present. Thirdly, of those adult rheumatologists who were seeing children and young people with JIA, 48% were not members of BSPAR, and there were few reported

hours of continued professional development in paediatric rheumatology. It is unclear what percentage did not have the support of an appropriately trained MDT, but this was also reported to be a significant concern. The survey predicted that many of the adult rheumatologist seeing children and young people would be retiring (18% by 2012, and 48% by 2017), and as a result there would be a short fall in work force provision; their successors would not have the appropriate training to continue to deliver care for children and young people with rheumatological conditions. There are no up to date figures, but anecdotally and from the NRAS survey, it is recognised that a number of adult rheumatologist still contribute to the clinical care of children and young people with JIA, with a number of them having variable access to and support from a specialist paediatric MDT.

The workforce shortfall has improved over the past seven years, with an increase in number of consultant paediatric rheumatologist positions (from 27 to 49 consultants, data source RCPCH 2008 & 2015). A workforce planning assessment in 2014, revealed 17 trainees had undergone specialty training via the national grid-training scheme since its inauguration in 2003, helping address some of the projected shortfall (H. E. Foster *et al.*, 2011b). However, there are still not enough trained paediatric rheumatology consultants to solely look after and manage all the children and young people with rheumatological conditions in the UK. Recent guidance from NHS Commissioning proposes one paediatric rheumatology consultant per 200,000 children to facilitate modern clinical practice (NHS England). These calculations are based on extrapolations of the British Society for Rheumatology workforce planning party for adult rheumatology[2]. Based on these recommendations, an additional 25 paediatric rheumatology consultants are required than the number in current post[3]. This number is likely to be an underestimate as not all current paediatric rheumatology consultants are in full time equivalent NHS positions. Low recruitment to the specialty and paucity of paediatric trainees applying to the national paediatric rheumatology training scheme have been suggested as a reason for the workforce shortfall (H. E. Foster *et al.*, 2011b). The reasons behind this are likely to be multifactorial, but may relate to a lack of exposure to the specialty during paediatric training, and the stipulation that grid training requires training at 2 tertiary grid

[2] Data source – personal communication from Dr Clarissa Pilkington, BSPAR President and Prof. Helen Foster, representatives for Paediatric Rheumatology NHS Specialist Commissioning Reference Group

[3] Based on an estimated childhood population (<19 years) of 15098000 [Data source UK Office for National Statistics 2011 Census].

centres, requiring some trainees to geographically move twice in their last 2-3 years of training.

The current workforce shortfall of paediatric rheumatologists means that tertiary specialist centres would be unable to cope if all children and young with JIA are managed in the tertiary specialist centres. Furthermore it contravenes current governmental policy of providing specialist care closer to home (Kennedy, 2010). The solution to both these problems and one which attempts to addresses the inequities in access to specialist care known to exist is the development of clinical networks. In order to understand the challenges associated with their establishment, and the support required for professionals working within them, an understanding of the historical background to the specialty is required.

1.5 Evolution of the Specialty of Paediatric Rheumatology

This section provides an overview of how the specialty of paediatric rheumatology has evolved in the UK, with a focus specifically on service development.

The literature relating to service development is sparse in comparison to publications relating to the growth of knowledge and clinical expertise about the conditions which make up this specialty (Woo and Petty, 2011). This is not surprising. Although undoubtedly important, it is unlikely to have been perceived by clinicians as necessary to devote time to documenting the process of service developments, whilst pre-occupied with ensuring that the children and young people get the 'right care, in the right place, by the right people, at the right time' (Kennedy, 2010). In fact, it would be impossible to record all the activities and contributions of individuals who have made what we know as the specialty of paediatric rheumatology today.

The British rheumatologist Dr Eric Bywaters (1977), in the mid 1970s, referred to the specialty of paediatric rheumatology as one of the 'smallest and latest arrivals' (page 145). He is reported to have said that 'although I would not say premature, I think I can say I saw it arrive, although I cannot specify its birthday or place' (page 145). Bywaters, and his then registrar, Dr Barbara Ansell (who subsequently became his consultant colleague), at the Canadian Red Cross Memorial Hospital in Taplow, Buckinghamshire, were amongst the earliest UK professionals involved in the field in the 1950s. Ansell, described as the 'doyenne of paediatric rheumatology' (Hull and Venning, 2003), demonstrated that early active management of children with arthritis could lead to significant improvements in outcome (Ansell, 1983; Ansell and Swann,

1983). She pioneered the coordination of an MDT to treat her patients, and was an advocate of 'training doctors all over the world [to understand] that children with arthritis are not just miniature adults' (Schaller, 2002). This was important, because across the country, adult rheumatologists had been looking after children with rheumatic disease. Ansell held a belief that optimal care of these children required good regional services, and organised peripatetic clinics, training paediatricians throughout the country. As a result of her beliefs and her work, services began to develop across the country where she had visited, with adult rheumatologists working in conjunction with paediatricians.

Gradually there was a wider recognition that many aspects of care for children with rheumatological conditions required a paediatric approach (Schaller, 2005). In the mid 1980s a group of interested clinicians who shared this view founded the British Paediatric Rheumatology Group (BPRG). This group initially had 10 members, However, there remained an unrecognised need for service development, and as a consequence a significant workforce shortfall (Woo, 1997); it was only at the start of the 1990s that the first two academic paediatric rheumatologists were appointed. In the mid 1990s, the scale of the disease burden and lack of service provision was documented by the British Paediatric Association Working Party (1994). In 1995, the specialty of paediatric rheumatology was finally officially recognised by the Royal College of Physicians, with the production of a syllabus for training. The responsibility for paediatric rheumatology postgraduate training was subsequently taken over by RCPCH when it was founded in 1996. By the mid 1990s, membership of the BPRG had grown to over 100, with increasing membership representation from the MDT (Woo, 1997). In the early 2000s, BPRG changed its name, forming the British Society for Paediatric and Adolescent Rheumatology (BSPAR).

Over the past 2 decades, the specialty has had increasing recognition in the field of paediatrics and rheumatology, as well as governmental departments (Department of Health, 2004b; 2006). This recognition has not just been limited to the UK, but also internationally (Wedderburn *et al.*, 2005). Within Europe, the Paediatric Rheumatology European Society was established in 1999, which runs annual educational congresses, and fosters research and clinical collaborations. There has been significant increase in the number of professionals joining BSPAR with a membership number now of 249 (British Society for Rheumatology Data Source 2015). From within the specialty there has been encouragement towards children

and young people with rheumatological conditions being managed specifically by paediatric specialist MDTs (Davies *et al.*, 2010), with it no longer considered appropriate for children to be treated in adult environments, or within adult clinics (Department of Health, 2004a; 2008; H. E. Foster *et al.*, 2011b). Along with these recommendations it is advocated that any health professional involved in the management of children and young people with rheumatological conditions, should have appropriate paediatric training, and be working as part of an identifiable paediatric rheumatology clinical network (Baildam and Davidson, 2008; Davies *et al.*, 2010).

This chapter so far has outlined optimal care for JIA, and highlighted the problem of delays and inequities in access to this care. Some of the inequities have arisen as the specialty has evolved, giving rise to a variation in the ways that services are provided across the country. Clinical networks have been proposed as a mechanism to address these inequities, by linking professionals and their organisations together, and working together to deliver high quality clinically effective services. In the next section, I review the literature in more detail specifically relating to clinical networks.

1.6 Clinical Networks

This section reviews the concept of clinical networks - what they are, how and why they have evolved, how they may be categorised, the benefits, challenges and concerns that their establishment may create. The literature relevant to the 'networks' is very large, and is spread over a wide range of disciplines. For this reason I have focused this review specifically on their relation to health care, with specific reference to the paediatric and adult medicine literature.

1.6.1 Definition

Some suggest that there is no single definition of a clinical network (Addicott *et al.*, 2007). However, the Scottish Office published the first formal definition in the late 1990s as

> 'Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing and professional and organisational boundaries to ensure equitable provision of high quality clinically effective services' (Scottish Executive Department of Health, 1999).

This definition describes a form of clinical network that is formally governed and managed, known specifically as a Managed Clinical Network (MCN). The definition conveys the fundamental characteristics of a formal network organisational model for hospital services. However, there appears differing opinion in regard to the role that primary care plays, as some specialties do not view primary care as part of their MCN, as well as similar views from primary care themselves.

The English National Service Framework for Children (Department of Health, 2003) has adopted the Scottish definition, which is now the accepted definition in the field of paediatrics (RCPCH, 2012a). It is important to note that the word 'managed' has been omitted by NHS England; this is perhaps controversial as the term 'managed' emphasises a clear management structure. This includes funding and governance arrangements, which are believed (by some) to be important in the success of a clinical network (Guthrie *et al.*, 2010).

There are significant challenges in regard to researching about networks relating to different definitions and also the varied terminology used to describe them; the term 'network' or 'clinical network' is often used interchangeably with 'partnership working' or 'integrated care' (N. Goodwin *et al.*, 2004).

1.6.2 Clinical Network Evolution

In the early 1990s networks were first described alongside markets and hierarchies, as a distinct style of organisational management (Levacic, 1991). Managers in network-based organisations were said to take on the persona of a diplomat (with an emphasis on negotiation), in contrast to that of an entrepreneur, or that of military personnel, seen in market and vertically managed organisations respectively (Ferlie and Pettigrew, 1996) . Around the mid-1990s, a shift from markets and hierarchies towards network-based organisations occurred in many public sector organisations, including the NHS (Bate, 2000). This innovative organisational form emerged from attempts to make services more 'joined up', replacing competition with collaboration, and providing novel ways of coordinating services (Ferlie and Pettigrew, 1996). There was drive and emphasis for integration, inter-organisational collaboration and partnership working, highlighted in numerous governmental reviews. 'Networks of care' were thought to be the answer, providing better, more equal provision of services for patients, as well as providing a mechanism to share knowledge and ideas (Klein, 2006). As a consequence network-based thinking involving health care and the development of clinical networks has become increasingly prevalent,

particularly in trying to improve patient journeys that cross a number of service providers.

The establishment of clinical networks within the NHS has been led by Scotland. Following the Scottish Acute Services Review which highlighted inequities in access to specialised services, funding became available to develop MCNs in the late 1990s for adult specialties in cardiac services, stroke, cancer and diabetes (Hamilton *et al.*, 2005; Greene A, 2009). A similar review on cancer services in England (Calman Hine Report, 1995), suggested that cancer services could be delivered through networks of professionals in order to decrease the delay in diagnosis and treatment, and enabled funding for England to develop MCNs for cancer services (Department of Health, 1995).

Paediatric clinical networks have evolved following evidence of their need from adult specialties both in the UK as well as globally (Cropper *et al.*, 2002; Thakkar and O'Shea, 2006). Service reviews highlighting inequities in service provision and substandard care became the driving force and political leverage for robust arrangements in the planning, commissioning and funding of neonatal MCNs across the UK and paediatric subspecialty MCNs in Scotland (Scottish Executive Health Department, 2003; Department of Health, 2004b). This resulted, in 2004, in a small amount of money becoming available for Strategic Health Authorities to establish neonatal networks in England. Similarly the need for this change was recognised in Scotland, with the National Framework for Service Change 'Building a Health Service Fit for the Future' (Scottish Government, 2005). Funding then became available via the National Delivery Plan (2009) for MCNs to be established to develop paediatric subspecialty care across Scotland. 'Bringing Networks to Life', the latest of a series of improving child health policy documents from the RCPCH finally made the case for the development and maintenance of formal and informal paediatric sub-specialty networks across UK (RCPCH, 2012a). Funding for clinical network development across the UK has been variable, with many informal networks continuing to evolve without any financial support. Lack of funding has been noted as a barrier to their development (Cropper *et al.*, 2002).

1.6.3 Strategic Clinical Networks

During the study period, NHS England introduced 'strategic clinical networks' (SCNs), as engines for change within the modernising NHS (Department of Health, 2012). SCNs have been proposed to bring together those who use, provide and

commission services to make improvements in outcomes for complex patient pathways using an integrated, whole system approach. Their purpose is to improve quality of care and reduce unwarranted variation. They are hosted by the NHS Commissioning Board, and sit along side a system of Operational Delivery Networks and Clinical Senates. There are 12 Maternity and Children's SCNs across England. Although they are relevant, particularly for funding streams for children and young persons services (Spencer *et al.*, 2013), exactly how these SCNs will work and their relevance to paediatric rheumatology clinical networks is still unknown.

1.6.4 Categorisations

Attempts have been made to categorise clinical networks or group them into types. For example clinical networks may focus on specialties (such as paediatric rheumatology or neurology) or diseases (such as cancer and diabetes) (Woods, 2001). There are also descriptions of a variety of network 'variants' ranging from informal communities of practice to fully integrated service delivery systems (N. Goodwin *et al.*, 2004). Different countries also use different terminology, for example in Sweden 'chains of care' describe linked coordinated activities within health care (Ahgren, 2003). The issue, mentioned above, of differing terminology poses a challenge in regard to research in this area. As a consequence the literature relating to network categorisation is somewhat disordered.

A form of network categorisation was suggested by Leutz (1999). He proposed that within integrated care there could be three different levels of integration: linkage, co-ordination and full integration. The levels of integration are summarised in Table 2, and reveals that the levels are not clearly defined and additional terminology is used to try and explain their categorisation. However, it has been argued that this method of categorizing networks is helpful because it explains the extent of the networking relationship - ranging from loose to something more structured and hierarchical (Guthrie *et al.*, 2010). What this categorisation system does not fully address is the degree of regulation or management.

Level of integration	Explanation
Linkage	Operates within existing system, characterized by ad hoc partnerships between providers, who keep their own eligibility, funding constraints, operational and service responsibilities. Linkage levels are loose. At this level protocols may be developed to facilitate collaboration to deal with service users needs.
Co-ordination	Involves mechanisms or defined structure to help discontinuity and poor communication between sectors and systems. Promotes information sharing. This would be typical of an 'enclave' type of network (see Table 3) in which social ties are present, and well developed but the network is weakly controlled).
Full Integration	This would be like a hierarchical network, which is characterized by a complete restructuring, with consolidation of responsibilities, funding and resources.

Table 2 Leutz's levels of integration

A different form of categorization of health care networks was suggested by Perri 6[4] (2005), which included an assessment of the degree of both integration and of regulation (N. Goodwin *et al.*, 2004). His categorization included networks being hierarchal, isolate, individualised or enclave. This typology is summarised in Table 3, and shows examples of existing 'networks' or care models being fitted into different categories.

[4] David Ashworth changed his name to 'Perri 6' in 1983

	Example	Description
Hierarchal	Managed clinical networks Hub and Spoke arrangements Integrated Care Pathways	Networks with an organisational core, which regulates the work of its members, often controlled by direct authorities or steering groups. Commonly work towards joint protocols and shared agreements. Strongly regulated and integrated.
Isolate	* No reported examples	Network has a periphery but no significant internal core. Strongly regulated and weakly integrated.
Individualized	Care Pathway Commissioning US integrated Health care systems	A single individual or organisation develops an association of affiliates in order to achieve a certain task. May be based on procurement of service. Networks tend to be innovative and flexible. Weakly regulated and weakly integrated.
Enclave	Professional groups Associations Information sharing groups Local partnerships Informal networks	A close-knit group, with high social cohesion, in which there is an internal equity between members, but markedly less with outsiders. Commitment and integrity are cohesive forces but relies on motivation of members and often create a 'bottom-up' legitimacy and trust between professionals. Weakly regulated but strongly integrated.

Table 3 Perri 6's typology of networks

From this typology, Perri 6 further developed a 'continuum' of networks – which ranged from learning and informational networks, coordinated networks, procurement networks to managed care networks. These are summarised in Table 4. The continuum incorporated not only the degree of integration or regulation, but also the dynamic nature of networks, which had not previously been addressed. The dynamic nature attempted to reflect that, over time, there might be differing levels of integration and regulation, and networks may move from between categories on a continuum.

	Description
Learning and informational networks	Most common form in healthcare. Organisations and individuals are brought together individuals to share information and ideas, and facilitate the development of best practice guidelines and policies. These are like national societies (such as BSPAR). Key lessons: behave like enclaves in that they depend on the commitment of their members to share information and as a consequence need to be 'useful' - if not then they will not be sustained.
Coordinated	Theses are similar to informational networks, but further along the continuum. New forms of integration are sought, frequently based on a care pathway or joint assessment. Financial and clinical responsibilities remain completely separated. Often given funds to provide incentives for network development. For example MCNs in Scotland. At one end of the continuum they have a simple hub and spoke that share tasks between hospital to better coordinate access of care or better utilisation of care between then, and the other end they are clinical networks which may be more based around professionals rather than institutions.
Procurement networks	Integrated health care network, in which all elements of care are provided (prevalent in America).
Managed care networks	Highly managed, integrated care. Created for durability and long-term network partner relationships.

Table 4 Perri 6's continuum of networks

The different categorisations described above were introduced in an attempt to account for an evolving literature relating to networks, with the caveat that within each network type there may be significant difference in network styles and structure (N. Goodwin *et al.*, 2004). How these different categories are related to each other is illustrated in Figure 2. What this figure attempts to illustrate is the overlap of network types and the complexity of the differing terminology.

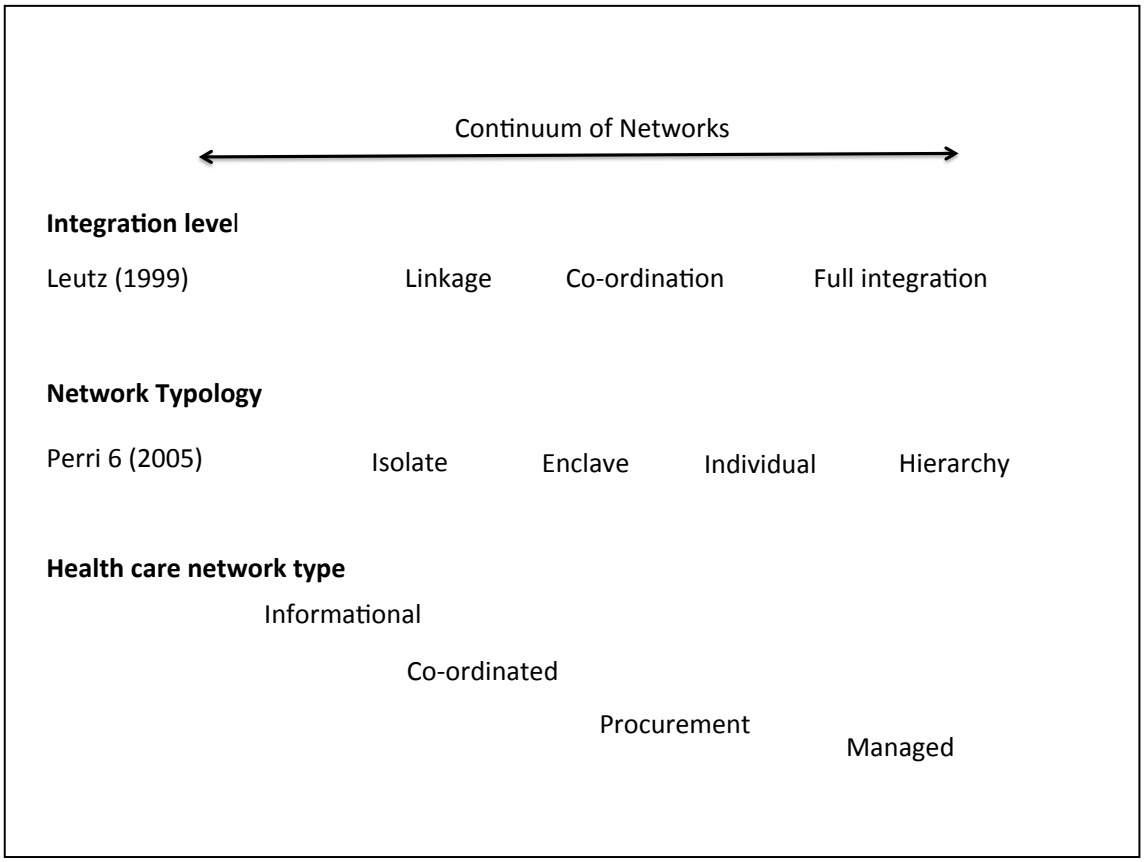

Figure 2 Continuum of Networks

Within the most recent RCPCH (2012a) document about networks, there are additional terms (clinical association, clinical form and developmental networks) which have similarities with Perri 6's network continuum. This is illustrated in Figure **3**. It is unclear where this terminology has come from or why the additional terms have been used.

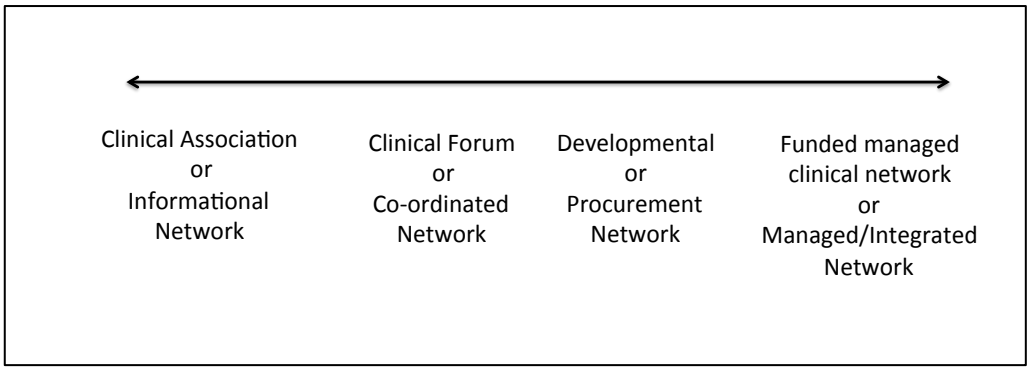

Figure 3 RCPCH types of networks

Ultimately, the problem with network categorisation is that the terminology has been developed to try and 'fit' the networks that already exist, rather than to an idealized structure that can be mapped to specific outcomes. The different approaches to the

categorization of clinical networks has created confusion when networks are compared (N. Goodwin *et al.*, 2004). Differences in network styles and structures within and between each categorization reflect the differences present in the clinical environment. Certainly, no one network is the same and therefore no one model will fit all circumstances (Guthrie *et al.*, 2010); they remain, as Ferlie (1996) first described, 'diffuse in nature' (page S99). This provides challenges to studying clinical networks. In this study I have therefore avoided attempting to further categorise the clinical networks studied. Instead in Chapter 8, I describe the different network structures by the way that care was delivered - what that actually meant in clinical practice.

1.6.5 Benefits

Despite the confusion in categorisation, the literature outlines a range of benefits of clinical networks. The Department of Health (2012) has heralded clinical networks as an NHS success story and have been quoted saying that they can deliver true integration across primary, secondary and tertiary care. However, much of the literature has focused on the theoretical benefits of clinical networks (Edwards, 2002; N. Goodwin *et al.*, 2004; Addicott *et al.*, 2006; MacDougall *et al.*, 2010). These theoretical benefits are summarised in Table 5. In fact, the distinction within the research field between theoretical and actual benefit can be quite hard to determine. The reasons for this are multifactorial, but include the challenge of defining what a network actually is, the evolution from existing services and difficulty defining objective outcomes.

- Improving clinical services
- Improving access to care
- Standardising and streamlining care
- Sustaining vulnerable services
- Making use of scare resources and specialist expertise
- Providing flexibility, increased efficiency and ability to respond to rapidly changing environments
- Increasing opportunities for health professional interaction and communication
- Increasing opportunities to share best practice, guidelines and develop collaborative practice
- Development of continuous working relationships
- Reducing professional and organisational boundaries
- Enhancing staff development, education and retention
- Providing a ‘sense of confidence’ for patients
- Providing a means of accounting for service performance across health care organisations
- Providing a powerful cohesive voice

Table 5 Theoretical benefits of clinical networks

Despite the debate surrounding their benefits, there is some emerging evidence of clearly tangible positive outcomes. These are summarised in Table 6.

- Successful in developing standards and protocols (Guthrie *et al.*, 2010)
- Clinical practice changed with creation and implementation of guidelines (Ray-Coquard *et al.*, 2002)
- Engaging clinicians in service redesign and reform (Touati *et al.*, 2006)
- Improved availability of clinics (NHS Scotland National Services Division, 2010)
- Improved timeliness of referrals (NHS Scotland National Services Division, 2010)
- Specialist expertise now provided locally (Guthrie *et al.*, 2010)
- Improved quality of care indicators
  - Cancer services - (Ray-Coquard *et al.*, 2002), (Ray-Coquard *et al.*, 2005), (McCullough *et al.*, 2014)
  - Cardiac services - (Hamilton *et al.*, 2005)
  - Diabetes care - (Greene A, 2009)
  - Neonatal care - (Spence and Henderson-Smart, 2011), (Gale, 2012)
- Improved clinical outcomes
  - End stage renal disease (McClellan *et al.*, 1999)
  - Myocardial infarction (Tideman *et al.*, 2014)
- Improvement in peer support, access to information, sharing knowledge and advice (Addicott *et al.*, 2006)
- Improved educational programmes (for staff and patients) (NHS Scotland National Services Division, 2010)
- Improved collaboration (Cunningham *et al.*, 2012)
- Opportunities for research (Hartel *et al.*, 2012)

Table 6 Evidenced based benefits of clinical networks

A number of the publications reported that networks could create opportunities in knowledge sharing and development of collaborating practice (Cropper *et al.*, 2002; Edwards, 2002; Addicott *et al.*, 2006; Nicolini *et al.*, 2008). If different professional and occupational groups work together in a well functioning network, then there is potential to form a ‘community of practice’ (Addicott *et al.*, 2006). This concept was developed by Lave and Wenger (1991), which describes a community of practice as a group of people who work together to achieve a common goal. The process of working together and sharing resources and knowledge can result in the benefit of an enriched learning experience.

1.6.6 Challenges and Concerns

Despite some emerging evidence of benefits, challenges and concerns have been reported in relation to clinical networks. Some remain sceptical about the networks as a mechanism to deliver care; their value and the opportunities they offer to increase productivity and efficiency across the NHS continue to be debated and challenged (Addicott *et al.*, 2006; Hogard and Ellis, 2009). There has been a suggestion that there is no evidence that they offer anything better than well managed hierarchies (Bate, 2000). Furthermore there is no generally accepted method of evaluating the impact of a clinical network (Guthrie *et al.*, 2010). The challenges relating to network definition and categorisation described above also add to this problem. Furthermore, much of the literature related to networks is internally published, often from commissioned governmental reviews and has not been subjected to the peer review.

I return to the most widely accepted definition of a clinical network (Scottish Executive Department of Health, 1999), and use this as a framework to discuss these challenges and concerns.

i) Establishing *linked groups of health professionals and organisations*

Even when there has been a strong mandate and rationale for improving services, establishing a network has been reported to be challenging (Baker and Lorimer, 2000). The process of their establishment is time consuming, requiring often long term investment (Ferlie and Pettigrew, 1996). The Swedish experience has been similar to the some of the Scottish MCNs, with reports suggested that defined networks objectives had been hard to implement because no single agency 'owned' the network. Furthermore when clinical networks were imposed, there was disharmony and professionals failed to engage resulting in network failure (N. Goodwin *et al.*, 2004). The reasons for this disharmony or lack of engagement were not clear in this study. However, it is recognised that there may be resistance encountered with network establishment, as it involves a process of organisational change (RCPCH, 2012a).

ii) Working together in a coordinated way, unconstrained by professional and organisational boundaries

Challenges and concerns have been reported when collaborative working does not happen, or when part of a patient's journey is undermined by the uncoordinated

activity elsewhere in the network, or when professional and organisational boundaries are constrained (Fournier, 2000; Cropper *et al.*, 2002; Currie *et al.*, 2008; Guthrie *et al.*, 2010).

A comparative evaluation of three children's services networks (nephrology; child safeguarding; and cleft lip and palate) found that professional hierarchies limited collaboration (Currie *et al.*, 2010.). Collaboration, even at an informal level between health care providers is a complex process amongst the same and different professional groups. They noted that there must be common understandings and only when collaboration proceeded without any problems, then true delivery of high quality care occurred. Collaborative difficulties have been reported, under conditions of stress because of differing professional backgrounds (Currie *et al.*, 2010.). These differences refer to differences in professional identities, skills, values, approaches and goals.

There has been a suggestion that although networks can create educational opportunities for knowledge sharing, they can also produce barriers to the flow of knowledge (John Seely Brown and Duguid, 2001). These barriers have not been created directly by clinical networks per say, but rather it is the professional, social and cognitive boundaries of the professionals working within them that act as barriers to organisational change and the spreading of novel work practices (Ferlie *et al.*, 2005).

iii) Delivering *equitable provision of high quality clinically effective services*

There have been few studies, which have aimed to determine critically, the effectiveness of a clinical network (Addicott *et al.*, 2006), although one study is currently underway (Haines *et al.*, 2012). There remains a challenge on how we will know whether networks have been effective, as networks are complex systems. Some advocate the need for a better data collecting system to address this issue (Marlow and Bryan Gill, 2007). If effectiveness of a network is defined as improving clinical outcomes then this can be challenging particularly when robust outcome measures are not easily defined or may take years to evolve, such as outcomes with chronic complex disease, which is particularly pertinent in paediatric rheumatology.

Delivering high quality clinically effective services which are equitable requires services to be resourced and professionals working within the to be appropriately trained, practicing up to date, evidence based care. This is highlighted in Principle 18 of the RCPCH 'Bringing Networks to Life' Document (2012a), which states that all

members of the multidisciplinary teams providing care for children in the network are appropriately trained to do so and have access to continuing professional development. There is a concern when this does not occur (RCPCH, 2012a).

Although the RCPCH (2006) has produced guidance to understanding pathways and implementing networks, it contains little practical guidance to help professionals overcome the challenges described. They acknowledge that many of the issues faced are inherent problems within the system that networks attempt to overcome (Table 7).

• The sheer complexity of provision. • Varying structures that do not map on to one another. • Incompatible systems and policies across agencies, e.g. IT systems, inspection methodologies and commonly used terminology. • Contrary policy directions. • Disassociation of commissioning practice between agencies. • Different approaches to quality improvement. • Concern about information sharing across agencies. • Lack of commissioning capacity. • Variable quality of commissioning. • Policies such as Payment by Results. • A shortage of high quality information on which to base decisions. • Organisational inertia, bureaucracy and unwillingness to change • Preoccupation with European Working Time Directives, targets and existing overspends. • Imbalance of power between consumers and providers. • No single model for an optimal network.

Table 7 Problems associated with network establishment

There is published guidance for those commissioning, providing and using paediatric nephrology networks which sets out core requirements for success and standards for commissioning and provision of services (RCPCH, 2012b). However, again it fails to suggest any practical considerations to the challenges that may be encountered.

As I will show in Chapters Six and Seven, as clinical networks in paediatric rheumatology evolve, anecdotally there have been challenges and concerns raised - with a call that there is need to support medical professionals establishing clinical networks to deliver optimal care for children and young people with JIA. The call has come not only for guidance in clinical network establishment and care delivery implementation but also for guidance supporting the education and training of professionals working within them.

1.7 Conclusion

This chapter has presented a review of the literature supporting to the statements behind the rationale of this study:

- Inequities in access to optimal care for children and young people with JIA are known to exist.
- Clinical networks have been proposed as a mechanism to help address inequities in access to optimal care.
- Clinical networks in paediatric rheumatology are establishing across the UK, and any health care professional involved in the management of a child or young person with JIA should now be working as part of a clinical network.
- Any health care professional involved in the management of a child or young person with JIA should be appropriately trained to do so and have access to continued professional development.
- Although clinical networks may be off benefit, challenges have been encountered.
- It is unknown how best to support professionals involved in establishing clinical networks to deliver optimal care for children and young people with JIA.

Clinical networks, in whatever form, are a recommended way to deliver specialist care, and appear to be here to stay (RCPCH, 2012a). If their establishment can facilitate the delivery of optimal care, then ultimately their effect would hope to give the best possible chance of improving outcomes for children and young people with JIA. There is a call from within the specialty to support professionals involved in clinical network establishment to deliver optimal care for children and young people with JIA. To date there is no practical guidance in this area and therefore this study aimed to address this problem.

The aim and objectives of this study are described in the next chapter.

Chapter 2. Aim and Objectives

The overall aim of this study is:

- To develop an educational framework to provide guidance for medical professionals establishing a clinical network to deliver care for children and young people with JIA.

The general objectives of this study are:

- To understand the evolution of clinical networks to deliver care for children and young people with JIA, and the relationship to the developmental needs of medical professionals.

The specific objectives of this study are:

- To describe the rationale for delivering care for children and young people with JIA within a clinical network.
- To describe how clinical networks for children and young people with JIA have been established.
- To describe the challenges of establishing clinical networks for children and young people with JIA.
- To identify how care for children and young people with JIA is delivered within clinical networks.
- To describe the challenges of delivering care for children and young people with JIA within clinical networks.
- To identify and describe the developmental needs of medical professionals involved in establishing clinical networks for children and young people with JIA, and delivering care within them.
- To describe existing continued professional development and training within clinical networks for JIA, in terms of format, content, target audience, and how it is delivered.

Chapter 3. Study Design and Methods

3.1 Introduction

This chapter describes the methodology of the study, the rationale behind the design and the analysis of the data. I have taken a pragmatic approach to describing the methodology by documenting transparently 'what I did', as suggested by Silverman (2009) [5]. The practical steps undertaken are outlined, and an honest account of the conduct of the research is given. I describe the process involved in choosing the clinical networks and participants to study, and give a detailed account of the data collection process and analysis. Within the relevant sections of this chapter, I explain and justify the decisions made and the challenges encountered. Finally I provide a discussion about the validity of the study.

3.2 Study Design

The overall aim of the study is to develop an educational framework to support medical professionals involved in establishing clinical networks to deliver care for children and young people with JIA. Within the time constraint of this project, to achieve this aim I focus on producing an educational framework, in the form of a guide, specifically for medical professionals. However, other members of the MDT, managers and commissioners of services may also find it beneficial. The need to develop guidance was outlined in Chapter One.

An overview of the study design is illustrated in Figure 4. This figure shows the relationship over time between the aim and objectives of the study (described in the previous chapter) and the research methods used. To achieve the study's overall aim, general and specific objectives were developed. These set out to step wise frame the purpose of the study and identify components to be included in the framework. As this project involved exploring experiences, the study lent itself to using qualitative research techniques. Qualitative research seeks to understand human behaviour; investigating the meanings people attach to their experiences of the social world (Silverman, 2009). Combinations of qualitative research methods were used to collect data, which included focus groups, one-to-one interviews and

[5] Silverman (2009, p333), and adapted from Spencer et al. (2003).

reflective field notes. Independently, each method has its own merits and when used in combination they provide an even richer data source.

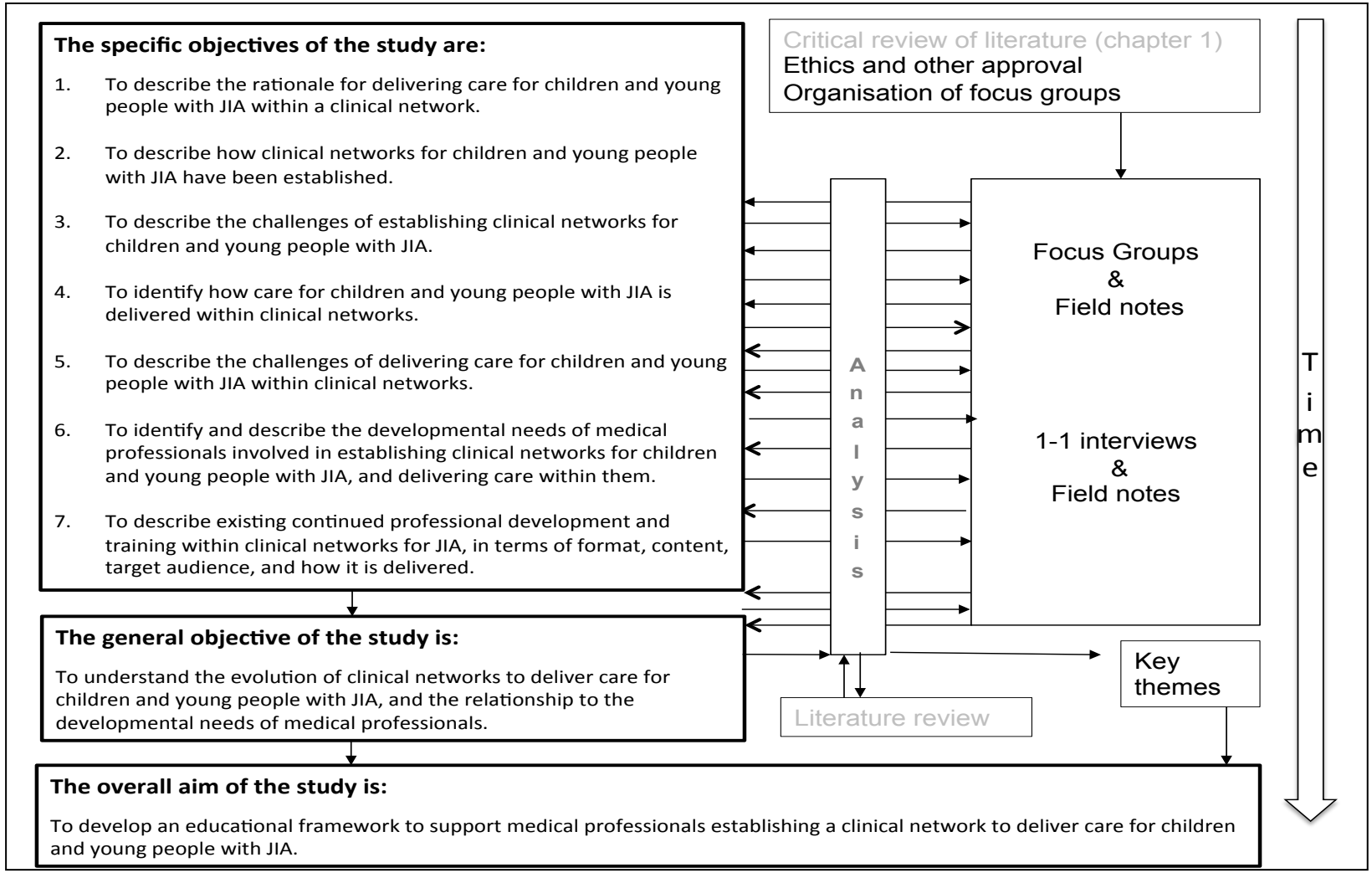

Figure 4 Relationship of Study's Aim and Objectives and Research Methods

I now discuss each of the data collection techniques used, and give the rationale for their use.

Focus Groups

I chose to use focus groups to gather data, as they are a familiar approach in health care research. They allowed participants to express their experiences and allowed me to explore specific issues relevant to the study area (Silverman, 2009). They have an advantage in comparison to individual interviews in that group discussion and group synergy can stimulate discussion and generate new ideas (Ritchie and Lewis, 2003).

One-to-One Interviews

I chose to use interviews with individual people (one-to-one interviews), as they allowed me to explore ideas and answers in greater depth, which I was not able to do during the focus groups. They also allowed me to explore more sensitive issues relevant to the study area (Morgan, 1997). Following a period of analysis, I used one-to-one interviews to follow up and explore specific themes, which emerged from the focus group discussion. I also used them to collect data from individuals who were not able to attend the planned focus groups, to ensure that all perspectives were covered (Morgan, 1997).

Reflective Field Notes

I wrote field notes to record behaviours, activities, events and other features that I became aware of before, during and after the focus groups and one-to-one interviews. I jotted down a few words or sentences whilst in the 'field' and then as soon as possible after the observation I wrote more detailed reflections. Through the process of reflection I was able draw meaning from the data collected during the focus groups and one-to-one interviews, and this facilitated an understanding of the culture, social situation and phenomenon being studied. They also helped jog my memory of the session in the field, and fostered the process of reflection, which was fundamental to gain a deeper understanding and of the data, and an important process aiding the analysis (Burgess, 1991).

3.3 Ethics and other Approvals

Table 8 summarises the ethics and other approvals, which were granted in order to undertake the study.

Approvals		Cover
Ethics	National Research Ethics Service North East – Sunderland (Reference 12/NE/0338)	All ethical aspects of the study
Research & Development/ NHS Permissions	Tertiary centre A All hospitals in network B	Tertiary centre A, all network linked hospitals from tertiary centre and charities All hospitals in network B
Other	Dr Clarissa Pilkington, President of BSPAR (Charity number 06978211) Arthritis Care (Charity numbers: 206563 & SC038693) Scottish Network for Arthritis in Children (charity number SC040193) Caldicott approval was granted.	BSPAR members Young people with JIA at a self-development weekend away Parents and carers of children with JIA during a family education weekend away.
Ethics amendments	Minor amendments Substantial amendment	Request to use WHO definition of the adolescence. This was sought after a discrepancy had been noted in the original ethics application. Request to change the end of the study from 03/09/2014 to 20/07/2015, to facilitate MB to undertake a part time locum consultant paediatric rheumatology position. Requested to increase the number of one-to one interviews (total n=12) and focus groups (total n=12) but with smaller numbers of participants in each group. The overall number of potential participants (n=68-104) would remain the same

Table 8 Study Approvals

I encountered two difficulties relating to the organisation of NHS permissions to cover health professionals working in networks. Firstly, during the initial study planning stages it was unclear ‘who’ and ‘which hospital trust’ participants would be recruited from. For example one tertiary centre was linked to over 30 different NHS trusts;

given the maximum number of participants likely to be recruited to a focus group was ten, obtaining NHS permissions to cover individuals working in each of these trusts was felt not to be best use of research time. Secondly, some NHS Research and Development departments did not support granting 'NHS permission' from the tertiary hospital trust, which would cover professionals working in 'other trusts' in a clinical network. To overcome these problems, an alternative approach to obtaining permission was sought, recruiting professionals via the BSPAR. BSPAR has charitable status and therefore permission to recruit participants may be obtained directly through the charitable route thereby circumventing 'NHS permissions'.

The study was registered with the local Clinical Research Network and adopted onto the National Institute for Health Research portfolio (IRAS 109505).

3.4 Study population

The study population included health professionals, young people with JIA, and parents of children and young people with JIA, who had experience of care delivery within paediatric rheumatology clinical networks for JIA in the UK. The study population therefore can be considered to consist of 'clinical networks' and 'study participants'.

Clinical networks

In order to identify the study population of clinical networks I first reviewed the current situation of known 'service set ups' for paediatric rheumatology across the UK. This included the creation of a geographical map of the ten National Grid training centres for paediatric rheumatology [6] (Figure 5).

[6] Both HF and MB were members of the RCPCH Specialist Advisory Committee for paediatric rheumatology, and therefore this information was readily known.

Figure 5 Approved National Grid Centres for Paediatric Rheumatology

As discussed in Chapter One, these National Grid centres are generally known as specialist centres for paediatric rheumatology, where paediatric rheumatology specialist MDTs are based. However, it is known that other tertiary centres (non Grid), which are slightly smaller in size or newer, also provide specialist rheumatology care.

I also reviewed the National Rheumatoid Arthritis Society's (NRAS) recent survey, which had geographically mapped services for children, young people and families living with JIA in the UK (NRAS, 2014). This was correlated with the project team's own knowledge of other tertiary centres that provide specialist services for paediatric rheumatology (non Grid centres), gained from working in different parts of the UK. These processes resulted in the creation of a list, the 'population' of paediatric rheumatology specialist centres and clinical networks in the UK.

Participants

Part of the definition of a clinical network consists of 'linked groups of health professionals from primary, secondary and tertiary care' (Scottish Executive Department of Health, 1999). The study population therefore included all the professionals which make up the paediatric rheumatology MDT as defined by the BSPAR position statement (Baildam and Davidson, 2008), from both the specialist centre (tertiary care) and the local centre (secondary care). It also included GP and community nurses (primary care). In addition it is recognised that a number of adult rheumatologist also look after children (H. E. Foster *et al.*, 2011b). The different professional backgrounds making up this study population of health professionals are illustrated in Figure 6.

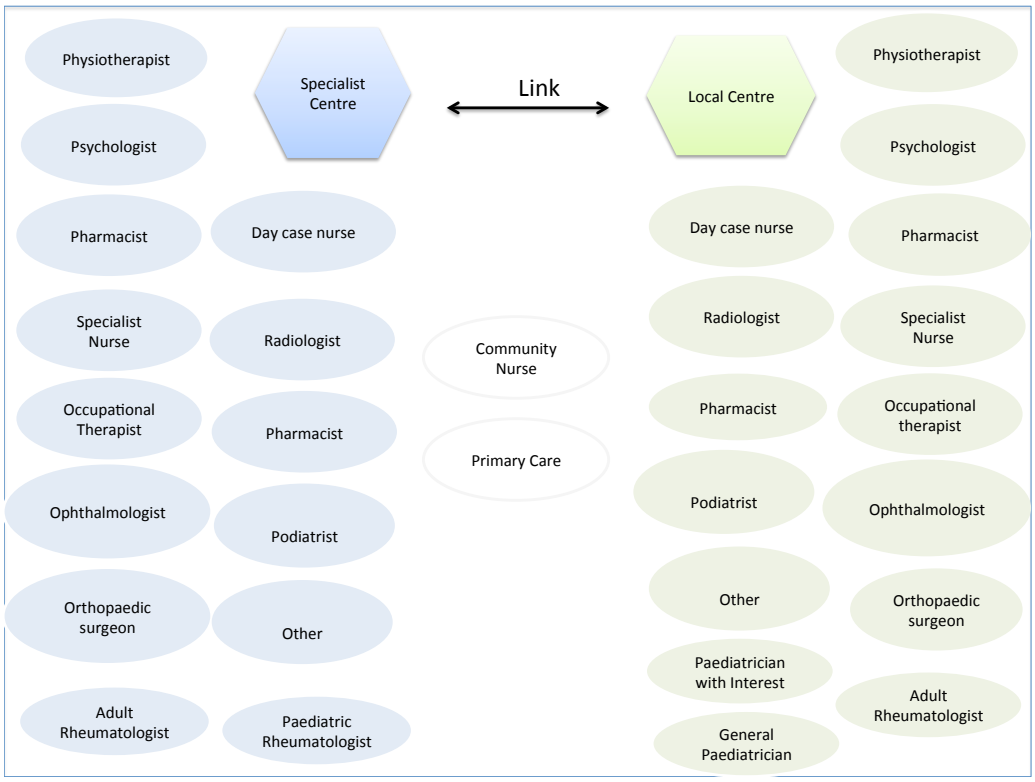

Figure 6 Study Participant Population

The total number of health professionals involved in looking after children and young people with JIA is unknown in the UK. It is recognised that not all are members of BSPAR, and therefore the latest membership figure of BSPAR (249) is likely to be an underestimation [British Society for Rheumatology Data Source 2015].

This next section provides a description of how I chose which of the clinical networks and participants to study and recruit from across the UK.

3.4.1 Sampling

The aim of the sampling strategy was to maximise the opportunity of gaining enough data to facilitate exploring the research question. In part this depended on the resources available to undertake the study, the setup of the services for children and young people with JIA across the country, and the availability of participants.

Clinical Network Selection

Purposeful sampling was used to identify and select networks to study, which were rich in information relating to the area of interest (Pope and Mays, 1995).

The following criteria were used and included:

- Geographical area of the UK, and population density
- Network size (number of hospitals and health professionals linked together)
- Grid or non grid tertiary centre
- Stage of network development (new or well established)
- Network structure (the way that care was delivered between the tertiary and local centre)
- Any other particular features

Five tertiary centres and their networks were chosen to study, four in England, and one in Scotland. The reason for choosing these specific tertiary centres and networks using the above criteria is captured in Table 9. In order to ensure complete anonymity I have called these centres by letter (A-E), and the geographical region and population density has been intentionally omitted from the table.

Tertiary centre & network	Size: Number of hospitals linked to tertiary centre by 'out reach/network clinics')	Type of tertiary centre	Network structure	Network Stage of Development	Other Issues
A	4	Grid centre	'Outreach clinics'	Different stages of development – some well established, others relatively new	Recent service reconfiguration and establishment of more formalised clinical network arrangement
B	11	Grid centre	Network clinics involving local specialist MDTs	Well established clinical network > 5 years	Only clinical network to be formally funded and managed
C	1	Approved Grid centre (No current trainee)	'Outreach clinics'	Network links in process of being established around region	Newly established tertiary centre for paediatric rheumatology
D	0 **	Grid centre	**No outreach clinics but >30 local hospitals 'Shared care'	Different stages of development – some well established, others relatively new	
E	7	Non grid centre	'Outreach clinics'	Newly established network	

Table 9 Tertiary Centres and Network Selection Justification

Tertiary centres A, B & D and their 'networks' were studied in depth using focus groups and interviews. The reasons for studying these centres in depth included geographical ease of study participant recruitment, and the different range of network structures ('outreach clinics', local specialist MDTs and 'shared care'). These terms are explained in detail in Chapter 8. Tertiary centres C and E and their 'networks' were smaller newer centres, one of which was a non-grid centre. They were chosen to challenge and refine findings generated from focus groups and interviews from Centres A, B & D.

Participants

Once it was decided which tertiary centres and networks were to be sampled, recruitment was predominately aligned with existing and/or established events such as network educational meetings or MDT meetings, which targeted selection of professionals from different professional backgrounds (Table 10). A key professional (such as the clinical lead or manager) was contacted and participants were invited to take part in the study (sample of invitation letter in Appendix 3). Following focus groups, further key people were identified from the networks to gain different perspective in one-to-one interviews.

The sampling strategy for participants was also purposive (Pope and Mays, 1995). I organised groups consisting of professionals from different professional backgrounds and networks, as well focus groups of consisting of single professional backgrounds and networks. There are advantages and disadvantages of focus groups with professionals who work together, as well as those who do not (Pope and Mays, 1995). For example, for those that do not work together in clinical networks, focus groups may be a fruitful way to explore different experiences of the same issue across different regions, and participants may be less inhibited to raise issues if other colleagues are not present. The converse may occur if a focus group work is held with participants who work together, for example allowing in-depth exploration of a single issue specific to their network or centre.

Centre/network	Existing Event/Arrangement	Types of Participants
A	MDT meeting Arranged interviews	Tertiary MDT Link paediatricians Adult Rheumatologist
B	Network Education Meeting Consultant Meeting MDT Meeting Arranged interview	Link Paediatricians Paediatric Rheumatologists Local MDT Adult Rheumatologist Paediatric Rheumatologist
C	Arranged interviews	Paediatric Rheumatologist Adolescent Rheumatologist
D	Arranged interviews Network Education Meeting	Paediatric Rheumatologists Paediatric Rheumatology nurse specialist MDT
E	Arranged interviews	Paediatric Rheumatologist Adult Rheumatologist
Other	Single professional group meetings	Nurse

Table 10 Participant Sampling and Recruitment Strategies

Overall, I found the recruitment process time consuming, and frustrating when attendance was poor. In an attempt to overcome the problem of poor attendance, a substantial amendment to the ethics committee was requested to increase the number of one-to one interviews, and focus groups but with smaller numbers of participants in each focus group. One health professional group in particular was difficult to recruit, namely clinicians from an adult rheumatology background. The reasons for this are likely to be multifactorial, but perhaps reflect historical inter-professional issues, which I discuss in more detail later in Chapters 5 and 6.

Study participants of young people with JIA and their families were recruited using a similar purposive sampling method. Existing events were looked for and chairs of charities contacted. This recruitment process of these participants is summarised in Table 11.

Event	Participants	Reason for choosing
Arthritis Care Charity Self Development weekend	Young people with JIA	Perspective of participants receiving care in different geographical locations, across a single country. Convenient date and location of meeting.
Scottish Network for Arthritis in Children Charity, family education weekend	Parents and carers of Children and young people with JIA	Perspective of participants receiving care in different geographical locations across a single country. Convenient date and location of meeting.

Table 11 Additional Participant Recruitment Opportunities

3.5 Collection of Data

A topic guide was used to facilitate data collection in both focus groups and one-to-one interviews. The topic guide consisted of a number of questions, with follow up prompts that enabled further discussion to be generated. An example of the initial topic guide is included in the Appendix. All focus groups and face-to-face interviews were digitally recorded, transcribed verbatim and anonymised. No names or identifiable details were present in the transcripts, or analysis, ensuring that anonymity was maintained. After each focus group reflective field notes were written, providing additional resource for analysis.

3.6 Anonymisation of Data

Once the focus group discussions and one-to-one interviews were transcribed, I checked the transcripts and added emphasis where audible. To anonymise the data I initially changed the names of the participants, hospitals, trusts and geographical areas to letter codes, such as AXXX, BXXX, and CXXX etc. However, with this simple 'find and replace' approach (Saunders *et al.*, 2015), I found it hard to remember similarities, differences or linked connections between people and places based on this coded information. This is a recognised problem which results in decontextualisation, and can limit the scope of the analysis (Baez, 2002), To overcome this I introduced themes for each network – such as "Animals", "Birds" and

“Fruit and Vegetables”. This made reading of the transcript much easier, and also ensured that relationships between geographical locations and people were not lost in the anonymity process.

3.7 Analysis of Data

In this section I describe the steps undertaken to analyse the data generated from the focus groups, interviews and field notes. The same process was used to analyse these three data collection techniques. I had guidance from my supervisors, and drew upon some practical techniques from qualitative courses attended and suggested literature. Data was analysed iteratively, as it was generated, and the analytical process evolved and refined over the course of the study. I include photographic and diagrammatic examples of the different stages. These examples have purposively not been ‘redrawn’ to overly neaten or sanitize the process.

1) The audio recording was listened to whilst reading the transcript in its entirety. This helped me engage with, and become familiar with the data, as there were often a few weeks between the collection of data and this first stage of the analysis.

2) I closely read the transcript line by line in small sections. I noted anything that appeared interesting in the margin of the transcript. This is illustrated in Figure 7. This began a process of coding. I was looking for interesting things people said or did, things that seemed odd or salient as well as repetition (Rapley, 2010). I used different coloured pens to denote different codes, and coded similar terms with the same code.

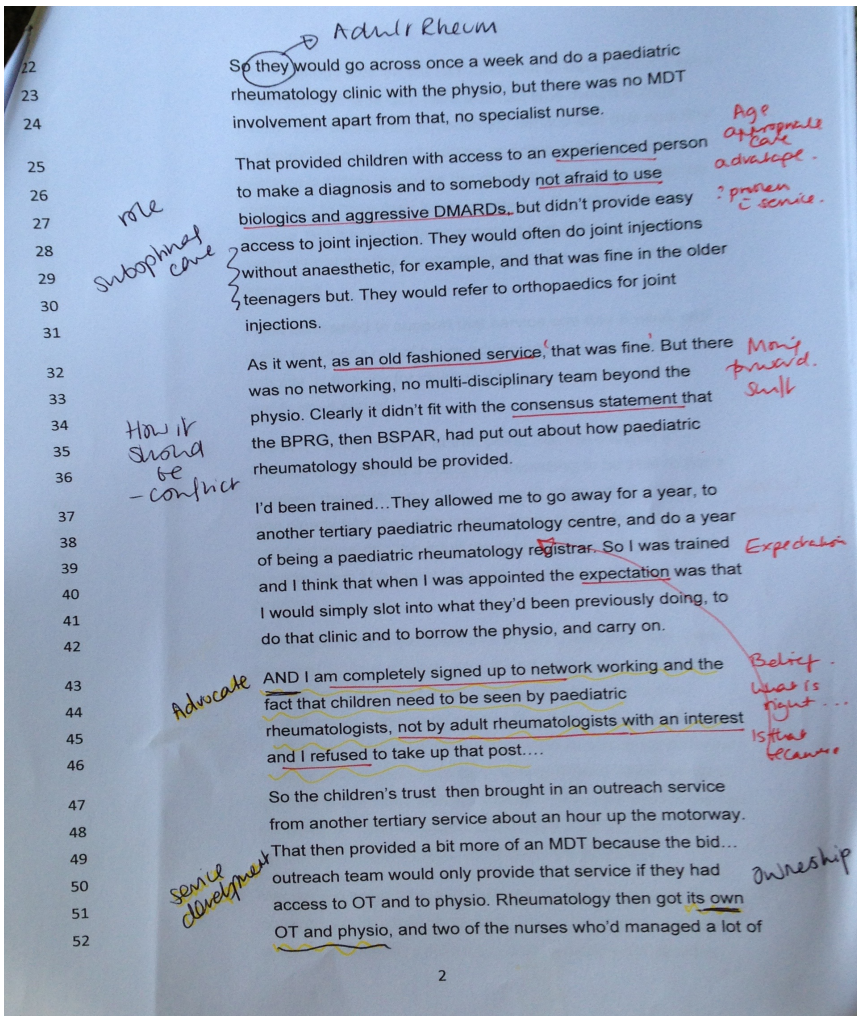

Figure 7 Transcript Noting and Initial Labelling

3) For each code, I challenged its use, whether it worked or did not work and this meant that I often had to refine the codes and create new ones. This process involved a lot of reflection, scribbling out and 'starting again' with a fresh copy of the same transcript. Overtime with the repetitive process I gained confidence and I developed a 'professional vision' for my analysis (C. Goodwin (1994), which involved making decisions and choices about which sections of the transcripts to highlight (Rapley, 2010).

4) These codes were transferred to a word document and a table created of a list of codes. I then took a fresh copy of the transcript and went through the transcript again, highlighting the data, which related to the code. I purposely used pen and paper, and only used a computer to generate tables in word documents for 'cutting and paste excerpts', rather than using any software packages. There were a number of reasons for this choice. Firstly I recognised that I am 'visual' person who scribbles a lots with colours and found that that process worked for me not only practically but

also conceptually. Secondly, I had limited time to learn how to use a software package.

5) I then systematically went through the original transcript on the computer and 'cut and pasted' the code examples (descriptive accounts) into the coding table, referencing line numbers. I show an example of a code table from one of the first transcripts Table 12. The first code I created for these excerpts was 'feelings' which became refined to 'emotional reactions'. Once the excerpts were transferred to the table, similar descriptions were moved together, creating sub-codes (in this example situations which caused a similar emotional reaction).

EMOTIONAL REACTIONS		
Situations causing surprise/ interest	701	F2what was really interesting is that that was sent across the whole of West Wood through their feeds and I actually got therapists contacting me saying can I come to
Situations causing worry	754	F4 one of the things that I have been worrying about is how do I know when I get to that hospital whose the best person to I don't know manage iron deficiency anaemia. Who do I send them to when they need you know just I don't know all sort of different things from school health input, when they need some psychology input, when they need …
Situations causing Frustration/ Difficulty	202	I don't believe they get the service there. There are a number of issues that affect that. There is the geography of the actual layout of the clinic, in Badger in particular is very difficult. They are only a very small number of rooms and those rooms happen to be the consultant's office as well. So you are in the position where you are sitting in someone else's office with all their clutter and seeing patients which to me doesn't feel very comfortable and I think that is apparent to the families as much as it is apparent to F9 and I sitting there. The actual layout of the room is long and thin so when you are sitting in that clinic you feel like you are sitting in a bus stop because we are all sitting in a row because of the geography of that … that room and from a support there is just the clerk that books people in, so there is no nursing support there either…
	618	F3 I went down to Sealion a few times and did a shared clinic with adult rheumatologist thinking again a bit of dialogue, I knew her professionally and personally. F9 I did OVERTALKING I Mhmm. F3 But it was clearly not comfortable. I Okay. F3 So I think yeah you need to ask people at commencement how it was for them. F9 It was frustrating yeah. F3 It was frustrating and uncomfortable for us but the leverage for change came from a higher level.
	820	F8 And if you don't meet it, it is frustrating for everybody isn't it and then may be people don't come back. *(Meet being everyone's needs)*
Situations causing Anxiety	669	we have been quite anxious about some of it, (*education in the network*) because it is about getting t … getting the right pitches is sometimes very difficult

Table 12 Example of Coding Table

6) After the table was created I wrote the individual codes on ‘post it’ notes, a process I refer to as memoing Figure 8. I then placed these on a large blank piece of paper and began to combine them together to look for associations, repetitions, odd ones or striking ones. Coloured notes and pens were also used to help facilitate links and relationships between different codes (Figure 9).

Figure 8 Memoing

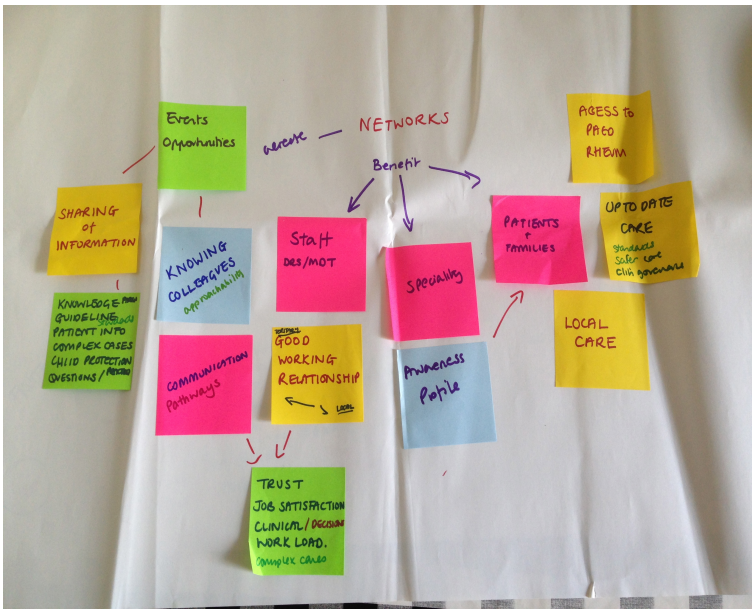

Figure 9 Relationships of Codes

7) The codes were then applied to each subsequent transcript. In some of the later transcripts if new ideas emerged, then additional codes were added and earlier transcripts rechecked to ensure completeness of analysis. This iterative

process of discarding, refining and confirming ideas helped me and encouraged my conceptual development.

8) Throughout this process, I wrote about the themes that were emerging and drew spider diagram maps[7] (Figure 10) to illustrate the relationships that were evolving from the data. These processes further helped support (or challenge) previous emerging ideas, and thereby refined the analytical process. The attempt at explaining and justifying my ideas consolidated my interpretation of the data and transformed my ideas. There were times during this analytical writing and drawing process that some of my initial ideas evaporated but others evolved and solidified. This allowed me not only to see which areas of interest I needed to explore further, but also offered me a way to conceptualise my ideas, and shift from describing the data towards explaining the underlying key issues.

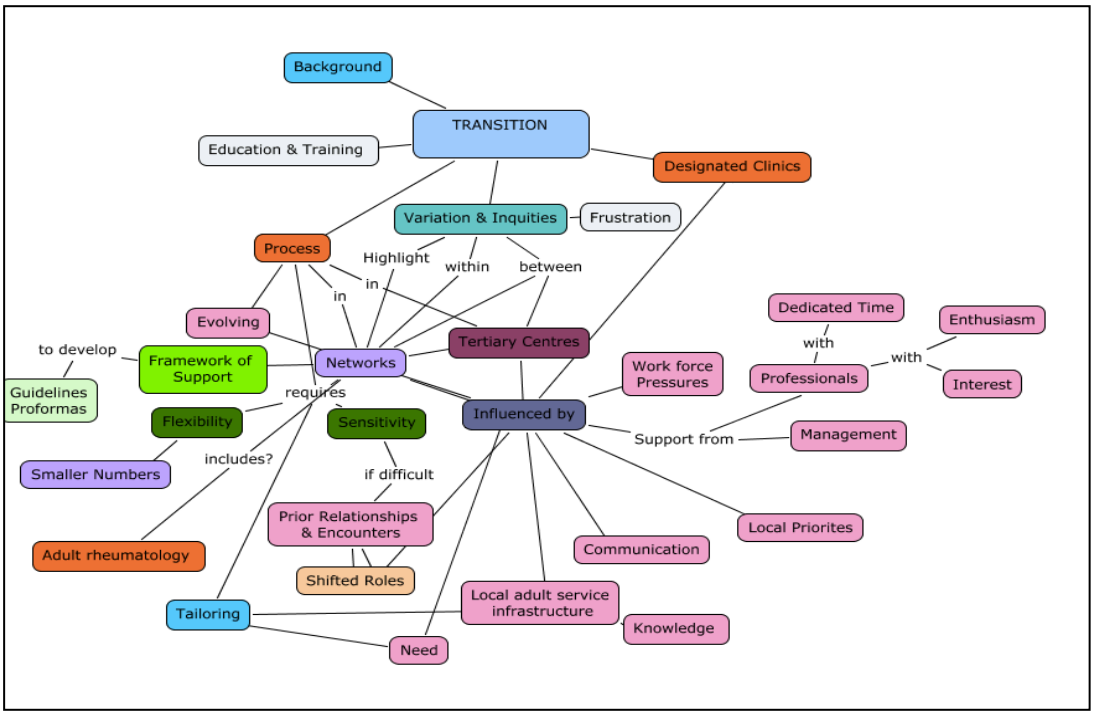

Figure 10 Spider diagram on transition

9) I acknowledge that at times during this analytical process, I became lost in the detail of the data, particularly when analysing each transcript line by line. However, over time, I developed my own 'qualitative analytical attitude' (Rapley, 2010), and became more confident in managing the copious amount

[7] Spider diagrams were created using 'CmapTools' (http://cmap.ihmc.us/)

of data generated from all the transcripts. Returning to the objectives of the study helped keep me focus and step back and look at the bigger picture. I frequently returned to a picture that I refer to as my ‘big picture diagram’ (Figure 11) to help select and focus on certain parts of the data.

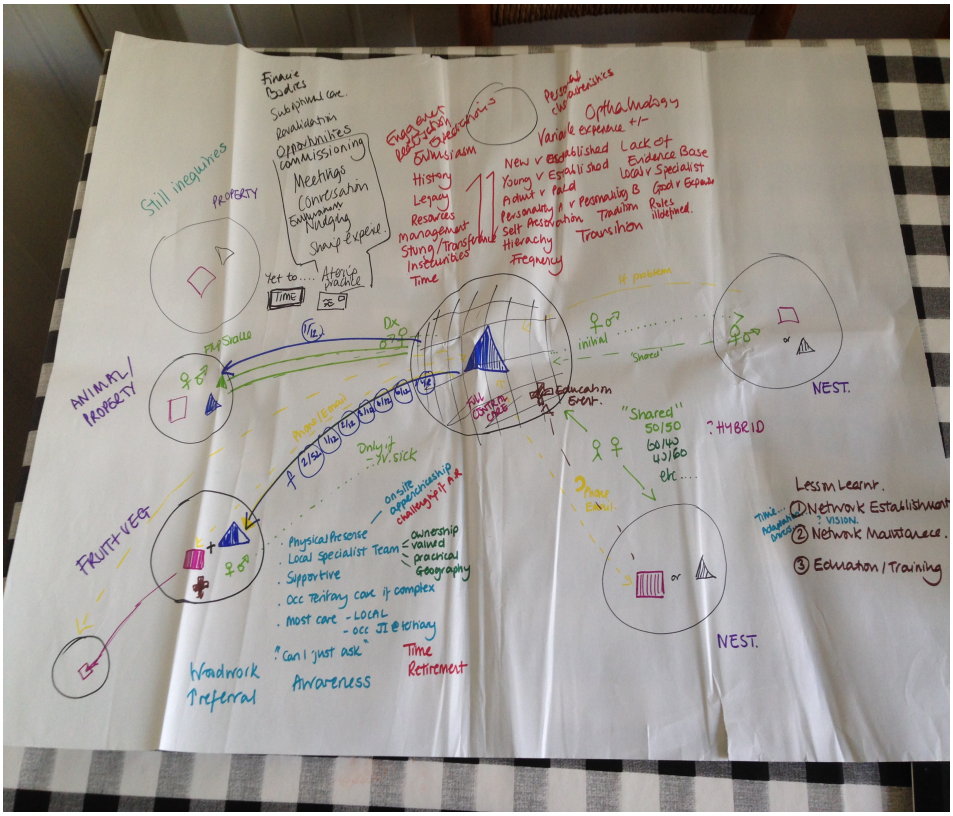

Figure 11 Big Picture Diagram

10) Over time there was a process of ‘data reduction’, which is a recognised form of analysis, which can help with data organisation and conclusion drawing (Miles and Huberman, 1994).

3.8 Development of an Educational Framework

The analytical process described above involved writing about key emerging themes. In the concluding chapter of this thesis (see Chapter 10) these key themes and concepts are brought together in an educational framework, which in the context of this study is a practical guide.

3.9 Study Validity

In order to assure that the key ideas and claims of the study have been thoroughly investigated, I employed strategies to ensure the validity of the findings (Morse, 2015). Validity can be defined as 'the degree to which inferences made in a study are accurate and well founded' (Polt & Beck, 2012, p745). I describe in this section, the processes undertaken:

1) *Participants knowing the interviewer*

   There is a view that with increased trust (and intimacy), between the participant and researcher then richer data may be obtained (Morse, 2015). A degree of trust was already present with some of the participants, as I already knew many of them through BSPAR connections, and having worked in a number of locations across the UK. For participants who did not know me prior to the focus groups and interviews, time was spent 'getting to know each other' informally, for example, by attending their network meetings, or over a coffee.

2) *Sample size and appropriateness.*

   The sample size (72 participants taking in part in 9 focus groups and 12 interviews, which I discuss in more detail in the next chapter) resulted in a manageable data archive, saturation to be obtained, and the process of theorising to be possible. This suggests validity in that the sample size was adequate. During the initial writing part of the analysis process, I began to see the same issues recurrently, and certain codes and themes emerging being of key importance. This suggests that the sample size was appropriate, although it is also acknowledged that the decision to stop collecting data was also influenced by the time frame of the study and ethical approval. Data was obtained not only from participant's own experience, but also 'shadowed data' from other's experiences they also knew about (Morse 2008). The 'number of participants' therefore was beyond the number recruited to the study.

3) *Deviant case analysis.*

   I looked out for deviant cases, which were unusual or extreme cases of the phenomenon of interest that I considered as outliers, to that which was emerging from the analysis. Deviant cases helped me understand the norm, by comparing less common situations with those that are more commonly

occurring. For example, a deviant ‘network’ was included in the sampling strategy; Network D did not have a model of ‘outreach’ or ‘network’ clinics. I also looked for deviant cases during the analysis process. For example, when a participant said something, which others had said the opposite of; this provided me with an area to explore further. The process of understanding the differences resulted in me developing a richer, more in-depth understanding of the phenomenon, which is an important analytical strategy for the development of validity.

4) *Researcher background and bias.*

My clinical background as a newly trained paediatric rheumatologist may have influenced the discussion and contribution of the participants. However, this was addressed by asking open questions whilst undertaking focus group and interviews. I was in a unique position of understanding the specialty, having completed my training in a number of places, and therefore could draw upon experience. I also had insight, acknowledging that for some participants there was potential for sensitive issues to arise. As a newly trained ‘junior’ paediatric rheumatologist I was also likely to be less threatening towards the participants.

5) *Member checking*.

During focus groups and interviews I conducted a process of validation of the findings. Validity of a phenomenon was gained when numerous sources suggested the same thing. In addition, there was deliberate attempt to ‘test’ emerging theories. This was done both between, and during different groups and interviews. For example, sharing a finding from network A with network B, or after one person had raised a specific point within a focus group, and asking about any similar experiences. I shared findings by describing situations previously that participants in other networks had offered. I also used diagrams, for example relating to network structure (Figure 12) that were generated from analysis of previous focus groups to aid discussion in other networks to find similarities and differences.

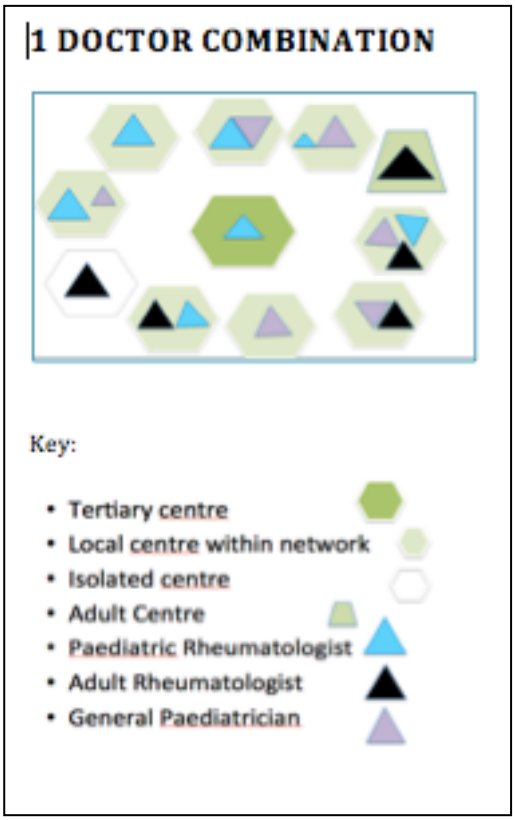

Figure 12 Picture diagram of doctor combination to aid discussion about network similarities and differences

The findings of the study were presented to the final two participants in the study, from a network not previously studied (Network E). They confirmed or refuted the findings, and then justified it by providing specific detail in relation to their experience. Such replication, helped determine normative behaviour and situations, hence increasing confidence in findings. However, this process also facilitated differences to be explored.

6) *Research team review and debriefing*

I was aware that it was important to consider the influence of my own background as a paediatric rheumatologist, having worked across numerous clinical networks. The influence of this background was moderated by the different backgrounds of the research team, some of whom were from a non-medical background. I discussed my findings and my writing was reviewed by my supervisors, who questioned my findings, and as such assisted with the development of validity (Morse, 2015).

7) *Philosophical Perspective*

I recognised the need to be aware of my own perspective and assumption about the research topic and approach to analysis when considering the

validity of data analysis. My approach relates more to that of the philosophical perspective of subtle realism (Hammersley 1992), in that my perspective is that 'truth' may be described and discovered through research. However there may be caveats and that later it may be disproved. I acknowledge there may be a range of readings of any particular data set and if someone else had undertaken the research project then they may offer a different focus, which may also be true. The test of the validity of the project will be in its outputs when the community it is intended for judges it. Hammersley (1992) notes that those judging the findings should assess how plausible they are, given their knowledge of the existing evidence. Where an argument made differs from existing knowledge, stronger evidence needs to be provided. Relatedly, the more core the argument the stronger the evidence provided needs to be.

3.10 Summary of the Methods

Within this chapter, I have provided description of the rationale of the study design, and given an honest account of how the data was collected and interpreted. I have provided an account of the measures taken to address validity of the study. However, I also hope that the process is detailed and transparent enough for the reader to judge for themselves aspects of the validity of the study as well as its applicability to their own, and other settings.

The next chapter provides an overview of the results chapters - the 'findings' of the study.

Chapter 4. Overview of Results

4.1 Introduction to Results

In this very short chapter, I describe the demographics of the study participants recruited, and give an overview of the empirical section of this thesis (Chapters Five to Nine).

4.1.1 Study Participant Recruitment

72 participants were interviewed over nine focus groups and twelve one-to-one interviews. One participant took part in a focus group as well as a one-to-one interview. Focus groups and semi-structured interviews lasted between 30–60 minutes, at locations suiting the participants.

A summary of the data collection is provided in Figure 13.

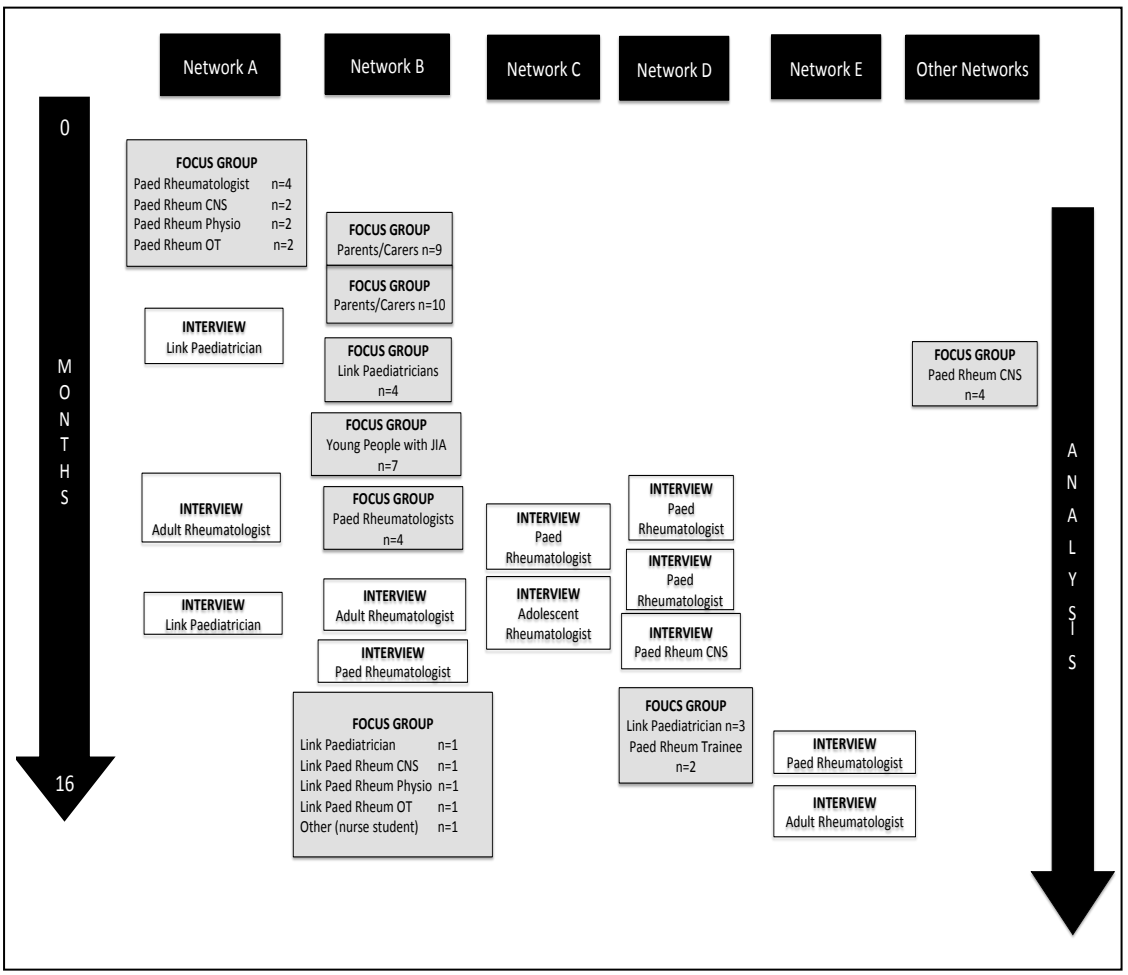

Figure 13 Overview of data collection

A summary of the recruitment of different professional and group backgrounds is outlined in Table 13.

Background	**Number (Total=72)**
Paediatric Rheumatologist	11
Adult Rheumatologist	4
Adolescent Rheumatologist	1
Paediatrician	11
Paediatric Trainee	2
Paediatric Rheumatology Nurse	8
Paediatric Rheumatology Occupational Therapist	3
Paediatric Rheumatology physiotherapists	3
Young people with JIA (Median age 15 years, range 12-17 years)	8
Parents/Carers of children & young people with JIA	21

Table 13 Participant Backgrounds

4.1.2 Overview of Empirical Chapters (Chapters Five to Nine)

Chapter Five describes the historical landscape of the networks studied. The evidence for the need to develop services to improve care for children and young people with JIA is presented, and the rationale for establishing paediatric rheumatology clinical networks across the UK is discussed. Building on the previous chapter, Chapter Six details the journey towards establishing clinical networks to deliver care for children and young people with JIA. I first describe the approaches used to link professionals and their organisations together. This is followed by a detailed account of the experiences of those who have been involved in this process. In Chapter Seven, I review the introduction and consequences of clinical networks, including the progress made towards improving care for children and young people with JIA. Then in Chapter Eight, I describe the structure of paediatric rheumatology networks and how care is delivered in clinical practice. In the final empirical chapter,

Chapter Nine, I describe existing continued professional development and training within the clinical networks studied detailing the format, content and target audience, and how it was delivered.

The key findings of the empirical chapters are brought to together in Chapter 10 to provide the content for the educational framework – to provide guidance for medical professionals establishing clinical networks to deliver optimal care for children and young people with JIA.

4.1.3 Data presentation

The empirical chapters include excerpts from transcripts with reference to origin: focus group (FG) or interview (INT) and line number. Emphasis from original audio recording is added in capital letters. In the interest of confidentiality the exact professional background of the origin of quotes is only disclosed if the background is significant in giving further context to the point being expressed.

Chapter 5. Rationale for Establishing Clinical Networks

5.1 Introduction

This first empirical chapter describes the historical landscape of the networks explored. I will describe experiences of how care was delivered for children and young people with JIA before clinical networks were established. 'Looking back' at the past is important because it helps make sense of the present day situation. I will highlight examples of where care was perceived as 'suboptimal', a lower standard of care to which is now expected (Baildam and Davidson, 2008; Davies *et al.*, 2010). I review the evidence for the need to develop services to improve care for children and young people with JIA, and discuss the rationale for establishing paediatric rheumatology clinical networks across the UK. I will introduce the concept of 'professional boundaries', which is a key concept throughout my thesis.

5.2 Historical Ways Care was Delivered

Across many parts of the UK, care for children and young people with JIA historically was predominately provided by 'established' and 'experienced' adult rheumatologists. Some of these clinicians had run paediatric clinics for many years, and were key medical professionals in care provision for children and young people with JIA. Some had been involved

> 'since it started really…. So I've got 20-plus-year-olds now, which is quite nice, because you've known them since they were little' (INT 8.1; 65/444).

Developing an area of clinical practice, which involved looking after long-term chronic conditions in children and young people had clearly been rewarding and enjoyable, and for some it had become central to their life time's work; as one adult rheumatologist described, it is 'my thing' (INT 9.1; 284).

An adult rheumatology-led model of care historically was widespread across the country, providing rheumatological expertise for a number of children and young people with JIA. Their role was important in many areas across the UK, because there was no alternative. An adult rheumatologist illustrates this in the following excerpt.

> 'So basically I was the first rheumatologist ever [in this area]. So everything, *everything* came my way, absolutely everything… kids started getting referred…. there was a real need… orthopaedic surgeons were managing them, and there were a lot of non-diagnoses for patients…. kids

> came out of the woodwork with no classification, correct classification criteria or anything' (INT 8.1; 37).

Participants described the number of paediatric rheumatologists across the UK historically as relatively few and where they were present there were limitations in workforce and clinic capacity to see patients. One doctor noted that when they started 15 years ago they were the only paediatric rheumatologist in their region, but eleven adult rheumatologists were looking after children and young people with JIA in eleven separate local centres.

Adult rheumatologists were described as 'very helpful partnerships in the evolution of service[s]' (FG 7.1; 198). Some paediatric rheumatologists acknowledged their important role -

> '[The adult rheumatologists] hav[e] worked really hard, and they've been supporting these services for years and they've done largely an incredibly good job, within horrible time constraints and so on. And very little support, and they weren't having MDT, and they have done really well' (INT 11.1; 147).

Despite limited resources, these adult rheumatologists provided a service for many patients and in some areas their role extended beyond seeing and managing patients.

> 'Those adult rheumatologists, for a long time they were the people who were confidently using the drugs. They were competent in clinical examination of joints. They had lots of skills that at the beginning were extremely useful to get paediatricians going' (FG 7.1; 188).

In this example, the adult rheumatologists had a specific role in educating local paediatricians who had limited experience and training in the specialty.

Adult rheumatologists were the professionals who generally led the clinical management of patients, but general paediatricians frequently joined them in clinic consultations. This combination - of adult rheumatologists, 'doing clinic together' with (general) paediatricians provided the skill set needed to manage the complex issues faced by children and young people.

> 'They've been there to advise about vaccinations, about the epilepsy, about the enuresis, about the social problems, the, I don't know, the behaviour issues, all the other paediatric things. So it was very much – I felt that I [adult rheumatologist] had been the one taking the lead, I was writing it in the notes, I was writing the letters and so on (INT 9.1; 218).

This set up provided access to, the sometimes needed, general paediatric advice. However, there were also reports of adult rheumatologists seeing children and young people on their own without input from paediatricians. In a few areas, other clinicians, such as orthopaedic surgeons and general paediatricians were also managing children and young people with JIA. Some of these clinicians were reported to have

> 'worked quite independently so without very much in the way of links to [the tertiary paediatric rheumatology service]' (FG 5.1; 89).

For children and young people managed by 'non rheumatologists' concern was raised by paediatric rheumatologists about their limited expertise in the management of arthritis.

As the specialty of paediatric rheumatology developed, for the reasons discussed in Chapter One, and specialist centres for paediatric rheumatology emerged, there was concern from professionals working in the specialist centres that care managed out their centre was not being delivered in 'the accepted way' (INT 6.1; 246). Suboptimal outcomes including disability and visual impairment were encountered. With optimal care focusing on early diagnosis and aggressive management by specialist paediatric multidisciplinary teams, these outcomes were attributed to suboptimal care being delivered. I describe in more detail examples of suboptimal care in the next section of this chapter. It is important to highlight however, that not all care managed out with specialist centres, was perceived as 'suboptimal'. Some local adult-led rheumatology set-ups were 'accepted' by the tertiary paediatric rheumatology teams.

> 'An adult rheumatologist who was very enthusiastic, and had set up a very good local [paediatric] team, who did an awful lot of the general care, but referred to [the tertiary paediatric centre] if there was a problem. Then, emailed us if that patient was getting into trouble, and needed to see us again. So they used [the paediatric rheumatology team] as the expert opinion, and did virtually everything else locally. They often did joint injections locally; unless they couldn't get them onto a list, or there isn't a paediatric list that they can get them onto, in which case, we did them. (INT 2.1; 130)

When adult rheumatologists or paediatricians in the local centres had clinical questions, appropriate communication as well as access to a local paediatric MDT appeared to be key for being an accepted way to deliver care. There were also reports of clinical governance awareness from clinicians who were managing children and young people with JIA in local hospitals, with

> ‘recognition that they were working in isolation and they needed a group of colleagues that they could reference' (INT 6.1; 196).

Some adult rheumatologists had organised educational events to ensure that clinical practice was in keeping with others in geographically nearby regions. It is unclear from this particular quote whether or not the paediatric rheumatologist(s) were invited to these events.

There had been attempts previously by some paediatric rheumatologists to try and link services across regions to develop services for children and young people with JIA. Some paediatric rheumatology consultants had gone out from the specialist centres to local centres, and ‘done clinics’ with local professionals, thereby providing a form of access to expertise from paediatric rheumatology. However, there were practical limits on what could be done within a small specialty; in many areas because of low staff numbers there were reports that at the time this way of working was not sustainable. Evidence to support the evolution of provision of care was also an impediment to driving change. In one region an adult rheumatologist reported entering discussion with their hospital management for many years to try and improve the service for children and young people with rheumatological conditions, particularly with regard to resources to develop paediatric rheumatology nursing posts. In this example, it was only when BSPAR/ARMA SOC were published, and shown to managers that funding became available to change and improve the service set up.

> ‘I used those [standards of care] to finally force the issue that there had to be – about having a paediatrician and a paediatric nurse. So I used those guidelines for recognised the need for paediatric involvement’ (INT 8.1; 487).

In summary, the provision of care for children and young people with JIA historically involved adult rheumatologists, paediatricians and orthopaedic surgeons all playing a part. As described in Chapter One, the management of JIA has changed over the past two decades with increasing use of chemotherapeutic agents, and the emergence of biological therapies. The specialist roles of a paediatric rheumatology MDT became increasingly recognised as important. Professionals within these specialist centres therefore naturally were concerned about how care was being delivered outside their domain of influence. In the next section, I describe examples of what was perceived as suboptimal care in this context. As detailed in Chapter One, the transition for all children and young people with JIA to have access to

paediatric rheumatology specialist teams is yet to be completed, and therefore I also describe more recent examples of suboptimal care reported from all of the study regions.

5.3 Perceptions of Suboptimal Care

5.3.1 In the Past

The adult rheumatology-led set up, was described by one paediatric rheumatologist as a

> 'very old fashioned model where the doctor did the medicine side of things without much of an MDT' (INT 6.1; 15).

This view was held widely, across different parts of the country, when there was no access to a paediatric rheumatology MDT. Sometimes, even where MDTs did exist, there were frequent descriptions of the service being delivered 'in a very sort of ad hoc' way (INT 11.1; 23), with either key members of the MDT missing, or having little or no specialist expertise in paediatric rheumatology.

> '[At the local centre] we [adult rheumatology] had a paediatrician there. We had a physio, a paediatric physio with an interest, the same one for years and years, so they were very good and very involved in the service. There wasn't a specific designated paediatric rheumatology nurse there; we just did [the clinic] in the paediatric outpatients with nursing support from whoever happened to be there' (INT 9.1; 54).

The consequences of not having a paediatric rheumatology MDT, specifically where there was no paediatric rheumatology nurse, were highlighted by reports citing that common issues arising in the childhood population, such as education about chicken pox exposure and immunosuppressive medication, failed to be addressed.

> 'We [paediatric rheumatology specialist team] talk to the families [who had been] under an adult system and I guess that its not surprising they haven't had access to paediatric nurses so you know they weren't aware of things like Chicken Pox' (FG 1.1; 497).

For some children and young people who were being managed under this model there were also descriptions that treatment monitoring was different to that available in tertiary specialist centres.

> 'So the children [at the local centre] were having a blood test done every two weeks and we wouldn't condone that, they were going to oncology of adult units to get their Methotrexate and they weren't necessarily seeing children's nurses' (FG 1.1; 447).

They may have been receiving appropriate treatment for their arthritis but where and how it was given was deemed inappropriate. Suboptimal care in these examples is positioned as problems of access to adequate multidisciplinary support, provision of information, appropriate care environment and monitoring regimes.

Another specific problem of the adult rheumatology-led model was that not all adult rheumatologists saw patients in clinic in combination with a general paediatrician. Not having paediatric presence during clinic consultations resulted in difficulties dealing with clinical problems out with their expertise.

> 'So there were children with non-organic illness who had been seen for four years [by adult rheumatology] and they couldn't move that situation on. That was very frustrating … I think the addition of a paediatrician into that system would have been extremely helpful at that time to move that on' (FG 7.1; 250)

The perception amongst paediatric rheumatologists was that some cases could have been managed better and were also accompanied by reports that there had been 'difficult[ies] in persuading some adult rheumatologists to behave in a paediatric way' (FG 7.1, 24). For example, a view held widely by the paediatric rheumatology community was that children are not just miniature adults and the way that care is delivered needs to be thought about differently.

> 'They [adult rheumatology] would often do joint injections without anaesthetic, for example, and that was fine in the older teenagers…[but not the younger ones]' (INT 6.1; 25).

So suboptimal care here is positioned as a problem of access to developmentally or age appropriate care.

Some local centres provided a service to enable joint injections to be performed under general anaesthetic. However, delays were reported in performing the injections because of lack of access to specific paediatric rheumatology theatre lists. In some cases this meant waiting a few months until there were enough patients to 'make up' a list.

> 'We [Adult rheumatologist] used to just really basically wait till we had a few patients who needed injections and then we would book an ad-hoc list. We didn't have a regular list in theatre. That, it worked okay, but quite often there were delays in getting them up to get their injections done' (FG 9.1; 85)

For others they had to be referred to orthopaedics, and wait, often for months, until they had been seen in their clinic before being listed for theatre. As such, the suboptimal care here was viewed as a problem in access to timely drug treatment.

In Chapter One, I described how over the past couple of decades there have been changes in medical management of JIA, with much more aggressive treatment regimes used than in the past. For some children and young people with JIA who had been managed predominantly by adult rheumatologists, their treatment regimes were described to not have been as aggressive as those children who were managed by paediatric rheumatology specialists.

> 'My secretary … used to hate me coming back because I [a paediatric rheumatologist] would come back with a huge lists of patients. "This one needs a joint injection, that one needs a joint injection, this one needs to change to subcut Methotrexate" …' (FG 1.1; 593)

In this particular example, the paediatric rheumatologist did some locum clinics, which were run by an adult rheumatologist who was on leave, and had found that children with JIA frequently required treatment escalation. In another example, despite the evidence and the preferences of specialists from the tertiary centre, an adult rheumatologist could only offer a less efficacious, short acting, steroid because the longer acting alternative was seen as too expensive for the local centre to provide. Here, suboptimal care is positioned as a problem in access to specialist review with expertise in management on children with on-going active disease.

5.3.2 In Recent Times

The examples outlined in the previous section were retrospective accounts of the way that care had been delivered in the past. As discussed in Chapter One, the transition towards all children and young people having access to paediatric rheumatology specialist care is still not complete. This next section highlights more contemporary examples. As one participant noted

> 'we [still] have a very old fashioned service in existence with an adult rheumatologist and a paediatrician providing what they regard as a tertiary rheumatology service, without a dedicated MDT' (INT 6.1; 157).

There were also current problems similar to those described in the past of suboptimal care being positioned as problems in access to paediatric rheumatology multidisciplinary team support, early diagnosis, up to date treatment regime and adequate specialist review including ophthalmological screening.

With the increasing recognition of the need for paediatric rheumatology specialist input, there were reports that children and young people with JIA who had been managed in local centres were now beginning to be referred to the paediatric rheumatology specialist centres. However, many of these patients were still being referred very late in their disease course.

> ‘There are patients who have been seen in a variety of frameworks, either by general paediatricians or adult rheumatologists or been seen privately, again in a variety of settings - orthopaedic surgeons and adult rheumatologists who, for one reason or another, have then been referred to us [paediatric rheumatology] quite late in the day, where maybe they’ve already got some joint damage. You’re already on the back foot then almost in that you’re wanting to progress a pathway of care management that’s different to what they’ve been on maybe for the previous year to two years’ (INT 5.1; 318)

These patients had frequently been treated suboptimally with very low doses of methotrexate, or had not had appropriate eye screening:

> ‘there's a patient who's been treated for a year for an oligo [by a paediatrician], and not had an eye check, and has come with rip roaring uveitis’ (INT 2.1; 184)

If ‘referred late’ in the disease course to paediatric rheumatology and not treated aggressively then complications may occur from having persistent active disease and allowing inflammation to continue. It can be then much harder to instigate disease remission. There was opinion that for these patients who came with ‘a little bit of trouble’ (INT 2.1; 156), their problems would have been prevented by earlier referral to paediatric rheumatology.

Access to paediatric rheumatology specialists early in the disease course not only is important to ensure up to date treatment but also to ensure that the diagnosis is correct.

> ‘There are adult rheumatologists who think they know what they're doing and don't, and will prescribe biologics. Then again, you'll get a patient who probably should have seen us a lot earlier, who haven't. So one example that's just recently come to light is somebody who's been treated for 10 years as an oligo, and didn't respond to steroids, Methotrexate, Etanercept. When we [paediatric rheumatologists] have looked at the MRIs, they look like a PVNS (Pigmented Villonodular Synovitis) so they're not going to respond to the treatment. Actually, that was an adult rheumatologist in conjunction with a paediatrician, where it's just gone very

> wrong, because they don't think about the alternatives that we do' (INT 2.1; 159).

There were also recent examples of clinical practice which are now viewed by the paediatric rheumatology community as outdated, for example:

> 'the patient is having to come into the hospital to have their injection given once a week by a doctor….that's not good practice for the patient' (INT 2.1; 319).

It would be now considered best practice for paediatric rheumatology specialist nurses to support families or community nurses to give subcutaneous treatments in the community setting, and only require hospital visits short term at the start of treatment regimes or to address needle phobia issues.

In summary, the findings in this section, from across all regions studied, provide evidence of widespread examples of suboptimal care across the UK, which occurred at multiple points along the patient's journey. Suboptimal care was positioned as a number of problems including inadequate multidisciplinary support and provision of information; developmentally and environmentally inappropriate care; untimely drug treatment; inexperience in managing on-going active disease; delay to correct diagnosis and inadequate treatment and screening regimes.

5.4 Discussion

Within this chapter I have presented a historical perspective on care delivery for children and young people with JIA based on focus groups and interviews with health professionals across the UK. The findings confirm what Foster *et al*. (2011b) have already described, that adult rheumatologists have played a significant role in service provision for children and young people with JIA. I identified that care was also delivered in the past by orthopaedic surgeons along with paediatricians. The different historical models of service delivery, and the subsequent development of specialist centres for paediatric rheumatology have created the variation of systems and models of care for children and young people with JIA, described in Chapter One, which are known to exist today (NRAS, 2014).

My findings emphasise the key role played by adult rheumatologists in the early years, not only in service provision, but often also for education and training of local paediatricians who were present in clinics. This would have been helpful because at the time, the training curriculum for paediatricians relating to paediatric

musculoskeletal conditions was extremely limited, and therefore few paediatricians would have acquired the skills or experience to provide this service were it not for the input of the adult rheumatologists. The role played by adult rheumatologists was acknowledged and in many cases appreciated, particularly by those who recognised that they had been working and providing a service with limited resources. However some of the challenges described later in this thesis related to how clinicians responded to service provision changes which resulted from network establishment. I discuss in more detail in the next chapter, that acknowledgment of roles may be important when engaging professionals to establish a clinical network.

Foster and Rapley (2010) have reported previously that, anecdotally, adult rheumatologists have not been resourced to deliver best practice. Our findings confirm that their resources have indeed been (and in some areas still are) limited. This specifically relates to service provision surrounding specialist paediatric MDT. Although Cropper *et al.* (2002), have suggested that establishing a network can make best use of scarce resources and expertise, this study also suggests that a critical workforce mass of expertise is needed in order for care delivery to be maintained within a clinical network.

Foster (2011b) has also suggested that historically adult rheumatologists who have been involved in the management of children and young people with rheumatological conditions have not had optimal training. The examples of suboptimal care, which relate to cases being under treated or misdiagnosed, support this. However, the issue relating to whether or not a professional is trained to deliver 'best' practice is a sensitive one – particularly when criticism may be personally directed towards an area of *their* clinical practice which they had established, found rewarding and enjoyed. However, keeping professional knowledge and skills up to date is one of the recognised domains of the General Medical Council's Good Medical Practice(2013), and an important part of the process of revalidation. Sharing knowledge by linking professionals and their organisations together in a clinical network may help address this issue (Addicott *et al.*, 2006), and support the continued professional development of professionals working within them.

I identified multiple reported examples of suboptimal care, which occurred along a patient's care journey, providing the evidence of the need to develop and improve services for children and young people with JIA, and educate professionals who may

be involved. The suboptimal care examples support the rationale for the establishment of clinical networks to improve access to optimal care for children and young people with JIA. The clinical networks studied were at various stages of development; the more recent examples of suboptimal care suggest an on-going need to develop linked services across the country. It should be highlighted however, that barriers to access to optimal care are multifactorial (Foster *et al.,* 2010), (Figure 1, page 4, Chapter One). Therefore it would be naïve to assume that development of clinical networks are the panacea to all the suboptimal care problems reported. Experiences relating to this particular issue are described in more detail in Chapter Six. In addition, although this chapter reports these suboptimal care findings for patients managed out with the specialist centres, many of the specialist centres have also recently fallen short on a number of standards of care for children and young people with JIA (Kavirayani *et al.*, 2013).

The findings in this chapter, relating to roles and areas of clinical practice introduce an important concept of 'professional boundaries'. Abbott (1988) described that boundaries between professional groups and their jurisdictions of work are the consequence of the system in which groups claim authority over an area of practice in the workplace. Boundaries demarcate territories, roles and responsibilities and are fundamental to what Fournier (2000) termed 'labour of division' or rather division of labour. For adult rheumatologists who provided rheumatological expertise for children and young people with JIA (as there was no alternative), this became *their* area of clinical practice, thereby developing a professional boundary. However, with the development of the specialty of paediatric rheumatology, and the establishment of specialist centres for paediatric rheumatology, this naturally introduced another group of professionals, who were involved in the same 'area of clinical practice'. When paediatric rheumatology teams from the specialist centres encountered patients from around their region who had been managed suboptimally in comparison to *their* way of clinical practice then this created not only the awareness that there was need to improve care, but also a tension between these two groups. It is recognised where jurisdictions or scopes of practice overlap, groups are reported to strive to stake a claim to an area of expertise (Larkin, 1983). I describe later in Chapters Six and Seven, some challenging experiences relating to territorial behaviour encountered during attempts to establish networks and delivery care within them.

5.5 Conclusion

This chapter confirms that there has been (and still is) a need to develop services to improve care for children and young people with JIA. There has therefore been rationale for establishing paediatric rheumatology clinical networks across the UK. The findings from this chapter introduce the concept of professional boundaries. I refer to professional (and organisational) boundaries throughout the remainder of this thesis and discuss their effect on clinical network establishment, education and training, and collaborative working. In the next chapter, I describe the process and the experiences encountered in the journey towards establishing clinical networks. Introducing change from the 'way that care used to be delivered', particularly for those who had made it 'their thing', has been challenging; the shifting landscape of clinical practice 'towards paediatrics away from adult rheumatology' has been welcomed by some, and harder to accept by others.

Chapter 6. The Journey towards Establishing Clinical Networks

6.1 Introduction

Building on the rationale for clinical network establishment described in the introductory and previous chapters, I will now detail the experiences of the actual journey towards establishing clinical networks to deliver care for children and young people with JIA. I first describe the approaches used by the specialist centres to engage local centres to link together in the form of a network. This is followed by a detailed account of the experiences of those who have been involved in this process. My findings demonstrate that it has not been without challenges. In particular, professional and organisational boundaries have exerted a significant influence on the engagement process and therefore on the level of specialist care that can be provided.

6.2 Establishing Links

Establishing a network, in whatever shape or form, requires an engagement process. This involves linking professionals from the specialist centres with those that are delivering care in local centres. Within this section I describe the approaches that were used to try and establish these links for the paediatric rheumatology clinical networks studied. In all but one example, the approach came from the specialist centre to the local centre. I demonstrate that a number of different approaches were used, and that it took time for these links to be established.

It might appear obvious, but rather than imposing a brand new service structure, allowing time for discussion for professionals to feedback and adjust to any suggested change, offered some benefits. For example there was evidence that professionals involved in the management of children and young people with JIA in local centres were given opportunities by the paediatric rheumatology specialists for their 'voices to be heard', in response to proposed network developments which included service delivery changes.

> 'You know, you just have to stand back and let thing's take its course and allow people [adult rheumatologists] to have their penny's worth. So there were a few uncomfortable meetings I [a paediatric rheumatologist] sat through where people were wanting to have their own penny's worth about how they wanted it to be and so on. That moved on eventually. It was fine (FG 7.1; 579)

Although in this example it was acknowledged there had been some initial difficult meetings, it just took time for professionals to adjust to, and agree to, proposed changes. As a consequence specialist centres had made progress towards establishing links with local centres in the form of a clinical network. This 'let things take its course' approach, with an opportunity given for views to be aired, facilitated service development changes for many; some paediatric rheumatologists who had used this approach found that this method had established 'good relationships' (FG 1.1; 612) with clinicians working out with the tertiary centres. In particular they had acknowledged the historical roles that these professional had played in service provision.

For others there was often some action required to 'sort of nudge people along.... to engage people gently' (FG 1.1; 609) to try to improve the standard of care for children and young people with JIA across their region. There was recognition that this may involve a change in the way that services were delivered and for some this would be a sensitive issue. Although this gentle approach worked for some, it was described as a

> 'very slow process, it's something that I [paediatric rheumatologist] undertook over years, and it would start with just initial discussions about how are you doing things, do you want to do things differently' (INT 11.1; 94).

This gentle approach between paediatric rheumatology specialists and adult rheumatology-led services across their region did not always work – 'it wasn't going to work that way...that [way] did not work' (FG 1.1; 613). A number of paediatric rheumatologist reported similar experiences. The perceived reasons for this lack of engagement were because some adult rheumatologists were seen as overly 'possessive' (FG 7.1; 570) about their area of clinical practice, and had become vocally resistant to proposed changes. One paediatric rheumatologist described that linking together of services across their region was

> 'met with pretty much hostility…. 'no thanks, we know how to do this, we don't want your empire building and that kind of thing' (INT 11.1; 103).

In some circumstances, little could be done to overcome this territorial behaviour. Change could only happen when the particular individual retired or left their post for another reason.

Events, such as retirement, particularly of adult rheumatologists offered potential for service transformation. This was reported to be 'a natural shift' (FG 7.1; 211) to the way that services were delivered, and facilitated new links being established between locally based paediatricians and paediatric rheumatology specialists at the specialist centre.

> 'The adult rheumatologist retired, which then left [local paediatric department to] approach their nearby tertiary paediatric rheumatology centre for support' (INT 5.1; 125).[8]

Such a change in personnel led to a change in the setup of services, with paediatrics taking over the lead. However, when there were no natural service reconfiguration opportunities and when gentler approaches had failed, alternative approaches were required. This included discussion about proposed changes within more formal meetings, and escalating matters by taking examples 'involving cases of suboptimal care' (FG 1.1; 569) to management and commissioners, confronting them with details on the current state of care in the context of published recommendations that were thought to have been contravened.

> 'Because the leverage for change had to come from commissioners in the end to say you know the standards of care are there and the parties who were not engaging in dialogue had to … had to engage in dialogue. And it was actually, it was actually uncomfortable for I don't know how long it was but a long time' (FG 1.1; 449)

When paediatric rheumatologists felt that these more formal approaches were required based on a perception of a need to improve standards of care against published recommendations, it was often not the easiest of transitions. This contributed to the process being lengthy.

In one network, the approach was part of a national development plan to improve access to all paediatric specialist services. This 'en masse' engagement process was formally organised with the invitation to all professionals involved with managing children and young people with rheumatological conditions. A network development steering group was established which had representation of the different geographical areas across the country, with representation from different professional backgrounds.

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[8] What is different about this example to the others is that the direction of approach came from the local centre to the tertiary centre. In all the other examples, the direction of approach came from the tertiary centres to the local centres.

There were also other approaches used, which reflected the similar problems seen in other areas. However, these approaches hinted at ways to overcome the deadlocks, which had blighted other engagement processes and service transitions. One team were aware at the outset that there were potential difficulties in engaging clinicians who had been involved in the management of children and young people with JIA in their region for many years. They therefore first took the time to raise the profile of paediatric rheumatology around the region through various educational events. Whilst doing this, they reported taking time to consider how best to engage with the local professionals involved the care of children and young people with JIA.

> 'We've agonised amongst the consultant team about how to engage, because there are two possibilities. There's the, "Right, we're going with a copy BSPAR of our guidelines saying that what you're doing absolutely contravenes good practice and wouldn't even be seen as safe, let alone acceptable." There's the, "We'd like to work with everybody..."'(INT 6.1; 171)

As noted in an example above, there was an inherent awareness that different engagement approaches – for example using BSPAR guidelines to show how current care contravenes good practice or a more collaborative approach, asking what can we do to help - may have different consequences. This particular team opted to remove potential professional territorial issues between clinicians, acknowledging that it was a sensitive area by abdicating the responsibility to their hospital managers.

> 'We got the Medical Director to write to the Medical Directors, so it didn't come from [paediatric] rheumatologists to [adult] rheumatologists, it was a genuine invitation to work together acknowledging this as a sensitive area.' (INT 6.1; 178)

The result for this particular team was the approach of

> 'negotiation to then try and arrive at that in a way that is acceptable to both parties, that involves meeting the clinicians and trust managers' (INT 5.1; 255).

The response was positive with expressions of interest from many trusts keen to have a more formal links. However, there were also report that some local centres had not yet entered into any negotiation, suggesting that perhaps other approaches in the future may still be necessary.

Whatever the approach taken by a paediatric rheumatology team to begin the development of a clinical network, the unifying experience was that the process took

time, particularly in areas where there was initial and ongoing resistance to establishing links. Furthermore, there was acknowledgement that only so much could be done at any given time.

> 'As part of generating a network you can only do so much at a time so we'll work with the trusts where there's more enthusiasm maybe to begin with. Then as time goes on and we've set up formal links with one trust, then another, then another, it may be as we work around the region that we find areas where people are less keen to work within a network framework as we do that process' (INT 5.1; 294)

The lack of specific time for service development in job plans was also a rate-limiting factor. Paediatric rheumatology specialists faced with the task of establishing a network, therefore often focused initially on developing relations with those that were most expedient.

> 'It's fine to start with the places that work and get them working well and then other people want to come and join in the party… people want to be part of that club' (FG 7.1; 656)

Some reported that developing the network with colleagues in local centres who were perceived as enthusiastic was easier. One specialist centre had then found that other colleagues who were the initially more resistant to change then followed suit, once benefits were shared.

I've shown in this section, that a multitude of approaches were used to establish links including allowing for opinions to be heard, gentle nudging, letting natural events take their course, discussion, negotiation and confrontation. For some it was also a lengthy process. The reasons why different approaches were used and why for some, it has not been the smoothest of journeys, is explored in more detail in the next section.

6.3 Experiences of the Engagement Process

Overall there were mixed experiences of the engagement process ranging from 'very positive' to widespread reports of 'difficulties', with a number who had described it as 'uncomfortable' (FG 7.1; 581), 'very challenging' (INT 7.1; 204), or were witness to an extreme - 'stressful…just awful' situation - requiring 'smoothing ruffled feathers on all sides [which] was a diplomatic nightmare' (INT 10.1; 607). It is important to point out that within each of the networks studied a range of mixed experiences was described from professionals from different clinical backgrounds. Some paediatric

rheumatologists had found that professionals from different local centres had varied reaction, which required completely different management skills for the engagement process.

> ‘But, so each one of sort of eight-ish centres had to be managed I guess in very different ways, and sort of politically, and diplomatically, [I found it] incredibly challenging’ (INT 11.1; 109).

Understanding the reasons why it was easier and potentially quicker to establish links between centres whilst it was harder, more challenging and longer to establish links with others is important.

> ‘Some clinicians [at local centres] work more closely with us [tertiary specialists] than others. Some of those trusts provide in house their own rheumatology services and don’t engage with us very much. Others engage with us lots and are quite happy for us to see their patients in our clinics for most of their care and provide things locally if we link in (INT 5.1; 129)

The degree of access to specialist paediatric rheumatology care is directly related to the link between professionals and their organisations, and therefore an important issue to be aware about.

Although more complex in reality, in the next section I have divided the experiences of those involved in the process of setting up a network into those which have been positive, where professionals have found the process relatively simple and easy, and those, where the process has been more challenging.

6.3.1 The Positive, Easier Experiences

For some, forming links between professionals was a relatively simple process particularly if links were already present. For example if general paediatricians and paediatric rheumatologists were already ‘sharing care’ of patients ‘on an informal basis’ (INT 5.1; 154) these links were ‘just strengthened’ (INT 6.1; 253). Paediatric rheumatologists also frequently reported an easier engagement process with professionals at the local centres when there was a link paediatrician or local team who were ‘on board’ (FG 1.1; 294). Being ‘on board’ meant that they supported the concept of clinical networks.

> ‘I [link paediatrician] think it’s absolutely the right way to go. I am very much on board with the concept. I think it is the right way to go because I think now good enough is not good enough. It should be the top flight. It

> should be the best opinion but care close to home also and you can only do that through a network' (INT 10.1; 496).

In this excerpt, the tertiary and local professionals shared 'the vision' that optimal care should be available to all no matter where a child or young person lived. Establishing a clinical network, which provided specialist care locally could achieve that.

As discussed previously, naturally occurring events such as an adult rheumatologist retiring facilitated opportunities for local services to approach their nearby tertiary paediatric rheumatology centre for support, allowing paediatrics to naturally take over leading that service. This avoided the issue of 'poach[ing]' (INT 5.1; 255) services or someone's area of clinical practice. This was reported to be a relatively easy process, as new adult rheumatology consultants did not have the training or expertise to undertake service provision for children or young people with JIA. Others also found it a relatively simple process, as establishing links with local clinicians in the form of a network was part of a national development plan.

For some paediatric rheumatologists, who at the time of my interviews were just embarking on establishing of links with local professionals, discussions, so far, 'have been very positive' (INT 5.1; 268). However, there was acknowledgement that 'there may be challenging negotiations to come and it may be we're just not far enough down that pathway' (INT 5.1; 308). There was however, awareness that the actual process of linking together professionals and services from different organisations was sometimes the more difficult thing to achieve.

> 'It can just be the actual nuts and bolts of nailing that down that can be the harder thing to achieve'. (INT 5.1; 206)

This next section discusses these more challenging experiences.

6.3.2 The More Challenging Experiences

There were a number of sensitive issues that arose during the engagement process.

> 'Starting a network… if it had been handled differently, it would have gone a bit more smoothly (INT 10.1; 394).

Linking professionals and services together for some involved a process of negotiations to then try and arrive at 'a way forward' that was acceptable to 'all parties'. All parties for some were just clinicians – such as between adult and

paediatric rheumatology, whereas for others it also included management where there was financial implications. The negotiation approach was used to try and enable a mutual understanding to be reached, allowing resolution of points of difference, and ultimately hoping to achieve an outcome which satisfied the interests of 'both parties' or 'on all sides' (INT 10.1; 496). There were challenges encountered when conversations were held but were not perceived to take into account the perspectives of all those that were involved.

> 'The feeling…the [specialist] people feel like they consulted everyone but other people don't feel like they did' (INT 10.1; 398).

The more challenging experiences or the ones where resistances were generally found all relate to attempts to establish links between adult and paediatric rheumatologists.

> 'So in general, it was the adult rheumatologists who were perhaps more resistant. Not always, and there are [rare] exceptions' [INT 11.1; 119]

This is where an understanding of the evolution of the specialty (Chapter One), and the historical context of the way that care used to be delivered (Chapter Five) becomes relevant.

> 'So to have some new kid on the block...to come along and say ooh, how about we try it like this, I can totally understand that…. it was inevitable, I think, that would be met with some resistance.' [INT 11.1; 151]

The resistance to network establishment was viewed by some as inevitable. When services had been provided by adult rheumatologists for a number of years, and where they had developed 'paediatrics' as *their* area of clinical practice, having a paediatric rheumatologist, whether new or established coming in to change the way that *their* service was run was met with resistance.

It is important to highlight though that difficulties in establishing links between these two professional groups did not necessarily mean they did not share the same vision. As an adult rheumatologist noted,

> 'I was very keen to do, to make sure that what I was doing was in line with what everybody else was doing, so I thought it was quite important to be part of the network' [INT 8.1; 61]

Equally, the difficulties encountered did not necessarily stem from a lack of support for the network concept

> ‘actually the Adult Rheumatologist was very much in favour of the clinical networks. I can remember them talking to me about it ….they were very … they could see that you know they had limits’ (FG 4.1; 660).

There was a suggestion from some that reluctance or resistance for change was simply because people didn’t necessarily know that what they were doing could be done differently. Engaging clinicians to change their current clinical practice was not only challenging, if from their perspective their service was running well, but also when the evidence base for change was sparse. As one paediatric rheumatologist described

> ‘And I think also it is very hard to prove that children got any different clinical outcome of the different setups because rheumatology we haven’t got very good hard and effective outcome measures so I think it was hard to prove that the care that was being delivered anyway was different to anywhere else and I think eh that’s part of the problem as well really. So it is very hard to create change if you can’t prove that what is happening at the moment is anything other than the right thing’ (FG 1.1; 336).

These examples suggest multiple reasons behind why professionals had found the engagement process ‘challenging’, hard’ and ‘stressful’. However, for the majority there was a central underlying factor, which resulted in the engagement process of linking professionals and organisations together being not the smoothest of journeys. This central factor relates to the so-called boundary concept, which I introduced in Chapter Five. I explore this area in more detail in the next section.

6.4 Professional Boundaries

6.4.1 Treading on Toes

For some the engagement process, of linking professionals who were involved in the management of children and young people with JIA, was not an issue if it solely involved invitation to educational meetings.

> ‘Now, they [adult rheumatology] weren’t unwelcoming in terms of – they came to network meetings…and they came to that and contributed and brought cases and so on. So they weren’t not engaging in that way. But they were slightly threatened about the idea of having people in’ (FG 7.1; 568).

Rather, the concern came when there was potential threat to their area of clinical practice. There was recognition that an outsider, for example, a specialist coming ‘into’ a local centre could be perceived as ‘very threatening’ (FG 7.1; 570). Difficulties in initial engagement from some adult rheumatologists was reportedly because there

was a fear amongst those clinicians that their area of clinical practice was going to be taken away from them.

> 'I [paediatric rheumatologist] was speaking to the [adult rheumatologist] who said to me, "Are you going to come here and tell me I shouldn't do this because I'm not a paediatrician?"' (FG 7.1; 599).

Although adult rheumatologists may have perceived that they did not have the specific paediatric skills required for the job, this issue of fear was not just limited to adult rheumatology. There was also the suggestion that a specialist from the specialist centre coming into a clinic at a local centre had the potential to appear threatening towards local paediatricians as well as other members of the MDT.

The potential impact of a specialist 'outsider' from another hospital was dependent on what was considered the professional norm.

> 'It already happens with lots of other specialties. So we already have … I mean cardiology and endocrine have been doing that for a very long time. Gastro started about the same time as rheumatology, genetics have been coming for a while and have now formalised it more, so I think it hasn't been a problem… not from a practical point of view anyway' (FG 5.1; 84).

In this example, general paediatricians were used to professionals from the specialist centre coming into their hospital to do clinics alongside them. Engaging these professionals in paediatric rheumatology network discussions had not been a problem. However, for others this issue or potential issue had caused a degree of caution affecting the way that links were established between professionals and their organisations.

> 'Again, I [paediatric rheumatologist] was a bit daunted by this whole process. You worry that you don't want to be perceived as, feel like you're treading on toes of other people who maybe perceive that they have services set up that they don't feel really need changing, or changes to be made, or areas maybe where a network is a new idea that hasn't been perceived to be needed in the past.' (INT 5.1; 268)

This anxiety has not only been at an individual level but also within the wider specialist team.

Professional boundaries also included differences in age and experience, as one clinician suggested

> 'So to go to a team, which has 40 combined consultant years, and make a very challenging statement, which is, "We want to see all your patients

> because we think you're not providing agreed standards." I think the quality they provide is excellent, but in terms of actual agreed standards they're outliers; you know, they don't work in the 'accepted way'.' (INT 6.1; 235)'

Younger clinicians coming into another clinician's environment, who were less experienced (in terms of years of being a consultant) had found it harder to work with consultants who had been working for a number of years.

> 'In many ways, I find that a little bit harder …with essentially somebody's who's had a lot of experience in rheumatology … because sometimes rather than full discussions with patients, you'll have, "Well, this is a patient with … new systemic that I saw a few months ago and I've been treating. Now we have an issue." That in some ways is much more difficult to then unpick and go back to the beginning. Because sometimes you'll get things like the sort of discussion like, "All the bloods are fine." But it's very hard to just accept that. You really have to start from the beginning and you have to go back and find out, well, what investigations were done?... it can seem a little bit like you're not trusting the statement that, "All the bloods are fine."… as a new consultant I've found that hard' (FG 7.1; 720)

In this example, a new paediatric rheumatologist discussed that they had found it harder initially to work with an 'experienced' paediatrician with an interest in rheumatology in comparison to a general paediatrician with no experience who 'ran by me …almost every decision, whether it's at the time in the clinic or via email or phone calls' (FG 7.1; 702).

6.4.2 When Toes got Trodden upon

The worry of not wanting to 'tread on toes' was not an unfounded worry as around the country there were examples where network discussions and attempts to engage in professionals to change service models had 'got a bit nasty' (INT 10.1 196). This was particularly when the process of local service reconfiguration was 'perceived [to be] an aggressive takeover' (INT 10.1; 401) by the specialist centre.

> 'there were some really horrible, predatory meetings with management and commissioners. Honestly, it was so stressful there. It was just awful.' (INT 10.1; 207)

This stress was experienced, not only by the local professionals (as in the example above), but also encountered by those from the specialist centre.

Fear of losing a service which had 'belonged' to a clinician 'for years' and being 'told' that the current service had to change was described as a 'difficult time' and had

'ruffled feathers on all sides' (INT 9.1; 607). An adult rheumatologist described their experience of when their service was 'taken away' having thought it was running well

> 'I was devastated, absolutely devastated. Yes. I mean you go with the flow but that was a hard – that was a difficult time … but it was – I was told that it didn't comply with BSPAR guidelines because I wasn't paediatric trained … but yes, … that was hard ... I was disappointed, I felt that we had a … I think the annoying, not annoying, but the upsetting thing was I thought it was running fine. I thought it was going okay and then we're suddenly told that it wasn't and it wasn't working and so on, was a bit of a shock. (INT 9.1; 264)

Others had similar difficult experiences and as a result one paediatric rheumatologist had come to the conclusion that

> 'for me, the only way it works is if people see you're not coming in and threatening their territory and not taking the patients away from them. I think with [an adult rheumatologist] that was there on the table right from the beginning. (FG 7.1; 586)

In this example, difficulties were encountered from the very outset at the start of network discussions. These difficulties were carried on when they had to collaboratively work together.

6.5 Organisational Boundaries

There was also evidence of management 'turf wars' amid financial implications for the hospitals involved in network establishment. For some networks it was reported to be

> 'quite expensive [to run clinics with two consultants] and then you have argy bargee between the trusts about who is paying for my time' (INT 10.1; 340).

The engagement process for some was influenced by the financial incentives or potential loss, particularly if services already existed in a hospital earmarked for possible closure. For some trusts developing the network as a business model, created a niche and helped engage managers in the process. When it came down to funding issues and 'balancing the books' then territorial battles from management was evident in some areas

> 'I went along with our managers and there was one meeting [between two trusts] that was so horrible that our departmental manager, she said she almost wanted to leave because it was so aggressive and threatening' (INT 10.1 211).

There was also a degree of confusion about who got paid or charged for what and what deals were set up in the initial negotiation process.

> ‘Of course the [specialist] team come down and they get the tariff for the patients but there are issues about them contacting me to do all of the tests and the scanning and this and that. We are paying for those and we feel we should charge for the clinic rooms. The management in [the specialist centre] said, “Well no, no because for six months, you’re going to be having monthly training in this and that.” It’s been well over a year now and we’ve not really had training and things.’ (INT 10.1; 250)

One suggestion to prevent this argument between trusts during initial network establishment was

> ‘things like the tariffs and stuff. I think actually that could be something that we could look at centrally and then people wouldn’t have to fight over it. It would take some of the tension out of it.’ (INT 10.1; 512)

The organisational boundaries described above added tension to what were an already ‘stressful’ process.

6.6 Discussion

I have described the approaches used to engage professionals and their organisations to link together in the form of a network. The multitude of approaches used – including allowing for opinions to be heard, gentle nudging, letting natural events take their course, discussion, negotiation and confrontation – suggests that establishing a clinical network is not a simple process. With no framework to work within or guidance, professionals were interpreting the situations they found themselves on the own and ‘feeling their way’. Findings that establishing a clinical network was challenging and time consuming is in keeping with experiences of others (Baker and Lorimer, 2000)). However, this is the first study to describe in detail the approaches used, and the specific reactions encountered during the process of attempting to link professionals and organisations together in the form of a clinical network.

Although guidance exists from the RCPCH (2012a) on establishing and managing successful networks for children’s health services, little actual practical guidance is given about the approach that may be required in the setting up process. They suggest that the public, politicians and professional colleagues may need to be persuaded by paediatricians that the network model is the best way to deliver high

quality, efficient and effective services for all children. The findings from this study suggest that more action than just persuasion may be required, particularly when areas of perceived 'clinical expertise' may be threatened.

Guthrie *et al.* (2010) reported that a shared philosophy or vision from all professionals involved is a key factor, which can facilitate clinical network establishment. Whilst the findings in this chapter do not dispute this, they suggest that even with a shared vision there may be other factors may influence the engagement process. A factor - evidenced by a recurrent finding across all networks studied - that affected the engagement process in paediatric rheumatology clinical networks relates to the concept of boundaries. Within the definition of what a clinical network is, there is acknowledgement and inherent recognition that professional and organisational boundaries exist and for a clinical network 'to be a clinical network' – then they need to be unconstrained (Scottish Executive Department of Health, 1999; RCPCH 2012). The findings from this chapter reveal that existing professional and organisational boundaries very much exist, and they have constrained the progress towards delivering equitable high quality care for children and young people with JIA. This is in keeping with an increasing body of research recognising the impact that boundaries have on service delivery and organisational change (Sanders and Harrison, 2008a; Martin et al., 2009). A number have reported that they have the potential to jeopardize the provision of safe, high quality patient care (Nembhard and Edmondson, 2006; Hewett *et al.*, 2009; Martin *et al.*, 2009; Dixon-Woods, 2010; Powell and Davies, 2012).

The experiences of engagement, which were described as challenging, all came from trying to establish links with adult-led rheumatology set-ups. As described in Chapter Five, adult rheumatologists historically played a fundamental role in service delivery for many children and young people with JIA. Acknowledging the important role that they had played helped for some to shift the way that care was delivered. I am cautious to conclude the challenges encountered solely rest with the 'adult rheumatology' group. Although I do not have evidence from this study that there were difficulties with other professional groups, from the literature it is recognised that any organisational change may be met with some resistance (Currie 2010). A professional identity of a clinician is often bound in the desire to practice as autonomous individuals, retaining control over actions, without obligation to follow standardized ways of practice (Degeling *et al.*, 2001).The reaction of territorial

behaviour, present in most organisations, was evident and it is this that can make inter-professional collaboration difficult and can create conflict (Abbott, 1988).

Inter-professional boundaries in health care, particularly the medical- nursing boundary has been well reported (Allen, 1997), and there is increasing recognition of intra-professional boundaries during service delivery and organisational change (Currie *et al.*, 2008; Sanders and Harrison, 2008a; Powell and Davies, 2012). Examples of intra-professional boundaries from this study included boundaries between adult and paediatric rheumatology, boundaries between paediatric rheumatology and paediatrics, as well boundaries created by staff at different levels of seniority. It is recognised that intra-professional boundaries can lead to independent working and for members of the same profession to compete for resources, influence and patients (Currie *et al.*, 2008). The consequence of observing, defending or expanding boundaries has implications, which may be significant for the way that care is delivered (Dixon-Woods, 2010; Nugus *et al.*, 2010; Powell and Davies, 2012), as they can impact on communication (West, 2000), sharing of knowledge (Ferlie *et al.*, 2005) and collaborative working (Powell and Davies, 2012). These particularly issues are explored further in the later chapters of my thesis.

6.7 Conclusion

The engagement process of linking professionals and their organisations together involved a number of organic approaches and for many it was lengthy process. Clinical networks establishment has not been without its problems. However, the problems encountered are likely to reflect the issues inherent within the system that networks attempt to overcome. The challenges encountered reveal a key issue - professional and organisational boundaries exist and they matter. They can influence clinical network establishment and subsequently the level of specialist care that can be provided. If clinical networks are to deliver high quality equitable care for all, then professional and organisational boundaries need to be unconstrained, otherwise care for children and young people with JIA is at risk of continuing to be suboptimal. For those involved in setting up a network support was needed at the outset, to help bring about effective organisational change by overcoming these boundaries. Although this chapter has focused on a number of difficulties and challenges, in the next chapter, I describe that with network establishment there has been some progress towards improving care for children and young people with JIA.

Chapter 7. New Links for Care and Education

7.1 Introduction

The preceding chapter detailed the journey towards establishing clinical networks by linking health professionals and their organisations together. This chapter reviews the introduction and consequences of clinical network establishment, including the progress made towards improving care for children and young people with JIA. I show that clinical networks can create benefits from new links for care and education. However, I also describe that their establishment has not been without challenges; old and new problems have been encountered.

7.2 New Links for Care

There was an impression that in general, the establishment of clinical networks has resulted in care for many children and young people with JIA being 'so much better now' (FG 4.1; 189). Linking together professionals and their organisations has resulted in many service improvements, with care now more in line with the BSPAR/ARMA standards of care for JIA (Davies *et al.*, 2010).

For some children and young people with JIA, who were new patients, there were reports of more prompt referral and treatment pathways. In some local centres new patients with suspected JIA were now no longer being seen solely by adult rheumatologists but instead were triaged by local 'linked' paediatricians and if suspected to have JIA, were referred quickly for review at the specialist centres. For some patients who were already known to have JIA, who had a disease flare, network establishment had also facilitated earlier treatment.

> 'We have [now] got the benefit of being able to send people up to [the specialist centre] quite easily if they do need … when they need joint injections' (FG 5.1; 331).

This streamlining of referrals facilitated not only timelier treatment than previously but also access at the same time to the specialist MDT for clinical review.

For some children and young people with JIA, who previously had care managed solely by a local clinician, clinical network establishment now meant that when they visit their local centre for clinic follow up they are reviewed by a paediatric rheumatologist.

> 'We [Paediatric rheumatologists] have changed quite a few patients management. ... And probably been a lot more aggressive. Certainly I can

> think of a few cases … and I notice [another paediatric rheumatologist] is nodding their head, where we have been much more aggressive than the management was in the past' (FG1.1; 421).

This access to a clinician with expertise in JIA facilitated changes to the medical management of children and young people with JIA, including the use of more aggressive treatment regimes.

Some local clinicians reported that following clinical network establishment there was 'strengthened communication' with the specialist centre and as a consequence they now had 'very easy direct access via email or phone call to a specific rheumatologist or colleague if that one doesn't happen to be there' (FG 5.1; 113). This was reported to have a positive impact on patients and families, who saw their local clinician as a point of local contact, but also had the benefit of access to specialist expertise through the network if required. As one parent reported

> 'It seems to be a better set up as they are all kind of in the same vicinity and communicating…. you know communication/relationship if that's working then you feel safe and you know you feel that your child is getting the best I think and all the information is kind of all tallying. Otherwise may be it can get confusing …(FG 2.1; 732)

In addition, some paediatric rheumatologists had found that the communication link between the specialist and local centre had improved patient monitoring and safety. As one noted

> 'It works well because it's closer to home. I think the local consultants in the hospital knowing about a patient is far safer' (INT 2.1; 481).

Relatedly, such an arrangement had also helped manage capacity issues at some specialist centres. This was particularly highlighted with radiological investigations, but only if the same scanning protocol was use. As on paediatrician described

> 'one frustration that we have and I think…I know…happens elsewhere is … is scanning them [patients with JIA] em in the local DGH because there have been a small number of cases where we have scanned, MRI'ed, and the protocol that is used in [the local centre] is not the same as is might be used in [tertiary centre]. And in particular it does not involve em contrast…..some have had to have the scans repeated because the rheumatologists can't comment [on the non contrast scans], and it doesn't give them the information that they want. So in that respect the children possibly have to have an extra investigation and had to travel (FG 5.1; 305).

In some regions with network establishment, locally based teams had taken on a broader range of clinical responsibilities.

> ‘Many of these patients are on weekly methotrexate. This treatment most of this is initiated at [the specialist centre] and then at the DGH we continue to carry on. So we do their blood monitoring … prescription. We also train them to give methotrexate injection, and initially we get them to attend their local hospital ward for injections. So this is an example where otherwise they will have to come more often to [specialist centre] for blood tests and things. This is an example where we are sharing the patients, the decision to treat, treatment has been shared and it works well’ (FG 8.1; 178).

This ‘shared care’ arrangement had the advantage of enabling patients to have treatment and blood monitoring closer to home. There was also evidence of development of treatment provision using the wider health professional community.

> ‘More recently, more and more community nurses are actually giving sub-cut Methotrexate, as previously there were quite a lot of areas that didn't do it. Now, we've only got a few areas that don't do it.’(INT 3.1; 35)

In some regions, clinical networks had resulted in establishment of local day case infusions.

> ‘Like years ago everybody went to [the specialist centre] to get infliximab, and that doesn’t happen anymore’ (FG 8.1; 80).

The consequences of clinical network establishment had now reduced travel for patients and their families to the specialist centre.

So in summary, in many regions that I engaged with, ‘linkage’ of professionals and services between the specialist and local centre has been a positive development, allowing increased access to optimal care. For a number of children and young people with JIA clinical network establishment has resulted in care more in line with that which is now expected (Davies *et al.*, 2010). Transformation in care was not the only consequence of network establishment. In the next section I describe that the new links have created opportunities for education.

7.3 New Links for Education

Network establishment created new links for education with opportunities for training and learning. These included network educational events as well as opportunities that occurred in the work place, during every day clinical practice.

7.3.1 Network Education Events

All clinical networks studied had evidence of 'a kind of portfolio of educational things going on at all sorts of different levels' (FG 7.1; 1325). 'Levels' here meant the different educational needs of the multidisciplinary team. The events varied in content and format. I discuss the portfolio of educational events in more detail in Chapter Nine.

There were reports of educational events, such as JIA study days, held 'before we set up the network' (INT 2.1; 85), having been organised and run by professionals with an interest in JIA, from different geographical regions. These events have some similarities to the more recent 'network' ones, such as the gathering professionals together for the purposes of sharing experience, as well as an awareness of a need for a reference group if 'they were working in isolation' (INT 6.1; 196). However, with clinical network establishment, educational events were reported to have happened more frequently with also better attendance. The suggested reasons behind this included clinical governance, revalidation and commissioning. As discussed in Chapter One, the BSPAR/ARMA SOC has recommended that any professional working within a clinical network needs be appropriately trained. To achieve this and in order 'to ensure that the governance side of things is covered' (FG 7.1; 674), the specialist centres have reported to have predominately taken on the responsibility of 'providing on-going education for the clinicians working in the centres around about' (INT 5.1; 448). There has also been requirement, due to the process of revalidation, for medical professionals to provide evidence of continued professional development. For others, who had found attendance at educational events previously poor, they reported that commissioning changes, which had financial implications had become a new driver to 'revive… or resuscitate' education events (INT 2.1; 72) with attendance being prioritized more.

7.3.2 Clinical Practice

All the clinical networks studied had evidence of learning opportunities in clinical practice. For example all reported that there were learning opportunities around outpatient clinics. However, different network structures gave rise to different types of learning opportunities. For example, in some networks paediatric rheumatologists went from the specialist centre to the local centres, and did 'clinic together' with a paediatrician.

> ‘There’s opportunity to talk about the patients, between patients and then at the start and the end of the clinic. Education happens that way’ (INT 5.1; 451).

In other networks, care was ‘shared’ between the local and specialist centre, but did not involve ‘outreach’ or ‘network clinics’. In those networks, some specialist centres had facilitated local ‘link’ clinicians to attend the paediatric rheumatology clinics at the specialist centre, enabling ‘the[m] to come and sit in in clinics, and then see patients in clinic’ (INT 8.1; 478). I discuss the varied learning opportunities that occurred in clinical practice in more detail in Chapter Nine. The next chapter, which details different clinical network structure, is also relevant to these findings.

7.4 Related Benefits of New Links for Care and Education

In Chapter One I described that strategies to address the barriers and inequities in access to optimal care included the BSPAR/ARMA SOC, education and clinical networks. In this next section I show that these strategies are all interrelated with shared benefits of new links for care and education (Figure 14).

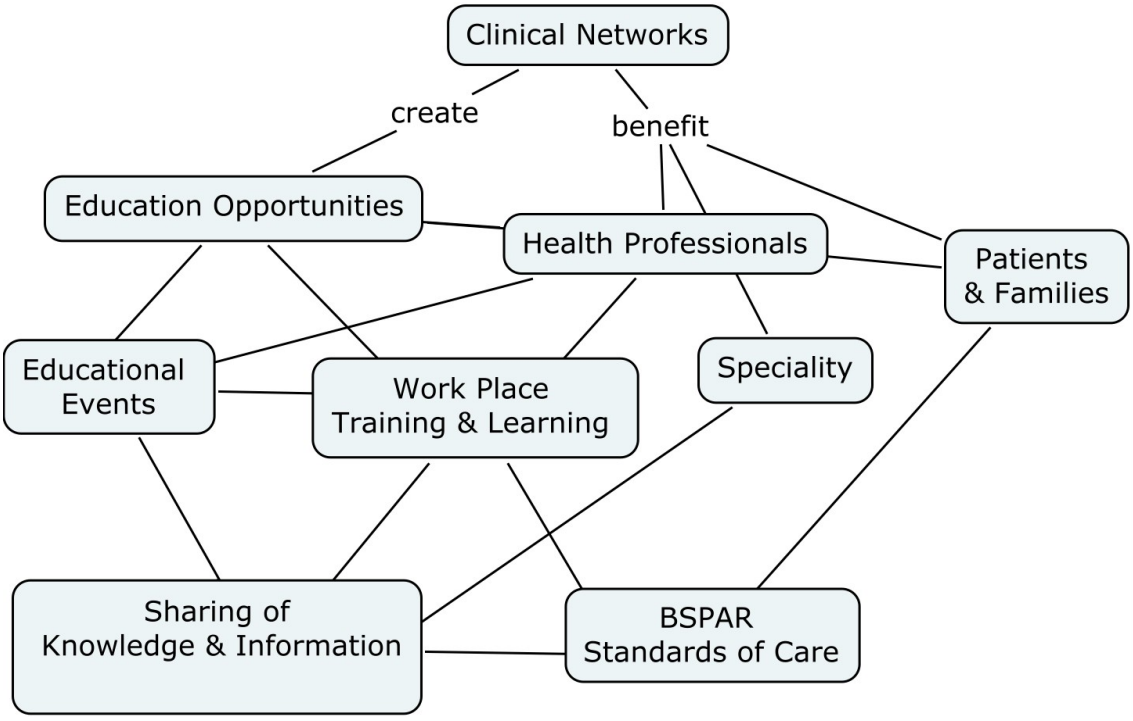


Figure 14 Relations of new links for care and education

The establishment of a clinical network, which involved groups of professionals coming together (in various forms and by various means) to deliver care for children and young people with JIA, was reported to benefit the speciality by raising its profile.

There were reports that network establishment had for some created a local identity for paediatric rheumatology with the emerging teams providing a local voice for paediatric rheumatology. This included invitations to present in local hospital education programmes, providing the opportunity to raise awareness about JIA, as well as other rheumatological conditions. Links between some local and specialist centres had facilitated opportunities not only for paediatric rheumatologists to provide teaching to a wider audience, but also for link paediatricians to have the opportunity to present and discuss local cases once or twice a year at hospital grand rounds. Notably since network establishment some local link paediatricians with an interest in the specialty reported to have been approached by local colleagues to discuss cases.

In networks, which had established local paediatric rheumatology clinics, there were reports of a local awareness of the scheduled clinic patterns.

> 'It is quite common for the other paediatricians to wander in. Either catches us [paediatric rheumatologists] either at the beginning or the end of clinic and say actually can I ask you about someone I have seen' (FG 1.1; 277).

These scheduled clinics provided opportunities for other local clinicians to ask about whether or not patients under their care needed to be referred to rheumatology.

> 'Going out and doing network clinics, you get a chance to contribute to complex patients who would never come here. You get a chance to influence their management. Because even if you ran a service where the model is everyone comes here [to the tertiary centre], not everyone does. Because a lot of families choose not to. Or local paediatricians choose not to send them. But if you're actually in [a local centre] doing a clinic, you get asked to see all sorts of things and patients who would never come here. Sometimes we pick up things that are really important and influence that. Certainly in the [one network clinic], after the clinic's done, there's a lunchtime kind of gathering. "What about this? What about this? Would you see this one?" and it's put on the next clinic. …People are happy to share their funnies that have been sitting around for a while and going, "I'm with you." By knowing that group of paediatricians, that's your link. That's the importance of actually sitting in their patch saying, "Hi, what can we do?"' (FG 7.1; 1067).

This also gave opportunity for tertiary specialists to contribute to the management of patients who might not otherwise have travelled to or been referred to the specialist centre.

The formal educational events that had been developed following network establishment in turn gave rise to more informal opportunities to meet and get to know colleagues, and to share experiences, knowledge and information within the network. This was recognised as an important part of establishing relationships required for collaborative working in clinical practice. This was particularly important for one certain type of network structures, where links between the tertiary and local centres involved 'shared care' but did not involve any other form of physical contact such as 'outreach' or 'network' clinics (described in Chapter Eight).

> '[They create] opportunity [for local professionals] to come and talk to us [tertiary specialists] directly ….the first time I personally actually met a lot of the paediatricians that I shared patients with, but who I had previously only emailed or talked to on the phone…and really shared patients with' (INT 4.1; 17).

This was deemed important in developing relationships and improved communication resulting for some with 'more direct emails and direct phone calls more' (INT 3.1; 53) than prior to face to face meetings.

Organised educational events often had opportunities for 'networking' (INT 3.1; 403). For example social events were held with food or drink during or after meetings as you 'get to know people in a slightly more informal way' (INT 4.1; 105)). Not only had professionals found these educational events helped 'you get to know people …[but also] therefore that takes away some of the anxiety about asking question[s]' (FG 9.1; 193).

> 'There's always a bit of chat before and after. People are less and less inhibited about asking a question or making a comment. In the early days, no one would have made a comment about biologics or asked a question.' (FG 7.1; 1206).

It is worth mentioning the additional benefit created by educational activities of getting to know people. Some viewed 'getting to know' people as their main reason for attending and the most important aspect of the activity.

> 'It is a forum not to just talk to people over the phone but be face to face. Also some of the sessions are of educational value which adds to…' (FG 8.1; 520)

This example suggests that education was, in part, secondary, an added bonus.

There were therefore multiple aims and outcomes of these educational events, depending on the agenda of the professionals involved, with some placing the

development of relationships as (or more) important that the actually educational or training content of the activity itself.

> ‘Apart from getting to know people, I think these meetings were very valuable for getting across important training points to your umbrella network of paediatricians who are working with you to look after patients with JIA. Additionally it was valuable getting feedback on what they want us to do to be able to I guess…provide and maintain good quality services for these patients.’ (INT 4.1; 28)

Here, although ‘getting to know people’ was recognised as one of the educational sessions aims, the tertiary specialists used it as a platform to not only impart important training points relevant to those looking after children and young people with JIA and sharing care with the tertiary centre, but also to provide a forum to be able to discuss wider management issues to improve the quality of services and standard of care for patients.

7.5 New Links and Old Problems

Despite the described benefits created by the new links for care and education, there was suggestion that there was still much work to be done to raise the standard of care for children and young people with JIA. For example, the networks studied were at various stages of development with some regions covered by the networks still without access to paediatric rheumatology specialist care.

> ‘We acknowledge that we are the tertiary referral point, but that geographically we have lots of cities around us who don’t have dedicated paediatric rheumatology. We have a very formal outreach service with one of them, and we’re in the process of setting up the outreach services to the others’ **(**INT 6.1; 104)

Timely diagnosis was also still a concern. A parent reported their recent experience.

> ‘We probably had eight different orthopaedic surgeons who thought it was an irritable hip and eventually discharged from the clinic and told that it will get better. It was only perseverance on our part that then she [patient] saw a different orthopaedic surgeon who then finally referred her across to the medical who then referred her across to rheumatology’. (FG 3.1; 448)

In this example, the child presented via orthopaedics, but there were also reports of children having encounters with a number of different health professionals in other specialties who failed to recognise that the child had arthritis, thereby leading to avoidable delays in diagnosis and treatment.

Interestingly, although the establishment of clinical networks had facilitated referral pathways for new patients in some regions, in other areas there were still problems as illustrated in this example; another parent describes their experience.

> 'Our problem was with the communication was when we were trying to get a diagnosis and the amount of administrative mistakes which were made… I should have put a formal complaint in but I didn't, there were so many errors and I know where they were. First of all it was the GP not making the referral timelessly, he delayed …and then once we got into the system…. It took within six months within the hospital itself…. And then they were meant to get him a referral through to a rheumatology clinic. They did refer him to the rheumatology clinic, they referred him to the adult rheumatology clinic; he was two! You know they had a child rheumatology clinic and it has been there for quite a long time so my issue was really is the hospital communicating with each other and GPs…. you know are they aware of the fact that there is this clinic and it is well established. It is ridiculous' (FG 3.1; 408).

This illustrates that referral systems within networks are by no means sorted..

Although network establishment may have improved access to specialist care for children and young people, for some the actual standard of that care they received was on occasion still below that which many in the specialty would expect. A local link paediatrician noted that

> 'We don't actually like our own joint injections, if the truth be told, here do we? We've had a lot of sub cut atrophy with wrists and ankles…. The ones, which are done here, sometimes, it's so unpredictable when they'll get appointments because it depends on which list they'll... (FG 9.1; 608)

In this context, although the local centre was now connected with the specialist centre through a clinical network, an orthopaedic registrar provided the local centres joint injection service. In this way there remains still 'huge gaps' across the country, not only between networks but also within networks (FG 4.1; 195), suggesting a need for education and training.

Gaps in provision of services for JIA were encountered across all aspects of care, consequently affecting many children and young people with JIA. For example, despite network establishment there were some centres without an identified link clinician, although some regions were in the process of trying to resolve this.

> '[One local centre] at the moment is unfortunately in a bit of a temporary phase because we haven't been able to organise a local paediatrician although that's in the … in the pipeline… but at the moment all the patients

are coming to us but we have very good links with the Nurse there'. (FG 4.1; 73)

Although there has clearly been progress with network establishment in one area, when a local link paediatrician retired, progress was halted.

> 'In [one area] where we've got a very big service, which had developed really well with a very experienced General Paediatrician responsible for it. [they retired] but it was never in their original job [plan]. They picked it up and ran with it when the previous person who'd done the rheumatology retired…. Then it grew and grew and grew. As a very experienced, very organised Clinician, they were able to pick it up and do it. We knew what clinics they were doing, but they were clearly doing a lot of stuff in between clinics that wasn't documented. So we had no real documentation of the workload. I think, when they then retired... It was a very challenging process [to get management to recognise the need for the service]. Now, [that service] is a particular case because it's such a big service'. (INT 7.1; 353)

This excerpt highlights the clear importance of documentation of workload created by networks to illustrate service provision need, alongside succession planning. It also shows how vulnerable network services can be. It is perhaps unsurprising that there are limits on what can be done to improve care if there are no local professionals to 'link' with.

The problem of inequity in access to specialist care was not just limited to the medical profession. It was also seen in relation to other various members of the MDT. For example, in one network

> 'The local set up for OTs in our local area is actually quite scanty. Some areas we have OT for teenagers but OT under nine or ten it doesn't really exist. In some other areas, some other PCT areas that we cover, they have very little, minimal OT support (FG 8.1; 372)

A particular area of concern related to on-going difficulties obtaining regular eye screening appointment.

> 'We [a parent] have an awful problem getting eye appointments. Uveitis guidelines say every three month and she … my daughter has had really bad uveitis. Em she has now got a cataract because of it so I like to keep it to three months because of that. We get our eyes done at [the local centre] and they changed the system erm… how they do their appointments and now you can be four, five, six months so you … it gets to the point after two months – you don't get your appointment to after two months, they then send it out but it could be for three months' time. So you end up having to spend your life chasing (FG 2.1; 295)

As this example highlights, there are significant consequences of untreated uveitis. However, such inequity in access to optimal care was not only an issue for local centres. For example, access to psychological support services was also an issue, not just locally as described in the excerpt below but also within a number of tertiary centres.

> 'Well the psychology service, until fairly recently had been completely rubbish, allowed to run down and worse than useless…. I wouldn't have thought to involve them for anybody quite frankly because our recent experience has been so bad. It's a different trust and the service has been absolutely dire and appalling.'(INT 1.1; 403)

Historically, access to specialist psychological support has been an issue for many patients with JIA and there were findings that network development has done little to abate this problem.

Transitional care was another area reported to have remained problematic despite establishment of clinical networks. It has lagged behind other service development areas, with inequities in access to care notable. A range of descriptions of transition care was found, from 'brilliant' (FG 7.1; 362) with a few centres having 'very clear transitional pathways' (INT 6.1; 118) to most others with 'not very clear' (FG 8.1; 631) services, and 'a big gap in an awful lot of places' (FG 7.1; 366). It was recognised that networks have predominately focused initially on providing (in a variety of different ways) specialist care locally and focus on transition and youth friendly services was not an early priority for paediatric rheumatology teams. Provision of designated transfer or hand over clinics in the networks studied was not a universal occurrence. Although some teams had prepared young people to manage their own consultations without parents, and had documented transition plans, one team acknowledged that they just 'put' patients straight into the adult service, akin to going 'with nothing' (FG 9.1; 473). One centre previously had 'a good service' but this had now 'collapsed' (FG 9.1; 469), due to no one being taking on the transition role after a clinician had left. Transition services within networks were vulnerable around the time of staff retirement when there was delay in appointing a replacement, or when there are/were no hours for transition in their job plan. This workforce shortfall included staff in both adult and paediatric services, and also the MDT; 'it was both medical and nursing, they couldn't get anyone in nursing or anyone continuous to do it' (FG 9.1; 479).

In summary, this section has described that many of the problems that preceded clinical network development (see Chapter Five) still persist after the networks had been established. The reasons for which are explored further in the discussion section of this chapter.

7.6 New Links and New Problems

The establishment of clinical networks was also associated with new problems that had not been in existence or apparent previously. There was evidence of a heighted need for clear communication pathways particularly if a child or young person's care was managed in different locations. As one young person with JIA reported

> 'Well, sometimes, there has been a bit of bother; like a bit of lack of communication between the local hospital and [the tertiary centre]…Well, it was just like I'd, sometimes, go for MRI scans or CT scans at [the tertiary centre] and they wouldn't tell my [local] hospital. ….it was just a bit annoying, really, to not know the results when you are the person getting scanned…. my mum and dad get really worried when the results don't come because they think something's wrong' (FG 6.1; 413)

Within the network structure of care, there were also reports of more children having escalated onto increasingly complex treatment regimes. This created problems with the number of children requiring day case admissions for treatment. This was a particularly problem if there was a mismatch in what could be provided locally compared to the specialist centre.

> 'And logistically it is much more difficult now isn't it because we … you know ten years ago we had hardly any inpatients. Not we are having major challenges with our Day Case Unit [at the specialist centre] to get the patients in for their treatments and there is a lot of to'ing and fro'ing over that '(FG 4.1; 285).

In this example, linking together of local centres with the specialist centre had resulted in more children coming under the umbrella of the paediatric rheumatology specialist team. As a consequence this has put pressure on the workload of the specialist centre. In their model of care, day case infusions were provided at the specialist centre, as the local centres were not resourced (in terms of staffing) to manage them. This resulted in some children and young people with JIA, and their families having to travel further for treatment. There were similar issues encountered for joint injection waiting lists. Having had no significant waiting time for joint injections at the specialist centres, with network establishment, long waiting times for joint injections were initially encountered as more children were being seen by

paediatric rheumatology specialists, and more children's care was being managed more aggressively. Over time this problem was reported to have settled, once the specialist centres increased the frequency of their joint injection service.

Restructuring of healthcare provision in some regions had resulted in a shift of children's care (or planned shift) away from an adult-led rheumatology service to one which was more paediatrically driven. For these services there became a new need, that was, to develop a more formalised transfer of care arrangement. This had previously not been required, as some young people with JIA had never met a paediatric rheumatologist, because, as one adult rheumatologist noted, 'they all stay with me' (INT 8.1; 433). New problems were encountered, with this reconfiguration of services in some areas.

> 'Even though there are interested people, they're only allowed to see the people who go into their geographic bit of the region.' (FG 7.1: 428).

So, locality was prioritised over a young person's specific needs. The development of designated transition clinics and transitional roles was difficult if adult healthcare services used young person's postcodes to dictate where they are referred.

With network establishment some reported as a significant challenge when families have had to adapt to changes in treatment regimes instigated when paediatric rheumatologists became involved in their care.

> **'**And at the beginning, why … why are you doing that, why do we need to do that, why do we need to get the joints, why are you putting up the Methotrexate, why are we going onto subcut …' (FG 1.1; 425)

In this example, there was resistance met by from a family when a local clinician had managed the care and then care had been taken over by the paediatric rheumatologist. Similarly for some patients who had been looked after in the tertiary centre, when a local network clinic was established, resistance was encountered from some families who were used to that particular care system.

Although 'closer to home care' was acknowledged to be better for families, when professionals from the tertiary centre perceived that *their* service was better than what could be provided locally, there was suggestion of frustration, and a tension between professionals.

> 'If they [patients] travelled here [tertiary centre], they would get a better service….so it might be convenient for them to be seen locally but I'm not sure that's the same *level* of service that they would be getting if they came here' (FG 1.1; 231)

There were a number of other similar problems – or challenges, which were related to collaborative – or rather, not so collaborate working. As one paediatric rheumatologist described:

> 'I've got one or two adult consultants [that I do network clinics with] like the one at [a local centre]. They do things differently, but they are very much open to discussion. And we can have a very nice, constructive, open conversation, and certainly in front of patients and parents, and come to an agreement. The adult rheumatologist in [another local centre], not the same at all, would be threatened by me, challenging anything, I find that really difficult. They have been used to working with a paediatrician with an interest, who's had much less rheumatology experience than them, who will always … who will agree with what they're saying … the problem I have with it is where does the ultimate responsibility lie, for the management of these children?' (INT 11.1; 450/427)

Many of these problems were dependent on the way that care was delivered, who was involved and the role and responsibility of those delivering the care.

7.7 Discussion

This chapter has detailed the new links for care and education that have been created since networks have been established. I have also shown that care and education are interrelated. The background for exploring the progress in the form of new links for care and education was to help understand the developmental needs of medical professionals in the context of the evolution of clinical networks. I highlight here that this study was not an audit of care against the Standards of Care for JIA (Davies *et al.*, 2010), nor did this study set out to prove whether establishing a clinical network could improve care. I am cautious therefore to conclude that all the progress in care and education described can be attributed specifically to network establishment. Although the goals may be linked this may not necessarily translate into improved outcomes. Just as barriers to access to optimal care are multifactorial (H. Foster *et al.*, 2010) so too are factors that may facilitate improving the standard of care. However, what I have shown is that with clinical network establishment, more aggressive therapy is being used, and this is known to result in better outcome for children and young people with JIA (Ravelli and Martini, 2007), thereby giving some indirect evidence of the benefits of clinical networks.

All the networks that were studied were at different stages of development. It was therefore perhaps unsurprising that there was evidence of old problems of 'sub optimal' care, similar to those described in the previous chapter. As described by

(Guthrie *et al.*, 2010) networks are dynamic in nature and continually evolving. It would be naïve to conclude that as soon as a 'link' between professionals and organisations occurs (in what ever form, by what ever means) that care immediately improves. Just as it has taken time for professionals and organisations to engage in the process of linking together, (see Chapter Six), so too has it taken time to change the way that care is delivered. Furthermore, progress has depended on the degree of resistance not only from professionals but also families, as well as the changing nature of the workforce, with professionals coming and going into various posts.

The findings of 'delay to diagnosis' in my study, although well reported (Manners, 1999) remain a concern, given the increasingly efficacious treatments available (Beresford, 2011); early diagnosis and treatment is key to improve outcomes for children and young people with JIA (H. Foster *et al.*, 2010). Educating all professionals who may come in contact with a child who may present with signs or symptoms of JIA is therefore important. The findings raise the question of how far a network boundary extends – which groups of professional are included, as this may have implications for earlier diagnosis and treatment. I discuss this point further in the next chapter about network structure and the professionals involved.

Some of the new problems encountered related to the consequences that service reconfigurations had on workforce resources, and the exposure of a latent population of patients. I raised a similar issue in Chapter Five and highlighted that Cropper *et al.* (2002) suggested that establishing a network can make best use of scarce resources and expertise, however a critical work force mass from the specialist centre was needed in order for care delivery to be maintained within a network. This chapter adds to that finding that additional resources may be required both at the tertiary and local centres in order to facilitate the implementation of the standards of care now expected for children and young people with JIA (Davies *et al.*, 2010).

In this chapter, I have described the progress that has occurred across the networks studied, and reported the old and new problems encountered '*for some* children and young people … .' Or '*for some* professionals … .' etc., with the caveat often 'it depending on … .' This contrasts to some of the clear benefits or challenges that are described in the network literature, which has often focused the benefits or challenges described in 'single' networks (Baker and Lorimer, 2000). Although there is recognition that no network is the same and no model fits all (Guthrie *et al.*, 2010), the mixed and varied experiences encountered, across *and* within networks,

particularly with the new problems relating to collaborative (or not so collaborative) working became a focus in this study. In order to identity the developmental needs of medical professionals involved in delivering care in clinical networks, it became apparent that network structure and its implications for collaborative working to deliver care, education and training needed to be explored further.

7.8 Conclusion

This chapter has shown that with clinical network establishment progress has been made towards improving care for children and young people with JIA. The establishment of clinical networks has benefitted patients, their families, health professionals and the specialty as a whole, by creating new links for care and education. Although networks may facilitate access to specialist care, they are not the panacea to known problems associated with suboptimal care. Clinical network establishment is an on-going process with many areas of care still to be developed in order to deliver the SOC expected for children and young people with JIA. Many of the benefits, problems and challenges encountered relating to network establishment, were dependent on the network structure - the way that care was delivered, as well as resources available to deliver the SOC. Network structure is explored further in the following chapter, as the different models of care delivery that different network structures give rise to have different implications for developmental needs of health professionals and the educational support required.

Chapter 8. Clinical Network Structure

8.1 Introduction

This chapter describes the structure of paediatric rheumatology networks. Structure variation has previously been acknowledged in the BSPAR and ARMA Standards of Care for JIA (Davies *et al.*, 2010). However, what has not been described is the specific detail of this variation and what this means for the way that care is delivered in clinical practice. This chapter therefore sets out the specific detail of the variations in network structure and in doing so reveals two key findings: firstly network structures are complex and secondly, network structure terminology can be confusing.

8.2 Network Structure

I describe in this section the structure of the networks studied by detailing the ways that care delivery occurred conceptually – 'where' care was delivered, 'who' was involved, and 'what' the terms used to describe care delivery in networks actually meant in clinical practice. I then illustrate these concepts by describing parts of two individual networks. The reason for describing network structure in this way, rather than comparing individual networks with each other, is twofold. Firstly, the way that care was delivered was in a constant state of change; during the study period the dynamic nature of networks was evident with new network links formed, new professionals involved, whilst others moved jobs or retired. Secondly, variation in care delivery occurred not only between networks but also within networks – making not only each network unique but also each link within them unique as well. As one professional described, in relation to their local network

> 'It's quite complex...there are no two network clinics [that] are run in exactly the same way…. There are lots of different ways of doing them' (FG 7.1; 149).

I described in the Chapter Five how networks have evolved from a number of different historical set ups, which has contributed to the variations between the networks. There have been many other drivers. For example, as one participant put it, 'there are very different problems everywhere and challenges' (FG 7.1; 182). As networks respond to these challenges it was unsurprising that a number of differences were evident.

8.2.1 Where care was delivered

In all of the clinical networks studied care was linked between the specialist and local centres, or in the process of being linked, or in the process of attempting to be linked, depending on the stage of network development (Figure 15). I have not included in this diagram care that was provided within the community, as it was out with the remit of this study.

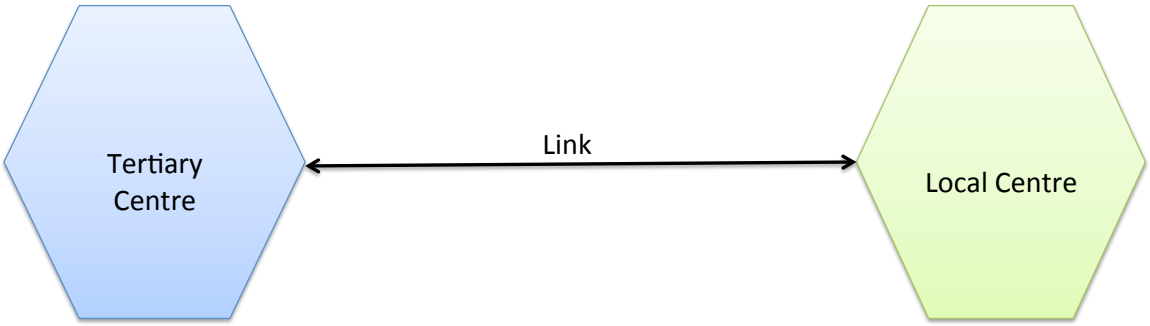


Figure 15 Care delivery between tertiary specialist centre and local centre

A patient's care pathway often swung, like a pendulum between the tertiary and local centres, at different points in time, and for different reasons (Figure 16). I present the evidence for this below.

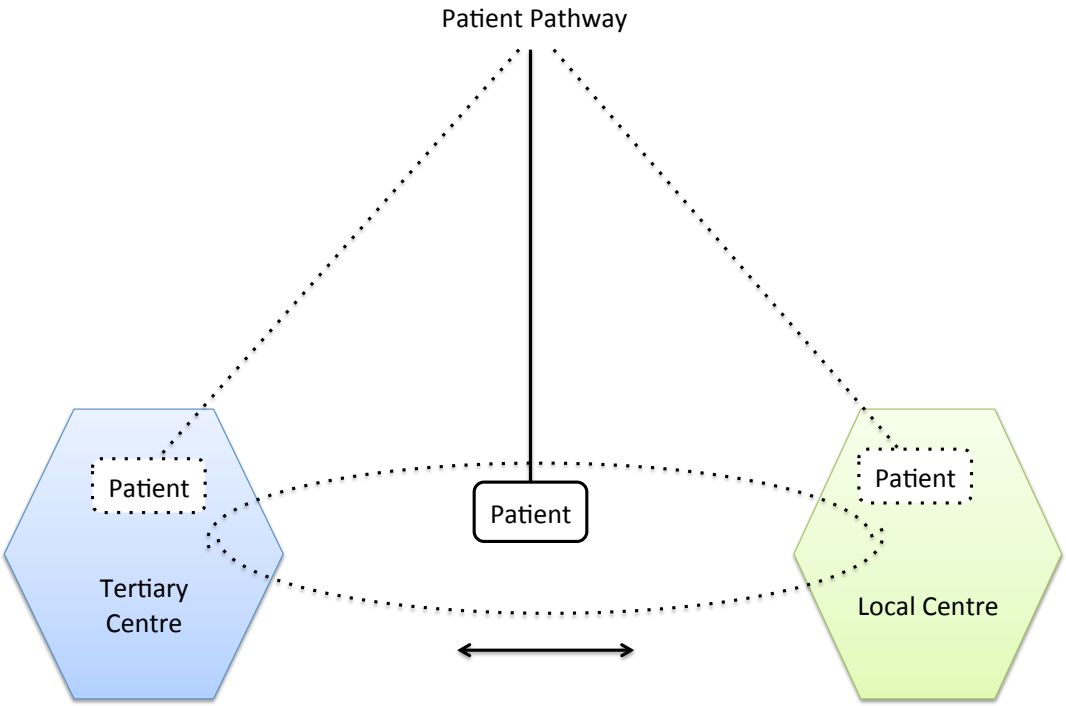


Figure 16 Patient pathways between tertiary and local centre

For some children and young people with JIA all their care was delivered in their local centre, but for others, particularly if they lived within the catchment area, then all their care was delivered at the tertiary specialist centre. More frequently, there were reports that children and young people were required to travel between the two at different time points in the course of their disease, or for different 'parts' of their care

> 'The new patients will be seen locally and triaged, sent up to us [at the specialist centre] for initial management and care and when they are stable seen by the team from here in outreach with a local shared care paediatrician and their team around there' (FG 1.1; 362).

In this example, travel to the tertiary specialist centre was required by some new patients to see the paediatric rheumatology specialist team to obtain or confirm a diagnosis and to commence initial treatment.

When a child or young person's condition was thought to be stable then follow up was either arranged entirely at the local centre (in an 'outreach' or 'network' clinic) or in a care model of 'shared care' with alternate appointments between the two centres.

> 'The patients were seen at both sites ….in the network we do three month appointments so we will have two a year with me and two with [the paediatric rheumatologist] and the team. In between times, we contact each other by phone or by email. It's easy to get hold of them. We don't do a joint clinic together but I can easily access them if I'm concerned. So I review the patients on my own knowing that they will be seen by [the paediatric rheumatologists] in three months time.' (INT 10.1; 56)

In this example 'shared care', meant patients moved location between the specialist and local centres for clinical reviews. For some patients, who had a flare of their disease or required therapies with day case infusions, they received their clinical review or treatment locally whereas others were managed at the specialist centre.

Location of care, close to home, was important for families, as for some it was reported to be

> 'a big deal to go over to [the tertiary hospital city]. A lot of my patients have never been to [the tertiary hospital city] in their lives, it's such a big thing''(INT 9.1; 295).

There were reports that some families preferred local care and had expressed to tertiary professionals that they

> 'don't want to come up to [the tertiary centre] that often. The travel is expensive and time consuming, particularly the expense, actually. Some

of them spend £70 to get up here and back, which is a lot of money.' (INT 2.1; 42)

Some families had expressed that they did not see any reason why care could not be delivered locally.

The patient pathway and location of care depended on a number of factors which included the historical set up, how far the local centre was from the specialist centre, the workload and number of paediatric rheumatologists based at the specialist centre, the number of local centres that were linked to the specialist centres (and this ranged from 3-4 to 30-40), local expertise and service provision, as well as the complexity of the patient's condition.

8.2.2 Who was involved

- *Professional Background*

A number of professions were involved in the care of children or young people with JIA, from a multitude of clinical backgrounds. These professionals were based either at the specialist centre or at the local centre (or in some cases worked across the two centres). There were differences in perception of network boundaries and in understanding 'who' was involved. For example, some professionals described a very clear picture of the professions and professionals involved (within in a defined geographical area), whereas for others it was not so clear or certain. The uncertainty about 'who' was part of a network is illustrated in the following diagram and excerpts when one specialist paediatric rheumatology MDT was asked to draw and describe the structure of their network (see Figure 17 and Figure 18[9]).

[9] Hospital site names have been changed to ensure anonymity (see Chapter Three, page 41)

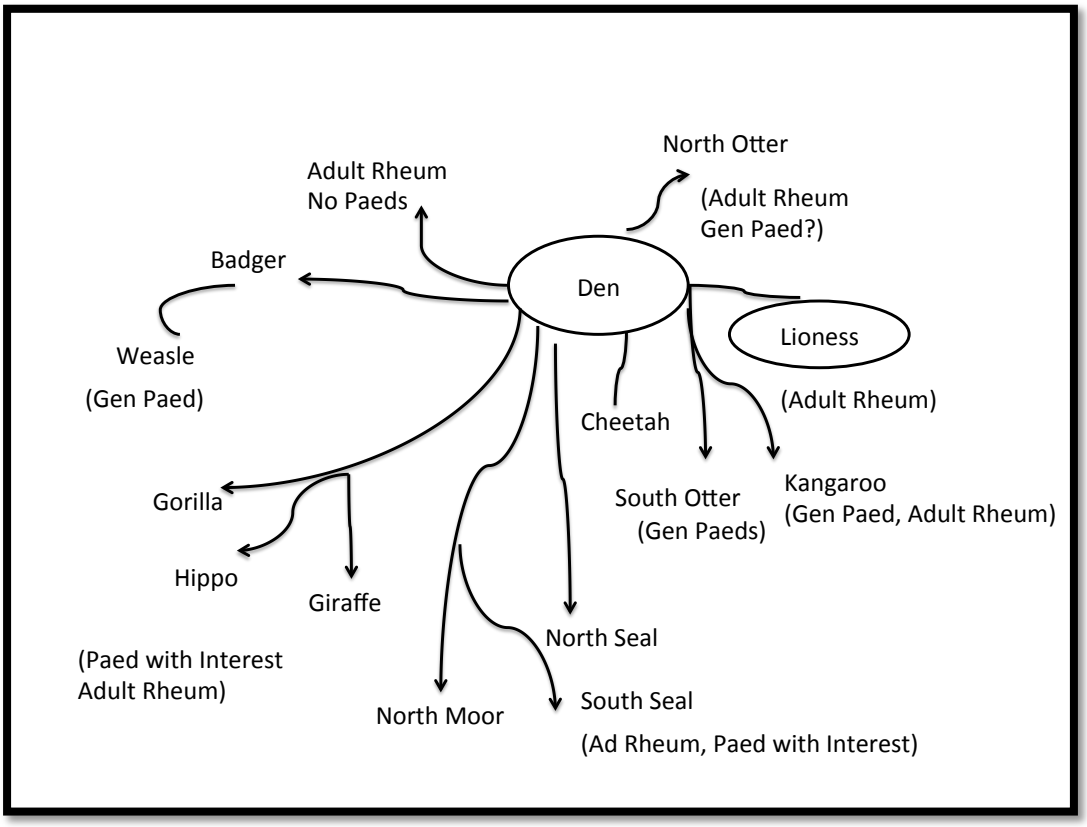


Figure 17 Animal Network drawn by participant F9

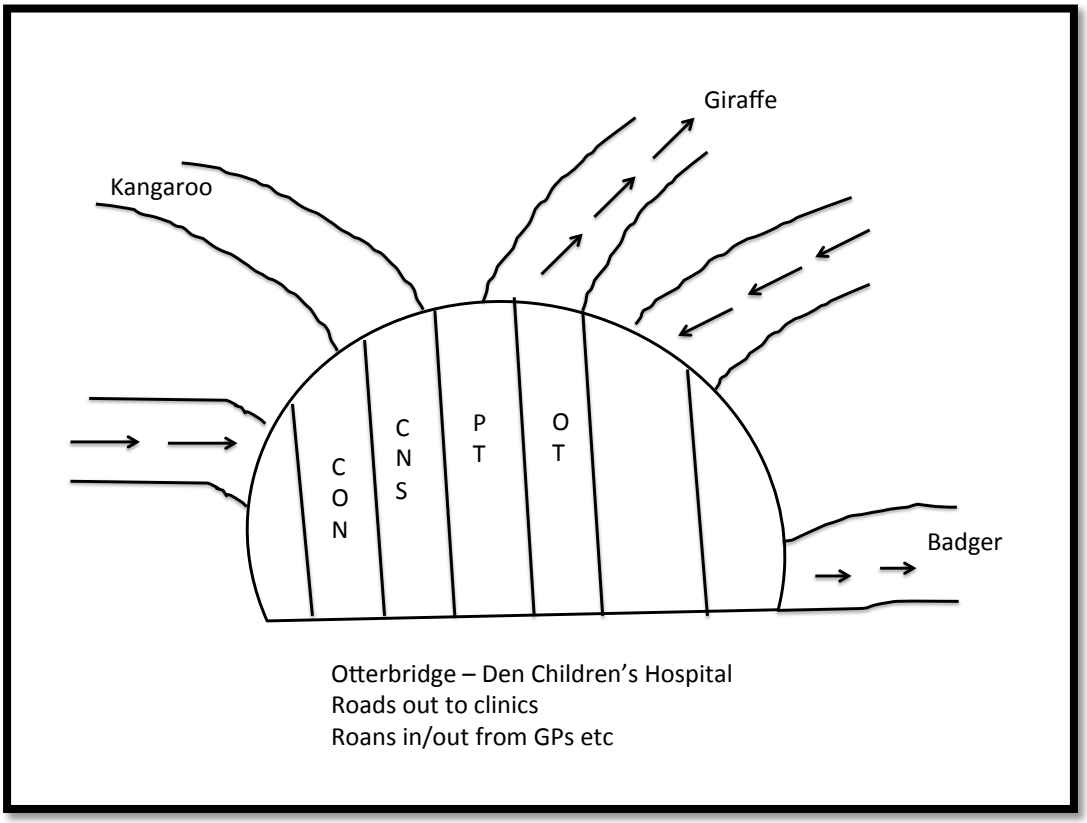


Figure 18 Animal Network drawn by participant F4

In Figure 17 there are arrows indicating the direction of care delivery from the specialist centre to twelve local hospitals, involving general paediatricians, adult rheumatologists, and paediatricians with an interest in rheumatology. In Figure 18 there are arrows, which represented patient travel, which go in both directions, to and from the specialist centre but only to three local hospitals, with 'roads' of care to and from GPs. The following explanation accompanied Figure 18:

> 'I have included the REGION that we cover because I thought that was really important to point out that … that we are RESPONSIBLE for patients throughout that region regardless of whether we have or haven't got secondary tertiary level care in that are (FG 1.1; 80)

Discrepancies of who was involved – or rather thought to be involved - was evident when they further discussed their network with other members of the multidisciplinary team as illustrated below:

> 'So er the hub of my network is eh the Children's Hospital here, the little side shoots to the Lioness where we have the adult rheumatology and then I basically have a series of little lines which go off to all the various different hospitals in the region. So there is one that goes off to North Otter, one goes off to Badger and from there to Weasle, one goes to Antelope, one South Otter to Kangeroo there is one that then slits off and goes to Gorilla and then to Hippo and then to Giraffe as they are all part of one Trust, one that goes to North Seal, and one that goes to South Seal and North Moor and I guess you should also include LOTS and lots of hundreds of little branches as well for all the GP practices in the area too BUT I haven't drawn those in yet' (FG 1.1; 52)[10]

In this case, the participant offered an extensive list of hospital and professionals that they work with. However, another participant offered a different version of the same network.

> 'Well mine is much simpler because I haven't included all of the other little hospitals and that is because I'm not sure from my perspective that they are part of the network … . I think we have a working relationship with them; I don't know if the paediatricians see themselves as part of our network' (FG 1.1; 63)

This participant makes a distinction between a 'working relationship' and a more formal agreement, where all parties agree and understand that they are part of a

[10] Hospital site names have been changed to ensure anonymity (see Chapter Three page 41)

formalised structure. Both these examples show that even within one paediatric rheumatology specialist MDT, network 'structure' may not actually be clear.

As discussed in Chapter Three, for the purposes of this study I have focused specifically on the medical professionals involved in the networks were (those in bold in Figure 19, below). I have focused on the paediatric rheumatologist and the local clinician(s) - adult rheumatologists and general paediatricians. In the next section I discuss the clinical experience, role and responsibilities of these professional groups.

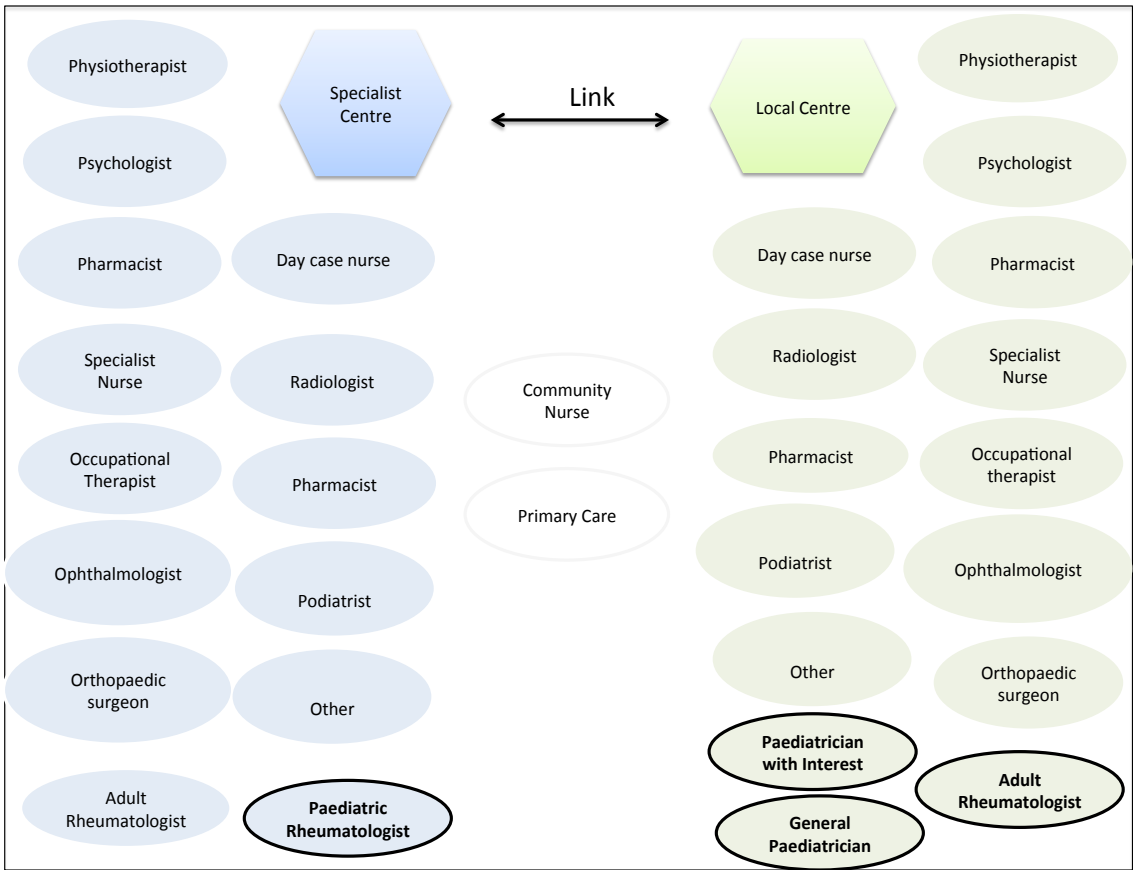


Figure 19 Health professionals that can be involved in the care of a child or young person with JIA

- *Clinical Experience*

The prior clinical experience of the medical professionals, who have become involved in paediatric rheumatology networks, was found to be wide ranging.

Paediatricians**,** who acted as the link clinicians in the network, had very variable skills and expertise. For example, there were paediatricians who had not had any formal training in paediatric rheumatology, who were starting from scratch, who voiced that when they started out they were 'quite scared' and 'knew nothing' (INT 10.1; 30). Others did have some, albeit limited, experience in rheumatological conditions and

were the only one of their general paediatric colleagues who had ever done any rheumatology. Notably, others had 'considerable' experience.

For those who had previous exposure to paediatric rheumatology, it was generally relatively limited, for example during undergraduate medical student training. One link paediatrician noted that 'we had a child with Still's disease [on the ward when they were training], but that's it' (INT 1.1; 54). For those who had gained some postgraduate experience during their paediatric training, it was generally limited; they reported that they could 'only observe and I wasn't really doing the hands on' (FG 8.1; 480). Others reported to having gained some experience by attending paediatric rheumatology courses, undertaking reading or attending network education meetings.

For those who had some previous training it made sense - was 'an obvious choice' - for them to become the link clinician and develop a specialist interest. For others it was because they had 'always enjoyed rheumatology patients' (INT 10.1; 23). However, some offered more ad hoc, serendipitous examples as to how they had 'ended up' in the role of the link clinician for paediatric rheumatology. For one paediatrician, it was not because they had any 'burning desire' or training in rheumatology, but rather because they 'happened to be around' (FG 5.1; 119). Similarly another clinician reported initially taking it on very reluctantly, but then, over time developed an interest and 'wanted to actually do it properly' (INT 11.1; 46). Another noted that they 'certainly didn't volunteer' but had what their other paediatric colleagues thought was related expertise such as:

> 'allergy that morphs into immunology which therefore morphs into rheumatology … . I think was the logic with my colleagues'. (FG 5.1: 98-99)

Other routes to becoming the link clinician included being the link person in another specialty that shared some of the similar medications with paediatric rheumatology, such as oncology. Link paediatricians appeared to have a diverse array of experiences and reasons for taking up the formal role.

In contrast, adult rheumatologists who were involved in the management of children and young people prior to clinical network establishment had generally been involved and had run the services for many years. For many of them they had gained skills and expertise during their training by attending paediatric clinics that other adult rheumatologist offered. They had what they described as 'sort of on-the-job type

learning' (INT 9.1; 10), and being the person in the service where 'everything, EVERYTHING came my way, absolutely everything' (INT 8.1; 28). Some were described as being very enthusiastic, often being very experienced in undertaking joint paediatric and rheumatology consultations.

The paediatric rheumatologists had a range of consultant year experience, with some paediatric rheumatologists being described as brand new, having been only in post for four weeks to others with over 18 years of experience. In the different specialist centres there was a spectrum of the number of combined consultant years within the paediatric rheumatology team. Some of the younger, newer consultants had gained experience via the National Grid Training scheme, where for others, they had been appointed to consultant positions via a number of 'non Grid' routes. The older, more experienced consultants had acquired experience via a multitude of training routes, with a number having been involved in the establishment of the specialty.

The variation in clinical experience is an important finding because it helps give context to the challenges of collaborative working and differences in educational and training support required for professional working within clinical networks.

- *Roles and responsibilities*

From discussing in detail the variations of 'where' care is delivered and 'who' is involved in care, it is not surprising that the roles and responsibilities for clinicians involved in the network also varied. In many areas they 'haven't really got a shared care guideline that we've set down' (INT 1.2.1; 54), and with that there also did not appear to be clearly defined roles and responsibilities.

> 'People have embraced [the job] at different levels. We have people who are very clear, they're just a link and they're not going to do complex management of patients locally. There are other people who have embraced the whole of paediatric rheumatology and want to do everything' (INT 7.1; 280)

For some areas this resulted in some conflict where clinical expectations differed. The variable network roles and responsibilities is not surprising, given the variation in clinical experience, specifically that of the link clinician. One paediatric rheumatologist suggested that there was a need for roles, responsibilities and competencies to be clarified.

> 'I think a new networking setting up would be to actually get the channels of communication, and what the responsibilities are, and what the competencies should be, and how you're going to achieve them. So

> actually set it up from the beginning to say, "Okay, if you're going to be a spoke for tertiary, but you want to do joint injections, this is the level you want to do, and these are the members of the team you've got"; is to set up an understanding, which probably should be written between the tertiary and the secondary care, as to how much is going to be done in the tertiary, and how much in the secondary. "So what are the roles of the two? What are the competencies, and how are you going to achieve that, and then show that you're continuing to achieve that" ' (INT 2.1; 461).

However, I highlight that this was a 'suggestion', and whilst there were similar findings for the need for roles and responsibilities to be clarified, practically how these competencies would or could be achieved was not suggested.

The variation in roles was matched by variations in training. Many paediatric rheumatologists reported finding a 'mishmash' of professional competencies within their network, arising because networks were established from existing services. Over the life of this study, link paediatricians in one network therefore began to pilot the RCPCH Special Interest (SPIN) modules, which have competencies originally designed for competency accreditation during postgraduate training that could also be undertaken by people whilst in a consultant position.

The recognition by individuals for the need for training to develop their competencies in turn depended on their perspective of their roles and responsibilities. Central to this is whether or not a particular clinician feels responsible for the patient. There were differing perspectives surrounding who was responsible for patients. As illustrated earlier in this chapter, one paediatric rheumatologist felt that they were responsible for all patients in their region, and they went to 'see OUR patients locally with the local link paediatrician' (FG 1.1; 142). The perspective of a patient being 'owned' by the specialist team was recognised by the local paediatrician in their area.

> 'I don't think [the tertiary specialist] really wanted me to see patients on my own for follow up but we have just taken an executive decision to do that sometimes if they are stable JIAs. (INT 10.1; 334)

Other paediatric rheumatologists reported that local professionals felt that they were 'their patient[s]', and that they are asking us the tertiary team 'for help, and there will be a dialogue' (INT 2.1; 388). However, some local professionals were less concerned, they described themselves as 'not somebody to get fussed about ownership of patients' (INT 1.1; 116).

There was evidence that roles had changed in some areas following network establishment – particularly for adult rheumatologists whose role in service delivery for children and young people with JIA has shifted, refocusing more towards transitional care.

> 'A lot of the adult rheumatologists, as they've kind of let go of the paediatric service, they've also begun to take on a transition service. (FG 7.1; 344)

As discussed in Chapter Six, for some this 'letting go' had been hard, particularly if the clinician had had a role in managing children and young people with JIA for many years.

8.2.3 What Network Terms Meant in Clinical Practice

In this section I describe an overview of care delivery in networks in clinical practice. I will then discuss in detail the specific terms 'network clinic', 'outreach clinic', 'shared care' and 'doing clinics together'. These were terms and phrases used by professionals and their families in describing how network care was delivered.

Similar to the patient pathway pendulum illustrated in Figure 16 that showed that the movement of patients between the specialist and local centres, the paediatric rheumatologist(s) spent differing amounts of time between these two centres (Figure 20). Some paediatric rheumatologists stayed solely at the specialist centre and communication between professionals about patients who were seen locally occurred by phone, e-mail or letter. These paediatric rheumatologists then saw patients at the specialist centre if specific patients were referred to them, or for clinical review (see shared care arrangement above). In other configurations the paediatric rheumatologist travelled to the local centre and saw patients in a 'network' or 'outreach' clinic. If a paediatric rheumatologist went to the local centre for a 'network' or 'outreach' clinic this for some involved linking with a number of different combinations of medical professionals, but for others they saw patients on their own. These different combinations are illustrated in Figure 21.

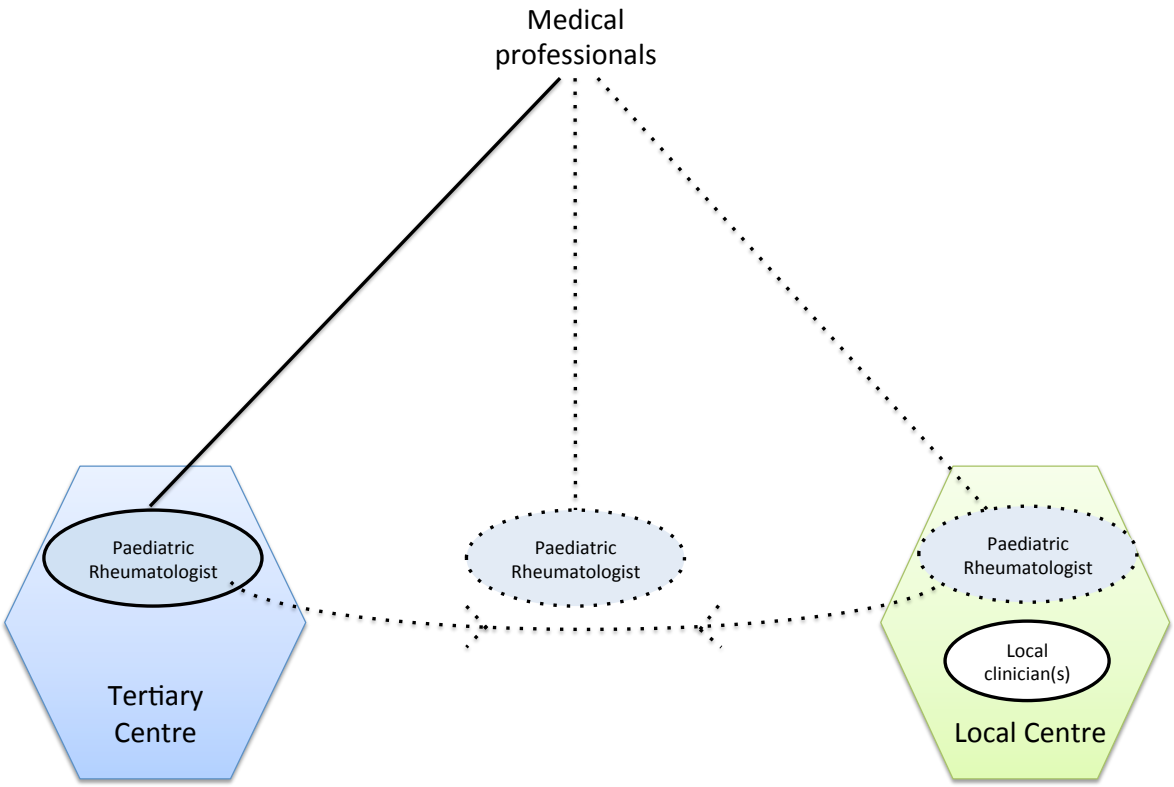


Figure 20 Movement of paediatric rheumatologist between tertiary and local centres

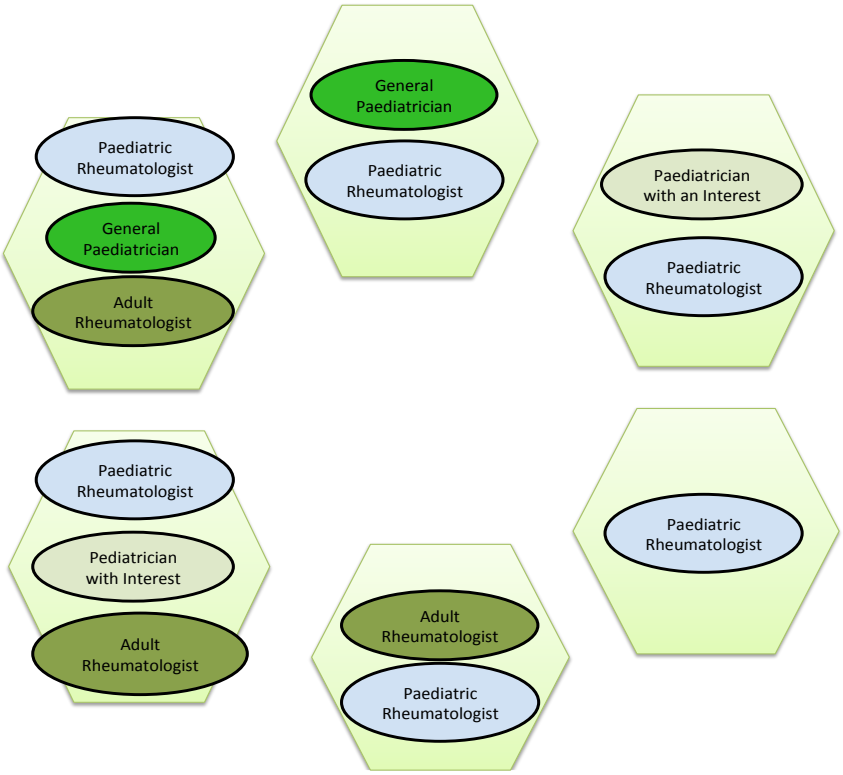


Figure 21 Different combinations of medical professionals involved in care delivery at local centres

The terminology used in relation to how care was delivered between the specialist and local centres was very variable and inconsistent; a number of synonymous terms were used, such as ‘outreach clinic’, ‘network clinic’, ‘shared care’ and ‘doing clinic together’ but what they meant in clinical practice, for individuals as well as across networks, was very different. In this next section I detail specifically what these terms meant in clinical practice.

- *‘Outreach Clinic’, ‘Network Clinic’, ‘Doing Clinics Together’ and ‘Shared Care*

The term ‘outreach’ was generally used to describe the model of a paediatric rheumatology specialist ‘outreaching’ to the local centre and delivering specialist care locally, akin to the traditional hub and spoke model (N. Goodwin *et al.*, 2004) - the hub being the specialist centre, and the spoke being the local centre. For some this outreach way of delivering care involved a single paediatric rheumatologist going to the local centre. For other paediatric rheumatologists it also involved ‘doing clinic together’ with other member(s) of the tertiary paediatric rheumatology MDT visiting the site with them (see below). The term ‘network clinic’ was also similarly used to describe a model of paediatric rheumatologists (+/- members of the MDT) going to the local centre to provide specialist advice and support, and ‘doing clinic together’ with local professionals. However, there was a subtle difference between the term ‘outreach clinic’ and ‘network clinic’, which I discuss in more detail later in this section.

At the local centre, ‘doing clinic together’ could involve a variety of combinations of professionals from different backgrounds (see Figure 19). These professionals were either all in the same room running a single clinic room, or alternatively the clinics were run in parallel in adjacent rooms. Clinics held at the local centre where the paediatric rheumatologist was present varied in frequency, occurring in some places every two weeks and in others networks just once a year. Outreach or network clinics for other paediatric rheumatologists also meant ‘doing clinic together’ with a member or members of the local team. For some they involved a variety of combinations of professionals from different backgrounds, and sometimes all in the same room.

> ‘They seem a really closely working together in [the local centre] with [the two doctors] and the physio and the nurse and I mean she is always usually there, is in the room. …They are obviously working very closely together and that is really helpful because they seem together [Laugh] and so they are always working from the same page so it seems like good communication even though we are seeing a physio in a different hospital somehow … I think [they] meet for the clinic there when [they] knows that

there is appointments with some of [their] clients. It has been very positive' (FG 2.1; 475)

As this excerpt from a parent highlights, all the professionals in the same room can be a positive experience, which can facilitate communication about management decisions. In this context, the parent felt the team was providing a true multidisciplinary approach to care. However, others had a different opinion.

> Parent A 'I think it was [a bit to much] to start with when we first walked in that room.
> Parent B Aye we did say that too….
> Parent A Yeah I was like that; all eyes were on you as well. You felt it was a bit of a project you know.
> Parent B Once you know yeah we were coming to see a consultant we expected the nurse to be there but there is the three other people sitting there and you are thinking oh Hell and then they say to your child can you please take your trousers off...' (FG 3.1; 620)

So, although 'doing clinic together' with all the members of the MDT may be beneficial, for some families this approach may feel impersonal, and awkward for them, particularly during the clinical examination in front of such a large group of people.

Depending on how busy the clinic was, some split the clinic load and saw patients individually and did clinic together but in adjacent rooms. For others doing clinic together in separate rooms was the norm. When clinics where done 'together' this could involve various combinations of the tertiary and/or local multidisciplinary team attending.

The conduct of the clinics varied when 'clinics were done together'. For example, some rotated who led the consultation, with the paediatric rheumatologist taking on a more supportive role, whereas in others the paediatric rheumatologist led the consultation, providing what was perceived to be:

> 'the same standard of care… the same patient EXPERIENCE as someone would get if they just happened to live next-door to the [tertiary centre]' (FG 1.1; 160).

For some link clinicians they only occasionally lead the consultation for simple cases, but for others when 'clinics were done together', the link clinicians had generally taken on the role of running and leading the consultation. As one paediatrician noted:

> ‘Certainly I can recall that at the beginning with [tertiary specialist] and subsequently [another tertiary specialist] that it would be me that was in the ‘hot seat’ as it were but I would defer for opinions and the paediatric rheumatologist could chip in and examine as and when they saw fit ‘(FG 5.1; 197).

In other contexts, the professionals took turns in leading the consultation. Others used the opportunity of ‘doing clinics together’ to support the training and development of local link paediatricians who had had little prior clinical experience.

> [The tertiary specialist] comes two weeks a month and we almost do a whole day clinic. Initially, yes, I used to sit in and [the tertiary specialist] used to [lead]. I think over the last few weeks what we’ve done is, I do a few of the patients and [the tertiary specialist] does the more complex two or three which are there. I think that really builds up my confidence also, you know the parents…. Parents also feel that’ (FG 9.1; 252).

Doing clinics together in this way, akin to an apprenticeship, enabled them to gain confidence to take on more responsibility as the link paediatrician for their local centre. This was also important to gain the parent’s confidence in the local link clinician who would be providing care the majority of the time.

There were also examples of a ‘mix and match’ approach to doing clinics together, with the paediatric rheumatologists leading the more complicated consultations or examining ‘the kids that are a bit more difficult’ (FG 7.1; 614), with the link clinicians still present in the consultation.

Relatedly, the term ‘shared care’ described a number of different ways relating to set up of care between tertiary and local teams. For some this described the process of seeing a patient with a local clinician, whereas for others ‘shared care’ did not involve ‘outreach’ - involving a member(s) of the paediatric rheumatology team physically going to the local centre - but meant a process of sharing care by alternating clinics between the specialist and local centres. The role and responsibility of the ‘shared care’ or ‘link’ paediatricians therefore varied and not only depended on their expertise and what resources where available locally, but also whether or not the shared care involved the presence of a paediatric rheumatologist at the local centre.

Although care was described in networks as ‘shared’, across different networks and also within a network, it might mean different things to clinicians. As a paediatric rheumatologist described when they saw a patient in a ‘shared care’ set-up:

> ‘Very simply, a case being seen in clinic; his parents said to me, "I don't know why it's called shared care. We drive to his [local] hospital, which

> takes us 20 minutes to drive -our local hospital, park the car, wait around to see the [local] paediatrician. We go into the clinic room, [the paediatrician] doesn't even acknowledge my son, just looks through the notes and says, 'Oh they looks well. Everything okay,' and doesn't examine the child at all, and that's the end of the visit" '(INT 3.1; 213).

The above example, although extreme, highlights a problem beyond just how the same terminology can mean differences in how care is delivered, but also differences in perceived roles, responsibilities and expectations. This was raised by one clinician as a significant issue in their network where problems had occurred engaging clinicians in their way of shared care (alternate clinic appointment), with frequent reports of local paediatricians discharging patients from their care once they had been referred to the tertiary centre. As a result for this particular network they were in the process of working on the development of some shared care principles.

There were findings also that getting the 'network structure terminology' right was considered by some to be important:

> 'I mean the term that I like to use is shared care, and I guess that's quite a broad thing, and we are sharing care. I don't like the term hub and spoke at all. I don't even like outreach actually…the term is important ' (INT 11.1; 305)

Some terms (particularly 'outreach') were viewed as inhibitory to collaborative working, with potential to cause disengagement particularly if they construed a degree of hierarchy. Some avoided the terms 'outreach clinics' or 'hub and spoke' in their network for this reason.

> 'The hub is great and the spoke's just doing the, "not very interesting, work." I don't think you get good engagement from people if you imply that they're just a spoke of a big hub'. (INT 6.1; 659)

Some completely avoided any hierarchy terminology and specifically used the term 'network' clinic instead. This was also conveyed when participants were asked to draw the structure of their network diagrammatically.

> PRhem A: 'I think, for me, the two things I've learned over the years is, one, it's very much about two-way communication. And it's not about a hub-and-spoke model. All my arrows have got points on both ends. I think other people similarly.
> PRheum B: I've avoided arrows altogether for exactly that reason.' (FG 7.1; 299)

As these examples allude to, lessons have been learnt over time that networking requires a two way process of communication and collaboration.

In summary, the four terms used to describe care delivering in networks - ‘out reach clinic’, ‘network clinic’, ‘shared care’ and ‘doing clinics together’ were often used interchangeably, and the terms also meant a variety of things in clinical practice. The different terms have the potential to cause misunderstandings and may be particularly pertinent if the language construes a hierarchical rather than a more egalitarian relationship.

8.2.4 Network Structure Examples

In this next section, I describe ‘where’ care is delivered, ‘who is involved’ and ‘what their network term meant for clinical practice,’ looked like in network examples. Two examples of networks are used in order to illustrate the complexity of network structure within and between networks.

In the first example, a paediatric rheumatologist, referring to care pathways, outlines the complexity of care delivery within a network:

> ‘They’re all different, and I think this is something that at one of our network meetings I want to try and rationalise and get some kind of sense that we’ve got a uniform pattern, because they’re all completely different, and some new referrals will go via the adult rheumatologists, some will go via the paediatricians, some of them will see new referrals, and then bring them to the clinic that I come to for follow-up. Others will let me know about a new referral, and I will say right, I’d like to see in [the tertiary centre], and then we’ll follow up out. So, it’s a sort of mess at the moment, there’s no uniform system at all. … [For local clinics], so around the region, there was a mixture of models, so there are some centres where an adult rheumatologist has led, sometimes on their own, sometimes with a paediatric colleague sat in the clinic. Other centres where it’s actually a paediatrician who’s lead and taken on the … . And done their paediatric rheumatology clinics with or without support from a named adult rheumatologist (INT 11.1; 253).

Children and young people with JIA were historically seen by a number of different health professionals in local hospitals around the region. Their network was established by linking these existing local professionals and hospitals together with the tertiary paediatric rheumatology service. As a result, care pathways and the way that local clinics are all run in different ways – a messy, non ‘uniform’ network being the product. Now that the links have been established, there were plans to address referral and care pathways across their region.

The second example is illustrated in Figure 22. In order to ensure anonymity, I have included only part of this network. The complexities and different ways of care delivery that occurred are still evident despite simplifying it in this way.

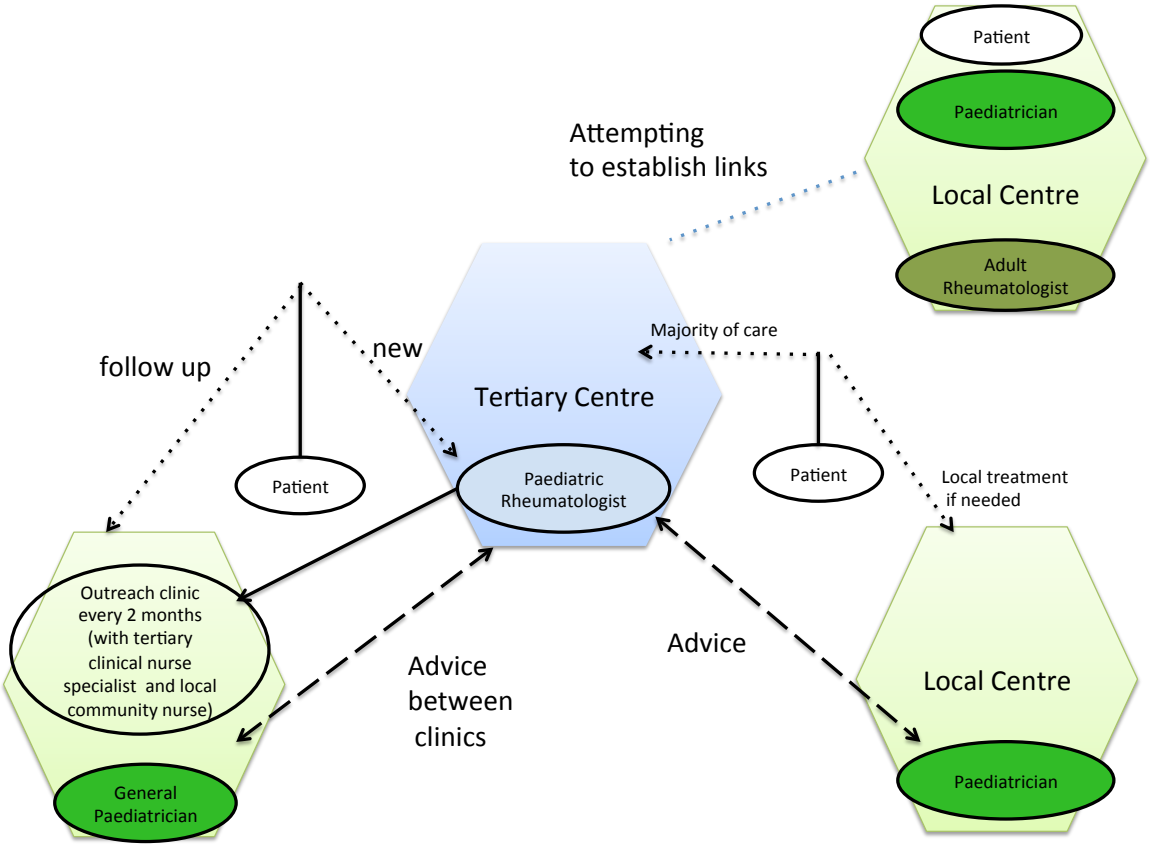


Figure 22 Example of different ways care was delivered across a network

In this above example, the tertiary centre linked with a number of local centres. There were ‘close’, ‘formal’ links both at a clinician and management level with one local centre, with established ‘outreach clinics’ occurring every two months. The paediatric rheumatologist went with the tertiary clinical nurse specialist to the local centre and follow-up patients with JIA, were seen in clinic was ‘done together’ with a local community nurse, and the link general paediatrician. Patients who were managed between these two centres were initially seen in the tertiary centre, and then when stable followed up in the local centre. If they required infusions for treatment, these have now begun to be established locally. If they required joint injections then the patient went to the specialist centre for that ‘part’ of their care. Within that framework there was expectation that advice is given in between those clinic appointments via phone or e-mail. This was a newly established link, with the local clinic having been run previously by an adult rheumatologist and the general paediatrician. Since more

formal links were established, the tertiary paediatric rheumatologists reported that with this local centre care pathways had been more streamlined

> 'Now certain aspects, like intravenous Methylprednisolone can be given locally safely, which before the local team weren't happy giving. … Having shared care protocols is important' (INT 5.1; 486)

The tertiary specialist team's networking philosophy acknowledged the importance of the role of the MDT within the outreach clinic

> 'having the nurse specialist in those outreach clinics and local nursing representation is really important to … to be able to demonstrate really the importance of the ethos of a multidisciplinary team approach and the important roles in the teams' (INT 5.1; 455).

It also included providing on-going education for clinicians working within the network.

Within the same region, informal links were evident with another local centre. The general paediatrician from this hospital referred patients to be seen at the tertiary centre, where most of their treatment and follow up care took place. 'Shared care' occurred on an informal basis, and if any treatment required locally then the tertiary team liaised with the local clinicians to help enable this to happen. This set up of care delivery within their network was described as 'informal' because at the current point in time there were not any management links.

Another local centre in their region was described as having 'in house' rheumatology provided by an adult rheumatologist and a paediatrician, without a dedicated MDT, and they 'don't engage with us very much' (INT 5.1; 129), and 'don't ask us to get involved very much with the care children with rheumatology issues' (INT 5.1; 151). Trying to establish links with this local centre was described as hard.

Within these two individual network examples, there were a variety of ways professionals interacted, and various ways that care was delivered, highlighting that not only each network is unique, but also unique is each individual link within each network.

8.3 Discussion

I described in Chapter One, that although networks may be broadly categorized into 'models' or 'types', it is recognised there a variety of network structures (RCPCH 2012). The findings reported in this chapter indeed confirm that there are a variety of

paediatric rheumatology clinical network structures across the UK (Davies *et al.*, 2010), and also adds to the literature by detailing specifically the different ways that care delivery in networks occurred for children and young people with JIA. It is apparent that network structure is complex and messy; children and young people with JIA received care to differing degrees, and for different reasons between local and specialist centres, provided by a number of medical professionals (and the MDT) from differing clinical backgrounds who had differing levels of expertise. This variation was not only evident between networks when individual networks were compared, but also within individual networks. The complexity of network structure is unsurprising given how the specialty of paediatric rheumatology has evolved from historical set-ups of care for children and young people with JIA (see Chapters One and Five). Furthermore, the links between professionals and their organisations were continually evolving. This dynamic nature has some similarities to that described by (N. Goodwin *et al.*, 2004) in that over time networks may have differing degrees of integration and regulation. There were also other factors, which contributed to the variations including geography, staffing resources and, the complexity of the patient's condition. These findings are important when considering how best to support education and training of health professionals involved in clinical networks.

By describing three network terms - 'outreach', 'shared care' and 'doing clinics together' in detail and explaining what that meant in clinical practice, I have shown that network associated terms were frequently used synonymously but what this looked like in clinical practice differs. As discussed in Chapter One, loose usage of terms, in regard to 'networks' has previously been described and noted to be confusing in the research field – for example 'network' or 'clinical network' are often used interchangeably with 'partnership working' or 'integrated care' (N. Goodwin *et al.*, 2004). Furthermore some have argued that term 'network' has become a ubiquitous metaphor describing too many aspects of contemporary life, where something that attempts to explain everything has the inevitable risk of actually explaining nothing (Thompson, 2003). The analysis relating to terminology in this chapter raises similar issues. The implications go beyond confusion and the difficulties encountered during qualitative analysis; if these terms are used - for example between health professionals, patients and families, managers, commissioners, policy makers, college and societal bodies - then there is a possibility that misunderstandings may occur, which could have implications for collaborative working and care delivery. Furthermore, there is suggestion that the terminology

used to describe and explain care delivery within networks should be carefully considered, as it has potential to affect relationships and collaborative working; some terms with negative connotations may set up barriers before any real engagement has occurred.

Not only did different network structures give rise to clinicians having different roles and responsibilities, as networks evolved roles and responsibilities also changed. As briefly discussed in Chapters One & Five, network establishment has resulted in some adult rheumatologists who historically used to look after children with JIA having a changing role, and for some this has been reflected in the way that care is now delivered. Building on earlier findings, and from the analysis captured in this chapter, there appeared to be five descriptors relating to the role of adult rheumatology:

- 'Historical' role - e.g. Adult Rheumatologist providing care without full local MDT support with variable local and tertiary paediatric links
- 'Shifted' role – e.g. towards transition
- 'Handed/Handing over' role - e.g. Paediatric rheumatology +/- paediatrics now leading or in the process of leading the service, with variable involvement from adult rheumatology.
- 'Accepted' role - e.g. Enthusiastic Adult Rheumatologist with good local team who refers to tertiary centre for expert opinion if required.
- 'Link clinician' role - e.g. Adult Rheumatologist acting as the local link clinicians, 'sharing care' / 'doing clinics together' with a paediatric rheumatologist +/- paediatrician.

As we saw in Chapter Six the changing role for adult rheumatologists has in some hospitals been amicable and welcomed, but harder to accept by others.

Another factor which influenced the way care was delivered and one that has implications for education and training was clinician's mind-set, their own belief of how care ('where' and 'who by') *should* be delivered. It may affect the roles and responsibilities of clinicians, and to some degree where care was delivered, but more specifically how network clinics were run. For example, in this chapter, there was evidence that some tertiary specialists felt responsible for patients with JIA within the whole of their region, that they were going to see '*their* patients' locally, whereas others went to support the local team, and they were very clearly 'local patients'.

There appear to be three beliefs from paediatric rheumatologists about the way that good care could or *should* be delivered within a network. These can be described as:

- Supporting local clinician(s) to deliver specialist care
- Delivering specialist care locally with support from the local clinician(s).
- Delivering specialist care at tertiary centre with support from the local clinician(s).

To some professionals this may not matter – but the subtle differences are important for the lines of responsibilities and the way that care within a network is delivered in clinical practice. Each of these beliefs influences the relationship between the local and tertiary hospitals and the clinicians involved, and if conflicting beliefs occur then collaborative working can be affected.

Clarification of roles and responsibilities was important, because some of the problems encountered in establishing links in networks and collaborative working, (Chapters Five & Six), stemmed from when professional boundaries and territories had been encroached.

8.4 Conclusion

Network structure is complex and somewhat messy, and network terminology is confusing. A shared language or a detailed explanation – with people being specific about that the term means in clinical practice may prevent misunderstandings during service development and collaborative working. The findings in this chapter confirm the existing literature that every network is unique (Ferlie and Pettigrew, 1996; Guthrie *et al.*, 2010), but adds to the literature by demonstrating that what makes every network unique is not only the different ways that care delivery occurs between networks but also between the individual links within the network . Now that I have provided an in-depth understanding of the way that care is delivered within networks, I can begin to explore what these differences in care delivery means for supporting professionals establishing clinical networks to deliver optimal care for children and young people with JIA. This chapter sets the scene for the rest of the thesis, which explores the implications of network structure on education and training, and collaborative working.

Chapter 9. Educational Activities in Clinical Networks

9.1 Introduction

In this chapter I describe existing continued professional development and training within the clinical networks studied. Continued professional development and training will be referred to here as 'educational activities' unless specifically otherwise stated. In the Chapter One, I highlighted that clinical networks can provide an infrastructure to support the delivery of education to health professionals, which in turn can benefit the care of patients (Edwards 2002). In Chapter Seven, my own observations confirmed that clinical network establishment had created benefits with new links for care and education. In this chapter, I explore the educational activities that were present in the clinical networks studied to establish what was available (at the time of data collection) in terms of format, content and target audience, and how it was delivered. In doing so I reveal that a portfolio of educational activities existed, and demonstrate that the opportunities for learning and training were dependent on and related to how care was delivered in the network. I also discuss the ways that professional boundaries have exerted an influence on the educational activities of the network.

9.2 The Importance of Educational Activities in a Clinical Network

All participants acknowledged that educational activities were an integral part of the establishment of a clinical network, and one paediatric rheumatologist went as far as saying that 'probably the most important activity of the network is the education and training of staff' (INT 7.1; 233). It was recognised that 'education [in a network], it's a big issue' (INT 5.1; 447).

The participants described different degrees of importance of the educational activities, which depended not only on their role, but also what other opportunities were on offer. For example, as one link paediatrician reported they had accessed a range of educational activities.

> 'They [the specialist rheumatology team] knew [from initial discussions] that I knew nothing but were supportive of that and tolerant of that and were prepared to educate me. The network meetings, the education meetings were very good. After that, when was that? That would have been probably four years ago … I was doing that, going to the network meetings, getting to go to clinic in [the specialist centre] but a lot of

speaking on the phone and email. I had and still have a great deal of email support and find it easy to access the team'. (INT 10.1; 38)

In this example, the link paediatrician benefited from educational input at different times points in their career and from the different types of educational opportunities that were on offer. This contrasted to the experience of another link paediatrician, who worked in a network of 'shared' care.

> 'As a consultant [link paediatrician] and after the network had started I think the ONLY way to get rheumatology CPD is actually coming to [the specialist centre education meetings] and learn something from them.' (FG 8.1; 24)

Here there was a particular emphasis on the importance of the organised education meetings to gain knowledge. Importantly though, the consultant also voiced that for them the organised educational meetings were a key place to get to know colleagues better.

For other paediatricians when I asked what the most important educational activity was in the network for them there was a unanimous reply.

> 'Link Paediatrician A Clinics.
> Link Paediatrician B Clinics.
> Link Paediatrician C Being in a clinic with a paediatric rheumatologist.
> Link Paediatrician B Yep.
> Link Paediatrician D Yeah.
> Link Paediatrician A And then actually doing it yourself.
> Link Paediatrician C Undoubtedly yeah, yeah.
> Link Paediatrician A And sort of seeing that what you are making the decisions are the right decisions and …
> Link Paediatrician B Yep.
> Link Paediatrician D Yeah' (FG 5.1; 601)

For these clinicians doing clinics with the paediatric rheumatologists provided an important learning environment and apprenticeship experience. Transferring what they had learnt in clinic and 'doing it on their own', and seeing the consequences for themselves was also perceived to be important.

One paediatric rheumatologist raised a specific point from their network relating to how education in their network was received. They highlighted the importance of the local clinician (and team) 'wanting it' (INT 7.1; 623), and by that they meant there was a specific purpose to it.

For the purposes of trying to describe educational activities occurring in the clinical network studied I have divided this chapter into ‘organised educational activities’ and ‘opportunities for learning and training within clinical practice’ – by which I mean the workplace. I specifically include ‘learning’ as well as ‘training’ as the participants interviewed were involved both in receiving as well as delivering education. I highlight that these were not mutually exclusive events – not an either/or but rather there were a number of educational opportunities that health professionals could access.

9.3 Organised Educational Activities

In this section I give describe examples of organised educational activities that occurred in the clinical networks studied. By organised I mean educational activities, which were pre-planned and involved health professionals most often being invited in advance to attend an educational meeting or event. In all the networks studied, no matter how they actually went about delivering care (see Chapter Eight), all had evidence of these types of educational activities, which contributed to the continued professional development of professionals working within their network.

Examples of the reported educational activities are listed in Table 14 with details of the formats, content and target audience.

Event	Format	Content	Audience
Allied Health Study Day	Interactive case presentations and discussions	Basic knowledge about JIA	New allied health professionals
Transitional Care Study Day	Presentation	Overview of transition issues in paediatric and adolescent rheumatology	Multidisciplinary audience
Musculoskeletal Examination Workshop	Interactive workshops involving patients with clinical signs	Examination skills of the paediatric musculoskeletal system.	Multidisciplinary audience
Basic Paediatric Rheumatology Education 3 day course	Patient centred education with lecture style teaching	Update in diagnosis and MDT management of children with rheumatologic diseases	Multidisciplinary audience
Paediatric Rheumatology Study Day	Virtual ward round in clinical skills laboratory	Common rheumatological conditions in clinical practice	Multidisciplinary audience
Paediatric Rheumatology Network Education meetings	Lecture Case base discussions Videoconference	Variety of topics	Multidisciplinary audience also linking with other network groups – including paediatric nephrology, adult rheumatology, and ophthalmology
Regional network paediatric rheumatology meetings	Lecture Case base discussion	Musculoskeletal conditions presenting in childhood.	Therapists, general practitioners, general paediatricians, orthopaedics, emergency care physicians
Regional and National network Education meetings –	Practical workshops Lectures Case base discussions	Hands on ultrasound Multidisciplinary audience Radiology, management of methotrexate in shared care, macrophage activation syndrome, non-inflammatory conditions, research studies, and biologics.	Multidisciplinary audience
Paediatric Rheumatology multidisciplinary teaching programme,	Videoconference Case based discussion	Varied programmes	Multidisciplinary
Hospital grand rounds	Lecture	Varied programmes	Multidisciplinary

Table 14 Portfolio of formal educational activities occurring in clinical networks

The table illustrates that there were a number of formats used to deliver these education events but most included face-to-face meetings with presentations, which were frequently case-based. The use by one network of a videoconferencing format to deliver their education programme is discussed in more detail at the end of this section. Overall, the content was varied and could be described as one participant put it as 'a kind of portfolio of educational things going on at all sorts of different levels' (FG 7.1; 1325). 'Levels' here meant targeting MDT audiences. These audiences included members of the MDT closely involved in the management of children and young people, as well as professionals who had less direct contact with the clinical teams but encountered musculoskeletal problems in this age group across their region, and also undergraduate and postgraduate students. The finding that the audience was generally MDT has important implications for what those planning educational activities. I will discuss this area further in a later section of this chapter, where I explore problems encountered with educational activities within the networks.

9.3.1 Videoconferencing format

Videoconferencing was used in one network to link the specialist centre with a number of local centres, and deliver an education programme around their network. I describe this specific format in more detail because it was a novel format introduced by one network to extend the regular educational activities at the specialist centre across a large geographical area, and prevented the need for participants to travel. In all the other examples of organised educational activities, participants had to travel to attend the educational activity.

The videoconferencing education sessions were initially trialled between the specialist centre and one other centre but over time, as it became more established and the participants more familiar with its use it resulted in the sessions being 'consistently 'attended' by between five to nine local centres each time' (FG 7.1; 1095). Professionals working around the region could 'dial in' and participate in the session, and did not have to leave their local centre. Through this mechanism, MDT education sessions were delivered every month, on a specific afternoon, with an advantage of overcoming travel time for geographically dispersed hospitals. A planned programme using this approach was coordinated by one of the paediatric rheumatologists, with a similar varied content to the other organised educational activities reported in Table 14. However, what was different was that the education sessions were initially organised and led by the team from the specialist centre, but

over time, professionals based in the local centres helped deliver parts of the programme. The format generally involved Power Point presentations, sometimes case based, with time afterwards for discussion. The videoconferencing service was provided by key stakeholders who deemed the role of tele-health and tele-care an integral and important part of their vision for the delivery of health care in their region. Funding had been provided specifically to enhance this form of communication technology, which included a service desk support and multisite conferencing facilities. There were reported initial difficulties, such as streaming video clips in presentations, but over time the feedback was positive.

9.3.2 Benefits of organised educational activities

Organised educational activities have created additional opportunities for health professionals. These benefits were introduced in Chapter Seven. There were described opportunities to share experiences and to get to know people around the region.

> 'I think it's helped, actually MEETING a lot of the paediatricians, because we only knew their name and vice versa, they only knew us [paediatric rheumatologists] by name (INT 3.1; 47).

This has 'also mean[t] that outside of the meetings, I [a paediatric rheumatologist] know who to ring up about… [patients managed in local centres]' (INT 6.1; 212). The opportunity to meet face-to-face and get to know each other was recognised by all health professional participants. However, this was particularly reported by those professionals who worked in networks where the paediatric rheumatologist (+/- members of the MDT) did not travel to the local centre to do clinics together with the local clinician(s) (see Chapter Eight). What was apparent however, was that a physical face-to-face meeting was not necessary need to facilitate this process of getting to know someone.

> 'I've never met…. I've never met any of those two [paediatric rheumatologists]. But because of these network educational activities, even when we do the telelinks, just talking to them I just feel that you know them'. (FG 9.1; 197)

Although participants reported that face-to-face meetings were key to getting to know colleagues, this excerpt shows that this can also be achieved through videoconferencing. Knowing each other from attending an organised event, whether

face-to-face or via videoconference, resulted in less anxiety, and people were less inhibited asking questions.

9.3.3 Challenges Encountered with (some) Practical Solutions

In this next section I describe a number of challenges encountered in delivering organised educational activities in clinical networks. I also describe some of the practical solutions offered, from those who had been involved.

- *Different and Changing Educational Needs*

There was a commonly reported theme of a 'difficulty of trying to think about people's educational needs' (INT 2.1; 96). This was perhaps not unsurprising given that professionals in a network were an eclectic group, with different backgrounds and experience with different roles and responsibilities (see Chapter Eight).

> Paediatric Rheumatologist A: 'Again, the problem is there are hugely different experience levels.
> Paediatric Rheumatologists B: I think [paediatrician X and Y] are just establishing [the link post in the local centre]. Their learning needs are hugely different [to more established local centres].' (FG 7.1; 1183)

As much as each network is different, so are the educational and training needs for those involved. Networks may create opportunities to be inclusive, and may provide benefits, particularly in getting to know people (see Chapter Seven), However, when educational events were organised and 'open to anyone' (FG 5.1: 559) pitching it at the right pace, and level for a multidisciplinary audience was described as 'a juggling act' (INT 2.1; 102).

When time allowed, and meeting rooms and professionals who could deliver the education were available, some networks had overcome the problem of an eclectic audience with parallel sessions and workshops running which were 'targeted' or 'tailored…appropriately' (FG 1.1; 733, 667) at different experience levels and backgrounds. For those involved in the organisation of these sessions, attempts had been made before hand to try and establish the educational needs (what they wanted to know or do) of those attending. Some used an email survey to facilitate this. When the education sessions were 'very much focused on what they [local professionals] want[ed] to know' (FG 1.1; 733), they had been reported to be well received but they also had found it much easier to pitch them at a specific level if it was a single professional group compared to a multidisciplinary audience. More frequently the

sessions were used to ‘get our [paediatric rheumatologists] agenda’ across (FG 1.1, 7.1 field notes).

Networks that had been established for a number of years had experienced a challenge of a continually evolving and changing workforce. One network highlighted that the content for the educational activities needed to be tailored to the needs of the network at a specific point in time, and they had found that this needed to be reviewed regularly.

- Attendance

Although, there were general reports that attendance at educational activities was better since establishing a network (see Chapter Seven, reasons include clinical governance, commissioning and revalidation) getting people to continue to attend regularly was reported by some as a significant challenge. This was particularly the case for ‘the ones that don't come that actually need to come’ (INT 3.1; 284). There remained a difficulty in engaging people to attend who might not appreciate the benefit or understand the need to attend, or did not buy into the network concept suggested by reports of ‘they haven't really quite realised the shared care network principle yet’ (INT 2.1; 46). Some specialist centres had found it ‘much more difficult to get the adult rheumatologists to come for things like CPD purposes’ (INT 2.1; 277) in comparison to paediatricians. Reasons for the difficulties with this group of professionals are likely multi factorial but may be dependent on the historical relationship between individuals and hospitals (see Chapters One and Five). There was suggestion also of failure of engagement or reluctance to change current practice, perceived as a lack of understanding, with professionals who ‘didn’t necessarily know what they were doing could be different’ (FG 1.1, 307). This was particularly the case with those ‘who just don’t get the paediatric rheumatology bit’ (INT 6.1; 147) or those who ‘don’t realize how different paediatric rheumatology is from adult rheumatology’ (INT 2.1; 305).

Attendance also was noted to be variable. For example, some link paediatricians who had been very enthusiastic about the network found that even when the format had changed to a videoconferencing programme the meetings clashed with other clinical commitments.

> ‘And I am not sure even if … even if it wasn’t on a Tuesday afternoon I would have to think carefully about how many I would schedule in’ (FG 5.1; 633)

This excerpt also suggested that the decision to attend was about more than availability. There was a personal choice whether or not to attend, and whether it was perceived relevant to the learner and their needs. In fact, in the case of this network, all the link paediatricians reported that 'learning on the job' was more useful than attending formal educational activities (see below).

There were reports of 'trying to explore ways that we can encourage [those who don't attend] to come' (FG I 3.1; 285). Many held their educational meetings at the specialist centre around meal times, encouraging attendance by also providing the social benefit offered by meeting together. Although the mealtime approach recognized amongst many as useful, some tertiary specialist teams reported that it was 'certainly you get more input [and better attendance] by going and joining their [local centre] lunchtime meeting[s]' (FG 1.1; 720). Others had tried to run educational activities, which 'move[d]…around the region, [but had found] it never really worked' (INT 2.1; 88).

Importantly, and unsurprisingly attendance was improved if session dates did not clash with other meetings, such as national conferences. There was realisation in one network that attendance was helped if meetings were well organised such that the date was communicated efficiently and repeatedly in advance.

- Time

A common challenge encountered by all was the limited time to attend educational activities, as illustrated in the previous section by the necessity to run meetings at mealtimes. If there was protected time away from the hospital, then attendance of educational activities was frequently reported to be 'depend[ent] on workload' (FG 7.1; 1257) with reports that clinical care took priority. As described previously, one network had attempted to overcome the travel time issue with monthly videoconferencing sessions. The total amount of time that professionals felt they could 'commit' (FG 7.1; 1167) to education meetings also varied.

> 'When education sessions used be a whole day every 3 months, for some this was felt to be too much, then when reduced to just afternoons and it's not always worth us going over for an afternoon. I haven't actually been to one since.' (INT 1.1; 622)

Obtaining the balance and finding a simple solution, for example 'a time that's convenient' (FG 1.1; 712) to fit into everyone's schedules and commitments to please

everyone was impossible. However, for those who had experience of an established education programme using videoconference, as described earlier in this chapter, some of the same issues of attendance existed, even though the important factor of travel time was overcome, emphasizing the multifactorial reasons behind poor attendance.

Those who were on the receiving end of the educational activities were not the only ones who encountered the limitation of time; those who were organising the events had a similar challenge of limited time.

> '[There is] endless education one could do….. I think we're stretched to as much – we can only – I don't think we could do very much more.' (FG 7.1; 1348)

Despite enthusiasm, the pressures of clinical work and limited time were rate-limiting factors in organising further education. There were reports that the paediatric rheumatology teams from the specialist centre have predominantly taken on the responsibility of organising or 'provid[ing] the education' (FG 7.1; 1116), which has been outward looking: providing education and supporting training of professionals who are looking after children and young people with JIA in local centres.

> 'We went out and actively sought participating grand round meetings and educational meetings in other trusts to make places around us…. Really just to try and raise awareness as well of rheumatological conditions and the delays in diagnosis that can ensue. We worked hard on that bit'. (INT 5.1; 248)

This may be viewed by some as hierarchal top-down teaching, which risks alienating the clinician to taking on the role of 'learner', but what was observed to be 'interesting' to those who had begun to educate and train and support local professionals was evidence of the beginnings of a wave of education and training occurring; education beget education. If this phenomenon can be harnessed then it offers a potential solution to the problems of limited time discussed above.

> 'I think the other thing is, it's interesting once you've got a confident [local] network team, they're rolling out education to other people in their region. Like the [local network] physio and OT have done teleconferenced education to the [other] physios and OTs. They set that up – the local ones actually. They've set that up and done it themselves'. (FG 7.1; 1227)

Similarly, community nurses in one network were invited to attend an organised education event on the administration of methotrexate. This was organised by local

nurse specialists, who themselves had been taught by the tertiary nurse specialist (FG 9.1 field notes). This observation was not just limited nursing or to the allied health professional group, it was seen in all groups of professionals. For example, network link paediatricians rolling out sessions on musculoskeletal conditions to undergraduate and postgraduates, and other general paediatricians.

> 'Similarly now that we have got a little team established….. It is may be only once a year or so but we will do once or twice a year … we will do one the paed … local paediatric grand rounds.' (FG 5.1; 563)

As mentioned previously, apart from the examples of the wave of network education and the few examples of organisation of events by other health professional groups, responsibility for the organisation of educational events rested with the tertiary specialist teams, with reports that 'it's certainly not directed to ourselves, as [paediatric] rheumatologists…we don't have time for that at the moment' FG 7.1; 1115). There was little time for any network educational activities, which the paediatric rheumatologists felt were purely directed at them. This is perhaps not surprising given the few paediatric rheumatologists there are in comparison to the number of other professionals who may be working within the network. These professionals took time, for example as study leave, to attend national or international conferences, or specialised training courses. However, time for additional training and developmental needs of working within a network were requested.

> 'For example, learning and developing training skills, teaching skills ... more in terms of interpersonal skills. … I'd like to develop my skills in terms of managing networks and setting priorities. I'd like to learn how to deal with negotiation, how to deal with conflict within the team.' (INT 4.1; 329)

This request was relevant given the challenges, which arose from professional and organisational boundaries.

9.4 Educational Activities in Clinical Practice

The next section looks at educational activities occurring in clinical practice – in the workplace. There was suggestion from a number of link paediatricians that 'working together on the job learning is much better than just sitting down in a lecture theatre' (FG 8.1; 430), but also it was 'the nature of what medics do a lot of the time' (FG 5.1; 434). This is where an understanding of network structure is key – as the interaction of clinicians and the way that care was delivered created different learning and training opportunities. The workload in paediatric rheumatology is predominately

outpatient based, with children and young people attending hospital for clinic review and therefore I describe the learning opportunities, which occurred around this event. The frequency of local clinics or the frequency of attendance at the specialist hospital, affected the amount of clinical experience that could be gained.

9.4.1 Outpatient Clinics

In Chapter Eight I discussed that there was variation in movement of patients and paediatric rheumatologists between the specialist and local centres, depending on a number of factors. In this section I describe also that some link clinicians travelled to the specialist centre to gain experience in the clinic setting (Figure 23)

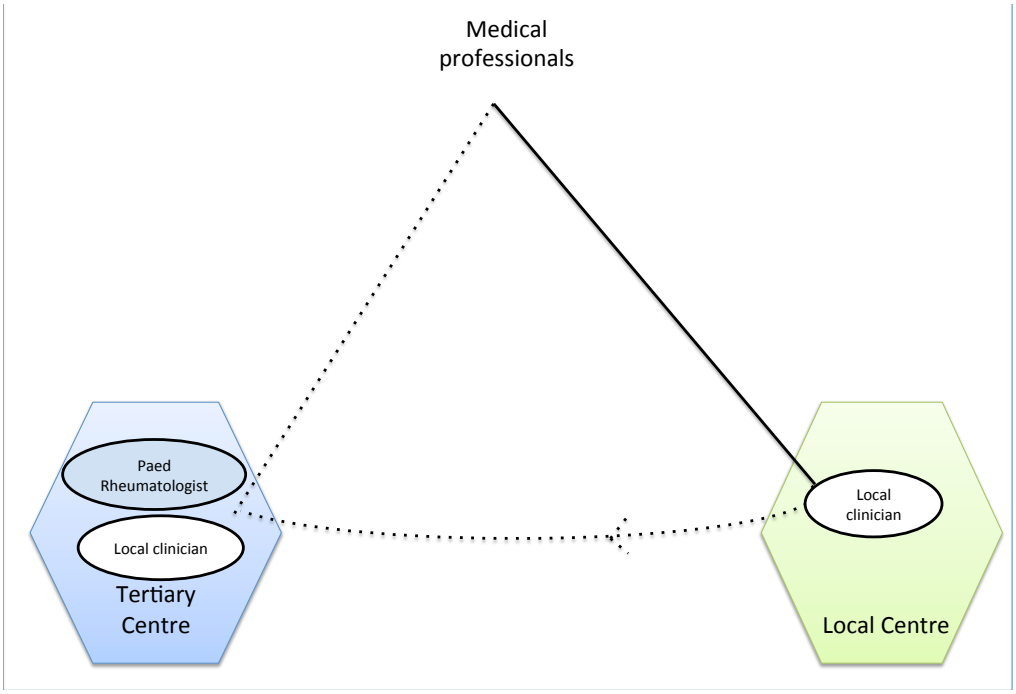


Figure 23 Movement of Local Clinician for Training at the Tertiary Specialist Centre

Some specialist centres offered opportunities for link clinicians from local centres to attend their paediatric rheumatology clinics, enabling 'the[m] to come and sit in in clinics, and then see patients in clinic' (INT 8.1; 478). Some reported that this opportunity enabled them to 'build their skills and to actually work in a [paediatric rheumatology] multidisciplinary team' (FG 4.1; 583). Some link paediatricians had found this beneficial if they were new in post,

> 'to go … particularly early on, to understand about some of the things, when it was appropriate to do certain things' (INT 10.1; 59).

By attending the specialist centre clinics, there were reports that link paediatricians had found it a good way to 'build up your confidence' (FG 9.1; 134).

In networks that had a model of care that involved the paediatric rheumatologist going from the specialist centre to the local centre, there was also potential for learning and training opportunities at the local centre (Figure 24.)

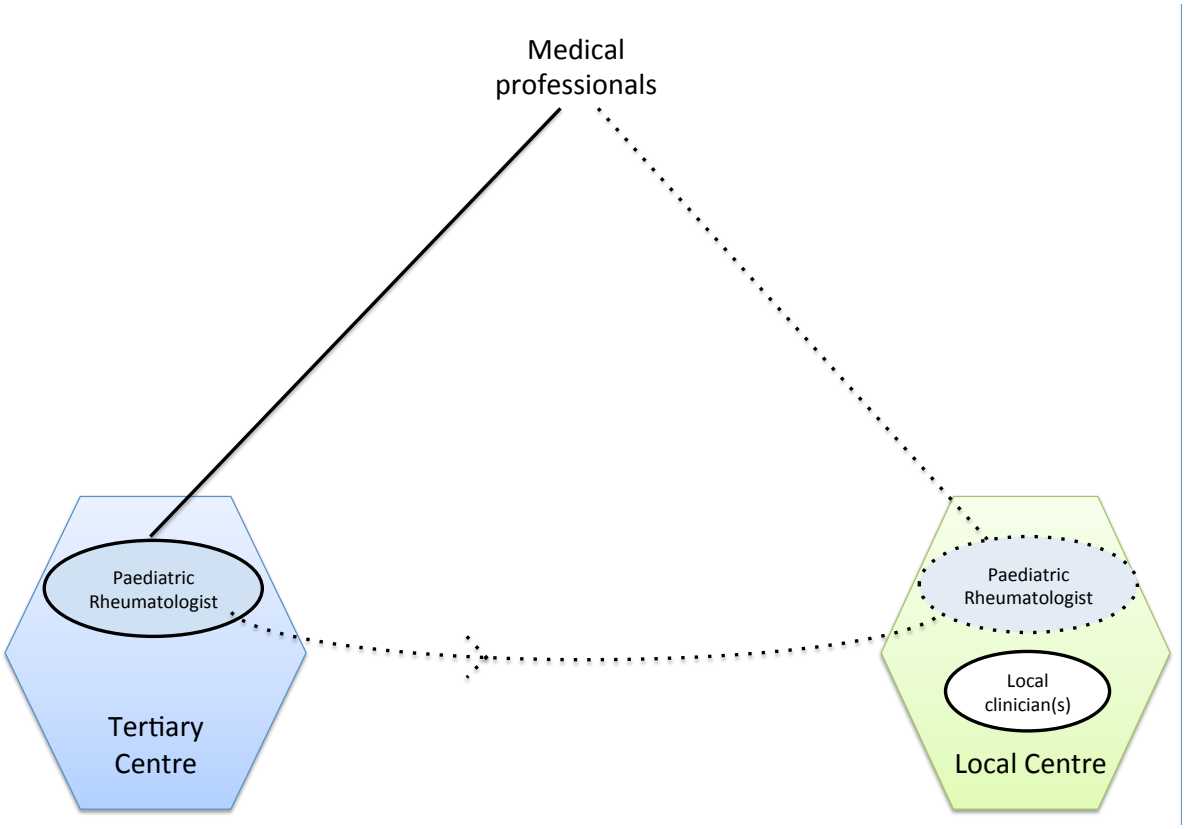


Figure 24 Paediatric Rheumatologist going to the Local Centre

There was a suggestion from one paediatric rheumatologist who delivered care this way that feedback from link paediatricians had been that education which centred on the clinic setting was their preferred way to learn in comparison to the organised educational events.

> 'A lot of [link paediatricians], I think, feel most of their education is around doing clinics together [in their local centre] and discussing patients rather than joining [the more organised educational events]' (FG 7.1; 1158).

This was also the finding with the link paediatricians who reported 'it is learning on the job' (FG 5.1; 460) that they had found the most useful.

When a paediatric rheumatologist and link clinician did clinic together then 'an opportunity was created for all to 'ask about things' (INT 1.1; 149). Depending on the

level of experience and role of the local link clinician and mind-set of paediatric rheumatologist different training and learning opportunities were created. In a network model where the *paediatric rheumatologist delivered specialist care at the local centre with the support from the link clinician* (see Chapter Eight), the paediatric rheumatologist usually led the consultation and made the management decisions. In this case, the clinic created an opportunity for education in the broadest sense – of developing an individual interest in the subject, which was facilitated if 'they have involved me…. by getting me to examine some of the children for example and taking bloods (INT 1.1; 80). The contrasting model in which the *paediatric rheumatologist supported local clinicians (and their team) to deliver specialist care locally* was also reported as supportive of education, but more specific on training to do the job:

> 'We let the local team do the work and make the clinical decisions and support their decisions. Just by doing that, you're allowing them – it's education time for them. To say, "I agree with that. That's good," or, "Have you thought about this?" It's multidisciplinary education. It's drawing the team together… A lot of our clinic time, I think, is not about seeing patients. It's about developing the skills of the local team' (FG 7.1; 490)

For some link paediatricians this way of doing clinics with the specialist rheumatologists which trained them on the job, was akin to an apprenticeship, and over time as their experience and confidence grew, their clinical decision making process evolved.

> 'There is apprenticeship and you kind of do it and then you sort of … confidence build the more you do, the more you see, and you move on from "should I give this one Methotrexate?" to "I have started this one on Methotrexate and actually it is not right now and I think I need to add in the biologic" and I think your decision making grows with your clinical experience'. (FG 5.1; 395)

In this way, paediatricians who had little prior experience (see Chapter Eight) could develop the specific skills required to act as the link paediatrician for paediatric rheumatology and take on more responsibility as time progressed.

> 'I'm four/five/six months down with it and I think I wouldn't have done it without the support' (FG 9.1; 130)

They viewed this training opportunity as invaluable to developing their clinical practice. This 'apprenticeship training' opportunity was available in models where the paediatric rheumatologist 'did clinics' locally with the link clinicians. However, although the network structure may facilitate this opportunity other factors, such as

the clinicians' expectations of roles and responsibilities resulted in variation of this training opportunity being fully embraced.

9.4.2 Immediately Before and After Clinics

The time before or after a clinic was used not only to discuss patients that were being seen/had been seen that day, but also other patients who were known to the clinical service.

> 'That's why we now meet at one o'clock, have a chat, talk about the kids, not necessarily the ones that we're seeing that afternoon, or talk about them, but others who are in the system for an hour.' (INT 8.1; 302)

The 'chat' or 'talk about' here acted as an informal, ad hoc, opportunistic learning and training opportunity, but invaluable to share and impart experience in order to facilitate the clinical management of patients.

Not only did the tertiary specialist doing clinics together (by whatever format) provide learning opportunities for the link clinicians who had or were in the process of developing an interest in paediatric rheumatology, the presence of the tertiary specialist also provided opportunities for other clinicians in the hospital to access specialist advice.

> 'We have one paediatrician who would do the clinic with specifically but it is quite common for the other paediatricians to wander in. Either catch us either at the beginning or the end of clinic and say actually can I ask you about someone I have seen' (FG 1.1; 275).

The regular physical presence of a specialist provided an opportunity for others to discuss clinical cases, and ask whether 'something rheumatological' should be included in the differential diagnosis. As the specialist became increasingly known within the local centre, then local paediatricians discussed increasing number of cases, benefiting other children and young people locally.

9.4.3 In-between Clinic (or if no 'Network Clinic' or 'Outreach' Clinic)

For those who had close physical links between the local and specialist centres in the form of local 'network' or 'outreach' clinics, communication continued (via phone or email) with learning opportunities created when a clinical problem prompted the need for obtain advice in-between clinics.

> 'We go out to [the local centre] every two months and provide an outreach clinic. Within that framework there's the expectation that advice will be

> given in between those clinics. So regularly the general paediatrician who provides that clinic with myself going over there, they will phone or email (INT 5.1; 93)

This facilitated further opportunities to 'talk about patients and shar[e] experiences that way (INT 5.1; 466). For those centres, which did involve doing clinics together, this communication between the specialist and the local centre via e-mail and phone was described as 'hugely' important (FG 8.1 field notes).

> 'In between times, we contact each other by phone or by email. It's easy to get hold of them. We don't do a joint clinic together but I can easily access them if I'm concerned. So I review the patients on my own knowing that they will be seen by [the paediatric rheumatologist at the specialist centre] in three months time' (INT 10.1; 59).

In one network professionals from the local centre also used videoconferencing as a form of communication to contact the specialist centre.

> 'If they [local] are having issues or got something that they want to discuss they will bring it to that meeting and it gives them the opportunity outside of the normal clinic time when we have the outreach clinic to bring any issues about patients they may have seen either as inpatients on the wards over there or in clinic in the recent past. They bring them to that meeting via a video link and there is a two-way discussion about how may be the best way of managing those patients. … that meeting was used to "bounce ideas off each other, look at difficult cases". ... it was set up because there was a perceived need for it so there is that extra input in between recognised clinic sessions' to help with clinical practice … it works well … it helps everybody' (FG 4.1; 506).

Although the date was preplanned (in a similar way to clinics), the content was not as preplanned as the organised educational activities described in the earlier section of this chapter. The content varied as the discussion was dependent on the recent clinical problems the local team had encountered.

9.4.4 Challenges Encountered with (some) Practical Solutions

Similar to the organised educational activities reported above, there were a number of challenges encountered with trying to deliver educational activities (and care) in clinical practice. These challenges not only affected learning and training opportunities, but also the degree of collaboration between professionals and their organisations . I discuss these challenges in turn:

i. Room space and number of professionals

Although doing clinics together may be beneficial for both patient care and training, some clinicians reported a practical problem because of limited space in clinic rooms. This problem could sometimes be overcome

> 'Also we've got a bigger room. To begin with, we just had this tiny room with all these people shoved in and it was really hot and unpleasant but now we've got this huge massive four-bedded ward we see them in' (INT 8.1; 308)

However, not everyone had this luxury and for many there was difficulty providing additional separate rooms for other members of the MDT to see a patient if required. Importantly, some patients also initially found the number of professionals a bit daunting when they conducted clinics together in large groups (see Chapter Eight).

ii. Competition for clinics

In some specialist centres in which the model of care was 'shared' and did not involve the paediatric rheumatologist going to the local centre to do clinics, link clinicians reported that there was competition with other link clinicians to attend clinics in the specialist centre. This problem of competition was encountered both in networks that had a large number of local centres and therefore link paediatricians, and also with other smaller centres that encountered competition in clinics from medical students, paediatric trainees, and members from the wider network MDT.

Although there was recognition from the specialist team of the importance of training health professionals, there were practical difficulties in having extra people sit in with them

> '… in fact I've got a real problem … in that I've got so many people that want to come and sit in that it becomes very disruptive to the clinic. It's a real problem … I think that if you present your clinic as an opportunity for people to come and see something different then they will come, and then they take that back. Then you get more requests and more referrals.' (INT 6.1; 422)

This created a conflict for this clinician who could nevertheless saw the benefits that this training opportunity offered.

iii. Clinical workload

When the clinical workload was high, and the clinic was busy, it affected the learning and training opportunity.

> ‘I went to an outreach clinic last Friday where we had eleven patients in the afternoon and we barely did the job let alone discuss. You know you just don’t have time and I don’t think it is the greatest place for you know supervision and education’ (FG 4.1; 574).

In this example, the participant did not feel that a busy clinic setting was the best environment for education and training, which is in keeping with what others had found if the clinical workload was heavy. One paediatric rheumatologist was aware of the implications of clinic numbers and how they could impact on the educational experience of doing clinics together.

> ‘We seek to keep the numbers in clinic to a degree that the clinic isn’t just about seeing the maximum number of patients, but there’s opportunity to talk about the patients’ (INT 5.1; 450)

It should be noted however, that this clinic was still relatively new in establishment. Other networks, who had set out with similar perspective, had found that overtime the local clinics had got busier and busier.

> ‘We thought that [the tertiary specialist] could do the clinic in the morning and some education after that, but that’s not worked for the last few months … because we had so many patients to catch up and catching up to do’ (FG 9.1; 734).

However, it is not just the patient numbers that impacted on the training or learning opportunities, it is also the length of time spent discussing patients, as one adult rheumatologist described

> ‘We did … discuss very much, and then it was JUST a bit of chaos. Because we took too long discussing things, we’d run horribly behind and then we’d have to split up seeing kids anyway. So [the paediatric rheumatologists would] be seeing somebody on their own while I was seeing somebody in order to catch back up again. So that didn’t really work, so that’s when we had a discussion [to review the situation]’ (INT 8.1; 293).

As a result a meeting was held, and the way that the clinic was organised was modified by reorganising which patients had specialist reviews, with a positive outcome.

> ‘It’s been so much better since we’re not in a busy clinic with people waiting. You’ve got time to talk about the patients and discuss them. I like having the hour beforehand because that’s very informal, and so you know, you can talk about all sorts of different things’ (INT 8.1; 349)

iv. Changing clinical practice

Paediatric rheumatologists had encountered particular difficulties in clinics which where 'done together' with adult rheumatologists, particularly around changing clinical practice. They felt that this was because:

> 'they [adult rheumatologists] were very resentful of [the tertiary specialists] coming and telling them what to do' (INT 7.1; 484)

Although the clinic setting could be viewed as a training and learning opportunity, as one paediatric rheumatologist put it ' there's something about educating and facilitating rather than telling people what to do' (INT 7.1; 520).

In Chapter One, I described paediatric rheumatologists being more aggressive in their management of patients in terms of dosage of methotrexate used and in the use of biologics, than their adult rheumatology colleagues. There were reports that changing clinical practice in this area was hard. In this situation, one paediatric rheumatologist had felt the only way to change a patient's management was to take the child out of the local service and review them at the specialist centre. This approach

> 'undermined [the local team]…. and it undermined them VERY visibly to the parents Actually, [the local team] were well liked by the families and families reported back to them. They would get a phone call from the family of a child who had been to [the tertiary centre] to be told, "Well, [the tertiary centre] says you're doing this all wrong…." This resulted in a complete stand off with the local adult rheumatologist, essentially, saying they wouldn't work with the network anymore, which we felt was not in the patients' interests' (INT 7.1; 456; 524).

As a consequence, another paediatric rheumatologist took over supporting that clinic, and gave the adult rheumatologist an opportunity to discuss what input they wanted. The solution found was to do something completely different. Instead of doing a joint clinic together, they organised a specific teaching clinic. This teaching clinic is described in the except below:

> 'They didn't want me [tertiary paediatric rheumatologist] to come along to their clinics and see lots of patients. Their suggestion was that they set up some separate, what they designated as 'teaching clinics', and they would just invite along patients that they wanted to discuss. They were setting aside additional time to do that, so they were set up out with their normal clinic structure. Actually, in terms of shifting mind-set, that's been incredibly positive. So, I'm not going to their clinics. I'm not telling them how to manage their patients. I'm seeing patients that they select they

> want to discuss, and we're looking at them together and discussing how I would do things, how we would do things and how they're doing things. Just that discussion around a relatively small number of patients has led to a huge shift in thinking locally. … You could say my time is not very well spent because I go over and will see maybe four patients. What it has led to is a recognition by that team that they don't know how to examine or manage the very young children and that they need help with that.' (INT 7.1; 493)

This was a non-threatening way of 'doing clinic together' resulting in a perceived shift towards a more paediatric management approach.

v. Tensions in clinic

There were other sources of potential conflict reported and if there was a tense atmosphere in clinic between clinicians then this was found to be a barrier to training and learning. Some reported that doing clinics together resulted in:

> 'Tensions about feeling that you're being watched or judged as to how you're managing and that sort of thing. You see, if I was a very brash person, I probably wouldn't give a monkey's, but you know … (Laughter) So that's why I say it comes down to personality and the other person's personality, and so therefore how it actually works in the clinic' (INT 8.1; 316)

A number of tensions were mentioned, for example, if the link clinician also perceived themselves as a specialist, or if there was an inexperienced specialist working with an experienced link clinician (INT 9.1; 440).

vi) Trusting colleagues and the influence of historic events

Some tertiary specialists acknowledged that they had found it hard to manage cases 'at a distance', particularly for 'high risk cases', for example a child with systemic juvenile idiopathic arthritic with suspected macrophage activation syndrome (MAS).

> 'So if you've had a bad experience of a patient going into MAS, then you're much more concerned to see the patients here [at the tertiary centre], rather than letting them be seen locally. So yes, there's also past experience that influences it'. (INT 2.1; 378)

For the tertiary paediatric rheumatologists to decide whether or not a child or young person 'can' be managed locally, not only depended on the skill mix and resources available locally, but it also whether there was trust. This was influenced by whether or not professionals knew each other as well as previous clinical encounters.

> ‘They[the local clinician] should have picked up the phone and talked to us earlier and said "We're concerned about this patient, you need to see….but they didn’t" (INT 4.3 283)

However, as one paediatric rheumatologist pointed in relation to educating and training professionals to deliver care in a network

> ‘it’s establishing that trust and communication that it’s all about…. I think there’s there is a learning curve of learning to trust each other (INT 7.1; 666).

Educational activities which facilitated ‘getting to know’ each other, as well as working together in clinical practice helped develop trust over time, between professionals which was deemed important for collaborative working.

9.5 Discussion

In this chapter I have described the continued professional development and training opportunities for medical professionals that were present in clinical networks reviewed in this study. This chapter confirms that clinical networks can provide an infrastructure to support the education of health professionals (Edwards, 2002). The findings from this chapter raise some interesting areas for discussion.

There was evidence of organised educational activities present in all networks surveyed. However, their importance to individuals depended on other network learning and training opportunities available. For networks that ‘shared care’ and did not involve network or outreach clinics, these organised educational activities provided were fundamental for colleagues to get to know each other which is recognised to be important for collaborative working (San Martin-Rodriguez *et al.*, 2005). Interestingly, there was suggestion that ‘getting to know’ colleagues was also possible through virtual means such as videoconferencing, perhaps because it permitted them to manage better competing demands when time was limited.

The findings that organised educational activities generally were targeted at a MDT audience supports the recognition and importance of the paediatric rheumatology MDT (Davies *et al.*, 2010) and also suggests that the education and training of medical professionals should not be looked at in isolation. The difficulties encountered in pitching to a multidisciplinary audience may be outweighed by the additional benefits that may result when groups meet together such as the development of working relationships. Some placed this as more important that the educational content of the meetings.

The issue of limited time and workforce resources, with clinical workload pressures is a recognised barrier not only for those involved in the delivery of education and training, but also those who it is intended for (Curran *et al.*, 2006). Although clinical networks may indirectly help the work force shortage that is known to exist (H. E. Foster *et al.*, 2011b), as discussed in Chapter One, a challenge still remains to ensure all the health professionals working within the network are appropriately trained and have access to continued professional development (Davies *et al.*, 2010; RCPCH, 2012a). Education and training of professionals in networks therefore has implications for job plans. Although initially the direction of education was 'hierarchical' from the specialist centre, over time as experience was developed locally, a wave of education from the local centres was evident, and may be another potential solution to part of this problem.

The findings of the request for help in managing conflict and negotiation are particularly important, given the challenges encountered relating to professional and organisational boundaries and territories of clinical practice. Furthermore the difficulties encountered in delivering education and training suggests a need for guidance in this area and gives further confirmation for the need for this study. However, the findings in this chapter reveal that 'education in a clinical network' is complex and is dependent of different needs and opportunities, which may arise from the different way that care is delivered.

The complexity of the situation may be helped understood (in part) by reflecting upon the work of the social learning theorist Etienne Wenger-Trayner. I briefly touched on his work in the introductory chapter by reference to Wenger and Lave (1991) who described the concept of community of practice in relation to situated learning. Wegner-Trayner has since then re-conceptualised communities of practice towards landscapes of practice (2015). He suggests that 'the human world may be viewed as a landscape, which contains a collection of hills or communities of practice, some of which are more noticeable than others'[11]. Different professionals (in this study from different backgrounds such as adult rheumatology, paediatrics or paediatric rheumatology) make up these communities and which have their own history and regimes of competence. Our learning may be understood as a trajectory through landscapes of practices: 'entering some communities, being invited or rejected,

[11] From abstract of talk 'Learning in and across Landscapes of Practice, Lancaster University, 5.4.2011)

remaining visitors, crossing boundaries, being stuck and moving on' [12]. The metaphor is engaging and touches a recurrent theme throughout this thesis of professional and organisational boundaries.

Wegner-Trayner suggests that communities of practice as well as boundaries may offer opportunities for learning, but also raises that they both be places of misunderstanding, confusion and conflict ((Wenger-Trayner, 2015), page 17). The findings from this study, as well as others, have found that boundaries (professional, social and cognitive) have an inhibitory effect on organisational change and how knowledge and new work practices may be spread (Ferlie *et al.*, 2005).

9.6 Conclusion

Clinical networks can provide an infrastructure, which may support the education of health professionals, confirming what Edwards (2002) previously reported. However, this study has shown that 'education of health professionals' in a clinical network for paediatric rheumatology is complex. Not only do the health professionals have differing educational needs but also, depending on the network structure, different learning and training opportunities are available to them. The problems and therefore the solutions are context specific. Furthermore, there may be influence of professional and organisational boundaries, which may inhibit health professional engagement in educational activities as well as learning and training. These findings are important to consider when developing an educational framework to support professionals delivering care for children and young people with JIA within a clinical network. Amidst this complexity this study highlights the importance that educational activities play in facilitating an opportunity for colleagues to 'get to know each other', a key facet in collaborative working.

[12] From abstract of talk 'Learning in and across Landscapes of Practice, Lancaster University, 5.4.2011)

Chapter 10. Development of an Educational Framework

10.1 Introduction

In this penultimate chapter I first summarise the findings from the individual empirical chapters of my thesis (Chapters Five to Nine). This is followed by a discussion about a common theme that runs through all the chapters relating to the influence of professional and organisational boundaries. I then discuss from these findings the 'kind of guidance' that may be useful for medical professionals establishing clinical networks to deliver optimal care for children and young people with JIA. The rationale behind adopting the design of an existing educational framework to present my findings, which attempts to takes into account the complexity of the subject is then described. The chapter ends with the production of an educational framework to guide medical professionals establishing clinical networks to deliver optimal care for children and young people with JIA, fulfilling the aim of my study.

10.2 Summary of Key Findings

In this section I briefly summarise the findings from each of the empirical chapters (Chapter Five to Nine).

10.2.1 Chapter Five: The Rationale for Establishing Clinical Networks

The first empirical chapter (Chapter Five) described the historical landscape of the clinical networks studied. This set the scene for the basis of my study, and contextualizes the challenges described during the processes of establishing clinical networks, delivering care within them, as well as educating and training the health care professionals involved. The detailed description of how care used to be delivered, and the experiences of those involved adds to the existing literature about the evolution of the specialty of paediatric rheumatology (Woo and Petty, 2011).

I identified that the medical professionals who were historically involved in the management of children and young people with JIA across the UK were from different clinical backgrounds (including adult rheumatology, paediatrics and orthopaedic surgery). This situation persists today with a variety of professionals from different clinical backgrounds involved in today's services for children and young people with JIA (NRAS, 2014). Similar to Foster's (2011) observation, I demonstrated that adult rheumatologists had been key providers in rheumatological expertise for children and young people, as paediatric rheumatology was a relatively 'new'

speciality. My research found that the role played by some adult rheumatologists was acknowledged and appreciated by the paediatric rheumatology MDT; there was recognition that adult rheumatologists had historically been the key care providers due to the paucity of paediatric rheumatologists at the time. I also confirmed previous anecdotal reports by Foster and Rapley (2010) that the adult rheumatologists and other professionals delivered services often with limited resources.

I established that some adult rheumatologists who had been managing children and young people with JIA for a number of years had developed a 'paediatric' interest, and for some it was more than just an interest; rather it had become *their* area of clinical practice, which they enjoyed. This observation became a key finding because it contextualises the territorial behaviour and resistance encountered during the process of establishing links between professionals and their organisations in the form of a clinical network.

I revealed that as the specialty of paediatric rheumatology expanded with the development of specialist MDTs based in the tertiary paediatric centres, there was concern from those working in the specialist centres about a discordance in the standard of care for children and young people with JIA, between those managed 'in' the specialist centre and those managed 'out with' them. This discordance was particularly highlighted by the variations in access to specialist MDTs, but I also identified other reported examples of 'suboptimal' care, which occurred at multiple points along the patient's journey, across all of the study regions. These included inadequate provision of information; developmentally and environment inappropriate care; untimely drug treatment; inexperience in managing on-going active disease; delay to correct diagnosis and inadequate treatment and screening regimes.

These findings confirmed that there had been a need to develop services for children and young people with JIA across the country. This provided the rationale not only for clinical networks to be established, but also evidence that there had been a need to educate and train professionals involved in the care of children and young people with JIA.

10.2.2 Chapter Six: The Journey towards Establishing Clinical Networks

In Chapter Six I described the journey towards establishing clinical networks. In doing so I identified that professionals had encountered a number of challenges and particularly paediatric rheumatologists had been 'feeling their way', interpreting

situations that they encountered on their own, as they had no framework to reference. I discovered that 'establishing a clinical network' first involved an engagement process between the tertiary centre and local centre, to get professionals and their organisations on board to consider changing the way services were delivered to try and improve care. I identified that professionals had used a number of different approaches, and for many it took a long time, suggesting that it had not been simple process. I found however that the BSPAR/ARMA Standards of Care for children and young people with JIA had been a key document used during discussion with managers and professionals to help support service development changes.

There is already recognition that a degree of persuasion may be needed to convince people that a network model is the best way to deliver high quality, efficient and effective services (RCPCH 2012b). My findings do not dispute this, with evidence that in some situations gentle persuasion was all that was required. However, in other circumstances more action was needed, particularly when areas of clinical practice and hospital services were (or were perceived to be) threatened. This resulted in lengthy and often difficult encounters by those people trying to engage professionals to link together. This is an important area to address, because any factor that inhibits professionals linking together will ultimately influence the level of, and access to, specialist care for children and young people with JIA.

10.2.3 Chapter Seven: New Links for Care and Education

In Chapter Seven I reviewed the process of introduction, and the consequences of introduction, of clinical networks to help understand the developmental needs of medical professionals in the context of the evolution of clinical networks. For a number of children and young people I identified that clinical network establishment had achieved care provision more in line with the BSPAR/ARMA Standards of Care. I revealed that transformation in care was not the only consequence of the network establishment. There was also evidence of new links between professionals and organisations to deliver (and receive) education and training, I demonstrated that the creation of new links for care and education benefited patients, their families, health professional and the specialty as a whole, and that these links were interrelated.

Just as it has taken time for professionals and organisations to engage in the process of linking together, (see Chapter Six), I found that it has also taken time to change the way that care is delivered so that children and young people with JIA have

access to specialist MDT care. I identified that establishment of clinical networks has not been without challenges; old and new problems have been encountered. For example, although clinical networks might facilitate access to specialist care, they are not the panacea to all the problems associated with suboptimal care. Unless there is a critical workforce mass (both at the tertiary and local centre) then it is difficult for care delivery to be maintained in a clinical network.

Crucially, I demonstrated that the establishment of a clinical network is actually a process that must be on-going in order to address change and to deal with areas of care still to be developed (not only at the local centres but also with in the tertiary centres). This included the need to address the education and training needs of the professionals involved, because these needs will change over time, for example as professionals are appointed to new posts and levels of expertise develop. I found that progress in the goal of delivering optimal care also depended on the degree of resistance from both professionals and also patient families to change. Many of the benefits, problems and challenges encountered relating to network establishment were dependent on the network structure. The way that care was delivered, the different people involved, where it was delivered, as well as resources available to deliver the care subsequently became a focus for understanding the support and guidance required for medical professionals.

10.2.4 Chapter Eight: Network Structure

In Chapter Eight I described the structure of paediatric rheumatology networks and detailed the variations in ‘where’ care was delivered, ‘who was involved’ and ‘what’ the terms used to describe care delivery actually meant in clinical practice. I demonstrated that structure terminology can be confusing and suggested that a shared language or detailed explanation about what a term meant in clinical practice may prevent misunderstandings during service development and collaborative working.

I revealed that network structures are complex and ‘messy’; care for children and young people with JIA was delivered in different places, for different reasons between local and specialist centres, and was provided by a number of medical professionals (and the MDT) from differing clinical backgrounds who had differing levels of expertise. This variation was not only evident between networks, but also importantly, within individual networks.

I identified that links between professionals and their organisations were continually evolving. They had a dynamic element, with evidence of being in states of change. Not only did different network structures give rise to clinicians having different roles and responsibilities, as networks evolved these roles and responsibilities also changed. I found that professionals had different mind-sets of how care could or should be delivered in a network, and that these beliefs influenced relationships and collaboration between the local and tertiary centres and the clinicians involved.

These findings relating to variation in network structure, 'who' was involved and 'where' care was delivered, as well as the dynamic nature of networks, and clinician's mind-set of how care could or should be delivered introduced the 'it depends' factors. These factors complicate the guidance for medical professionals establishing and delivering care in a clinical network for children and young people with JIA.

10.2.5 Chapter Nine: Educational Activities

In Chapter Nine I described the educational activities (continued professional development and training) that were present within the clinical networks studied. I confirmed Edwards's (2002) findings that clinical networks can provide an infrastructure to support the education of health professionals. I revealed that a portfolio of educational opportunities and activities existed consisting of organised educational events as well as training and learning opportunities in the work place, during every day clinical practice.

I found that different ways that care was delivered - the clinical network structure (see Chapter Eight), gave rise not only to different learning and training opportunities for medical professionals, but also different educational and training needs. This was recognised to be a challenge when organising and delivering education and training for professionals working in a clinical network. A number of other challenges were identified including addressing the educational and training needs of the wider MDT, encouraging attendance at educational events, the limitations of time, space and geography, as well as the influence of professional boundaries on the engagement in educational activities and changing clinical practice. I described potential practical solutions to these problems, which had been suggested by professionals who had experience of these challenges.

I identified that educational activities, in what ever form or by what ever means, facilitated an opportunity for colleagues to 'get to know' each other. This was a key

facet of collaborative working that was deemed integral to delivering care across organisations. However, I also showed that changing clinical practice wasn't the easiest of processes, and for some tensions in clinic between professionals could inhibit learning and training. I concluded that educating and training medical professionals involved in the delivery of care in a clinical network for children and young people with JIA was complex. The problems and therefore the solutions are context specific. These findings were important to consider when developing an educational framework to achieve my study's aim.

10.3 Discussion of Findings

In this section I first discuss a common theme that ran through all the chapters relating to the influence of professional and organisational boundaries on establishing clinical networks, delivering care within them, as well as educating and training the health professionals involved. I then return to the aim of this study and discuss from my findings 'what kind of guidance' is needed. I discuss how the guidance needs to take into account the complexities that I revealed relating to how care delivery occurs in clinical networks.

10.3.1 Professional and Organisational Boundaries

I found a common theme that emerged through all the empirical factors, which related to the influence of professional and organisational boundaries. Within the formal definitions of a clinical network[13] (Scottish Executive Department of Health, 1999, RCPCH 2012a) there is acknowledgement and inherent recognition that professional and organisational boundaries exist, and that in order to deliver care in a clinical network they need to be unconstrained. The findings from my study confirm that professional and organisational boundaries in clinical networks for children and young people with JIA very much exist, and can influence the interrelated clinical network processes of linking professionals and organisations together, delivering care, and educating and training those involved. In keeping with the literature they

[13] '[Clinical Networks are:] linked groups of health care professionals and from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by *existing professional and organisational boundaries* to ensure equitable provision of high quality effective services' (Scottish Executive Department of Health, 1999)

have impeded the effective implementation of organisational change (Currie 2007), and have the potential to jeopardize the provision of safe, high quality patient care (Nembhard and Edmondson, 2006; Hewett *et al.*, 2009; Martin *et al.*, 2009; Dixon-Woods, 2010; Powell and Davies, 2012).

From the literature it is not entirely clear exactly what '*professional* or *organisational* boundaries in healthcare are,' but the terms professional and organisational are frequently used synonymously. In Chapter Five I introduced the work of Abbott (1988) who outlined that boundaries between professional groups and their jurisdictions of work are the consequences of the system in which groups claim authority over an area of practice in the work place. They demarcate territories, roles and responsibilities. Where jurisdictions or scopes of practice overlap then individuals or groups are reported to stake a claim over *their* area, and may exhibit territorial behaviours. These boundaries may also influence belief systems particularly if there are evident or perceived differences in service standards between the tertiary and local centres. The notion that 'our service is better' may come from a professional perspective, believing that one's own professional group, services or hospital is 'superior' to another creating tensions between individuals and organisations. Although this concept is more familiar in the context of inter professional education (Pecukonis *et al.*, 2008), there may be lessons learnt by developing a shared understanding of the ultimate goal and exploring ways to improve services together. Having an awareness of this and a knowledge of barriers to change is fundamental to enabling change to occur and to the development of strategies to manage change (NICE 2007) .

10.3.2 The Need for a Guide

The findings throughout Chapters Five to Nine confirm that medical professionals across all study sites have some shared experiences in the process of establishing clinical networks, delivering care within them, and educating and training (or being educated and trained). A number of these professionals reported these processes to be challenging. As discussed previously my findings revealed that professionals had been interpreting these situations on their own and had no framework to guide or reference their actions, often just 'feeling their way'. This confirms the need, 'the call' described in Chapter One, to develop guidance for these professionals.

In Chapter Six I described that guidelines already exists (RCPCH 2012b) for professionals 'establishing and managing successful networks for children's health

services'. However, I highlighted that this document gives little practical guidance. The findings from my study therefore supported the need to develop this practical guidance, particularly around organisational change. I describe in the following section that because of the complexity of networks a 'one size fits all' practical guide is not the answer, rather this guidance should include "things to think about when…" in the form of *considerations* that depend on certain contexts*,* with "suggestions for solutions to problems that may be encountered" in the form of *practical tips.*

10.3.3 Complexities of Clinical Networks

Throughout the empirical chapters I reported findings relating to clinical networks '*for some* children and young people.' Or '*for some* professionals.' etc., with the caveat often that 'it depends on.' It was apparent that in order to fully understand the developmental needs for medical professionals involved in establishing clinical networks to deliver care for children and young people with JIA I needed to understand in detail network structures and the ways that care was delivered. I acknowledged in Chapters One and Seven that no network structure is the same, (Guthrie 2010), and the findings described in Chapter Eight support this. Guidance for medical professionals establishing clinical networks to deliver optimal care for children with JIA, and for educating and training those involved, is therefore complex and 'it depends on' a number of different factors relating to how care itself is delivered (where and by whom). To take account of these complexities I chose to adapt the design of an existing educational framework to form the basis for my own framework and in the next section I discuss the rationale behind this decision.

10.4 Educational Framework Design Template

In search for a way to present the guidance that my research had identified, and that took into account the complexities discussed in the previous section, I undertook a literature review on educational framework designs. I found that the majority of medical educational frameworks were designed for defined groups of learners from the same professional background, and that most of these educational frameworks covered curricula for specific topics (A. K. Brown *et al.*, 2007). However, I did find one framework by Dijkstra *et al.* (2010) for programmes of assessment of medical competence that addressed (or attempted to address) the issue of complexity of different groups of learners and situations (Figure 25). Dijkstra's framework design

was suited at least in part to addressing the level of complexity I identified relating to clinical networks, as I will demonstrate.

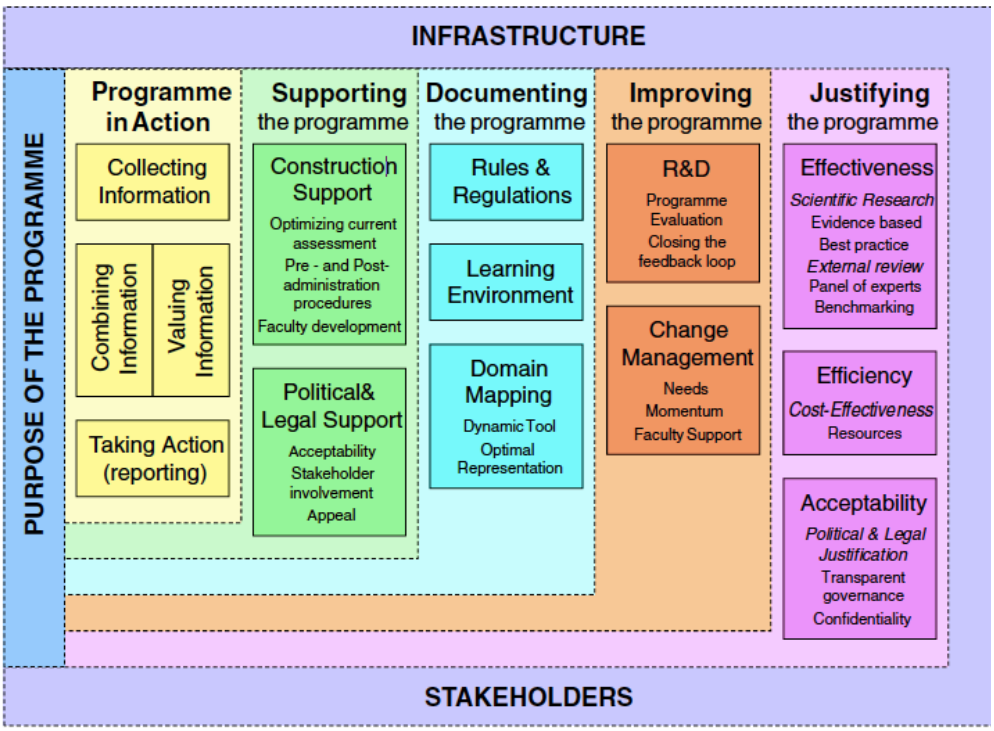


Figure 25 Dijkstra's Framework for Programmes of Assessment

Dijkstra *et al.* acknowledged that assessment of medical competence was complex and that no single assessment measure could ever provide all the information required for a comprehensive evaluation of medical competence. Dijkstra *et al*. concluded that to assess competence different approaches were needed to encompass different strands depending on the stakeholder or the infrastructure. In doing so Dijkstra *et al*. developed a framework that was made up of *framework layers* and introduced a *fitness for purpose principle* for it's applicability stating that the relevance of their framework was determined by the extent to which it fulfilled its purpose or function. Their framework had been devised using similar qualitative methods to my study, and although their framework was not a perfect template, because my study was not about assessment, the concepts of *framework layers* and of the *fitness for purpose principle* had transferability to my study. In the next section I describe these two concepts in more detail.

10.4.1 Framework Layers

Dijkstra *et al.* divided their framework into a number of conceptual layers, illustrated by different colours (Figure 25). These layers represented different aspects of the

assessment programme. They described first the *purpose of the programme, (*blue coloured layer), as the key element in their framework. The key element being 'the overall purpose' around which all aspects of the programme revolved. Linked to *the purpose* were five *inner layers,* yellow, green, light blue, orange and pink coloured layers, that consisted of a number of different programme elements and approaches. An outer layer of *stakeholders* and *infrastructure* (purple coloured layer) surrounded these inner layers. Dijkstra *et al.* purposely placed the layered elements and approaches inside, 'in the context of,' the outer layer and in doing so conveyed that there should be a relationship between all the layers. This indicated that the programme of assessment elements and approaches were dependent on different people (*stakeholders*), places, set ups and situations (*infrastructure*). Dijkstra *et al.* also described that in different contexts there may be advantages, compromises and trade-offs of the different programme elements and approaches.

This layering concept had transferability to my study, because it conveyed relationships, the 'it depends' factor.

10.4.2 Fitness-for-purpose principle

Dijkstra *et al.* included a *fitness-for-purpose principle* in their framework. They discussed that the relevance of the framework was inextricably linked with the purpose or goal, but those goals may be different for different stakeholders. They avoided specific content references such as 'should contain' and included references such as 'the need for x, y, z… should be considered in light of the purpose'. In different contexts, whoever is using the framework may decide how relevant or important the content is.

The *fitness-for-purpose principle* had transferability to my study; medical professionals who use the framework may decide the importance or relevance of the guidance depending on specific contextual circumstances, for example their clinical background or the way that their network delivers care.

10.5 Educational Framework Design Adaptation

In this section, I describe the adaption of Dijkstra's educational framework design, building it up in a series of diagrams, to produce a framework design on which I can 'hang' or rather present, the findings of my study.

10.5.1 Purpose of the Guide

The key element of my framework is the *purpose of the guide*, being the overall purpose around which all aspects of guide revolve (akin to Dijkstra et al's *purpose of the programme*) (Figure 26). The *purpose of the guide* provides clear reasons for what and whom the guide is intended, why it has been developed, how it should be used, and what it hopes to achieve. A detailed summary of the purpose of the guide is provided in section 10.6.1.

Figure 26 Purpose of the Guide - Key Framework Element

10.5.2 Inner layer elements – processes involved

From the challenges encountered by medical professionals that I have demonstrated, this study has revealed that guidance for establishing clinical networks to deliver optimal care would be helpful for three related processes (akin to Dikjstra's et al.'s inner layers elements). These processes include

- Establishing links between professionals and their organisations
- Delivering care
- Educating and training

These processes are illustrated in Figure 27, where the framework inner layers are all connected to the *purpose of the guide.*

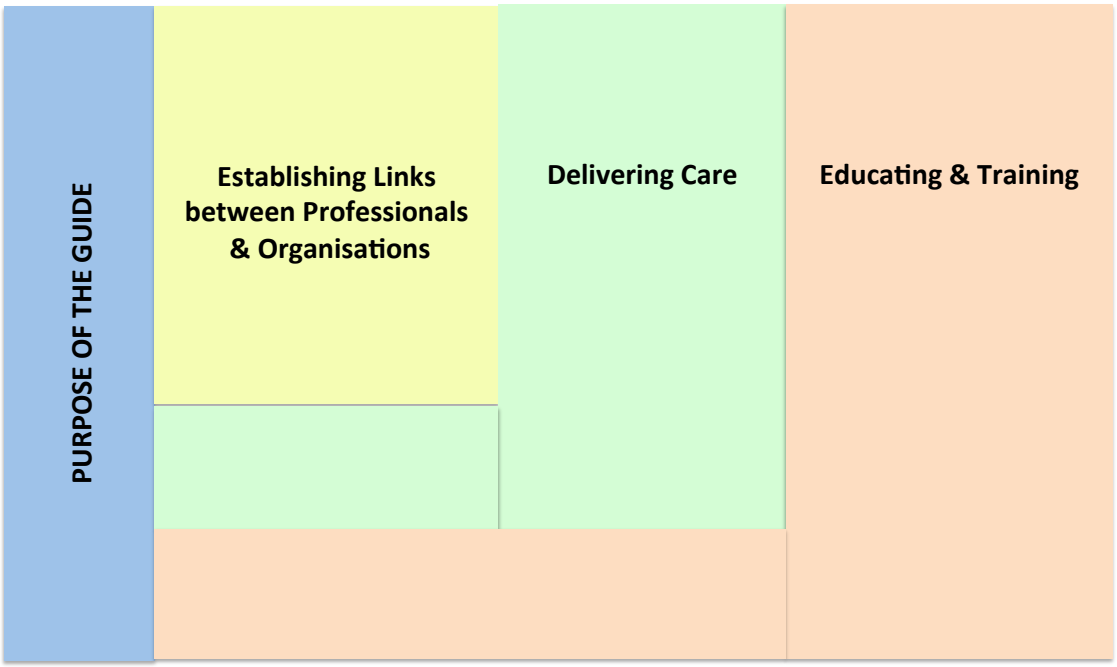


Figure 27 Processes involved in delivering care for children and young people with JIA in clinical networks - inner layer elements

A detailed summary of the guidance for these processes is provided in sections 10.6.3, 10.6.4, 10.6.5 and includes description of "things to think about when…" in the form of *considerations,* in combination with "suggestions for solutions to problems that may be encountered" in the form of *practical tips.*

10.5.3 Outer layer - context

The processes involved (inner layer elements) in establishing links between professionals and their organisation, delivering care, educating and training, are context dependent. By this I mean that they are dependent on a number of factors relating to both *network structure,* akin to Dikjsta's et al.'s *infrastructure,* and to the *medical professional* group, akin to Dikjsta's et al.'s *stakeholders*. I have therefore purposely placed the processes involved (inner layers) inside the context (outer layer) to convey this relationship (Figure 28).

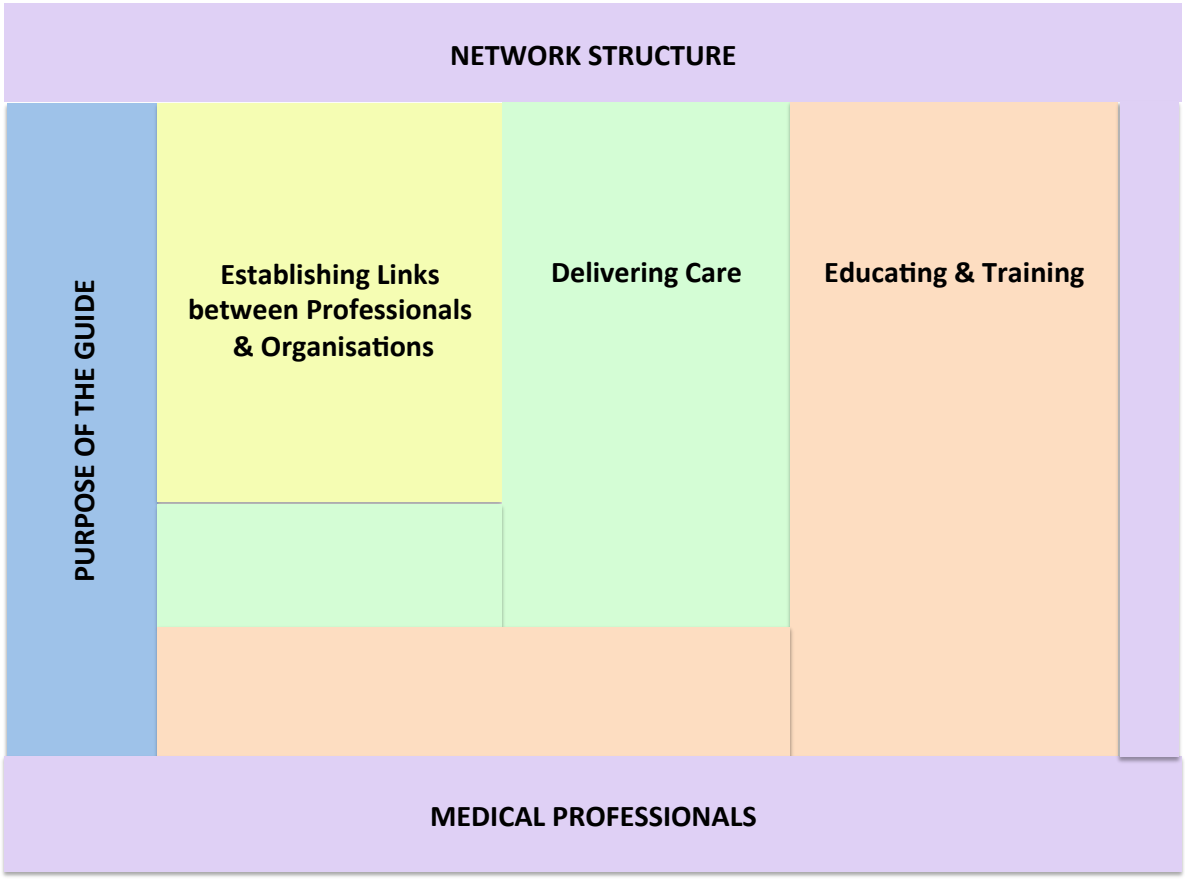


Figure 28 Outer and Inner Layers

The ‘networks structure’ and ‘medical professional’ context of the framework, the ‘it depends’ outer layer of Dikjstra’s work, includes the variation of medical professionals background, clinical experience, roles and responsibility, the combination of professionals involved in delivering care, geography and location of where care is delivered, work force resources, the mind set or belief system of the way that they think care ‘should’ be delivered. The outer layer may also include ‘other’ factors, which are important and pertinent to individual networks and were not captured in the networks studied or during the study period. Many of the ‘it depends’ factors are interrelated and I have therefore adapted the outer layer to have a concertina effect to illustrate this inter-dependency (Figure 29).

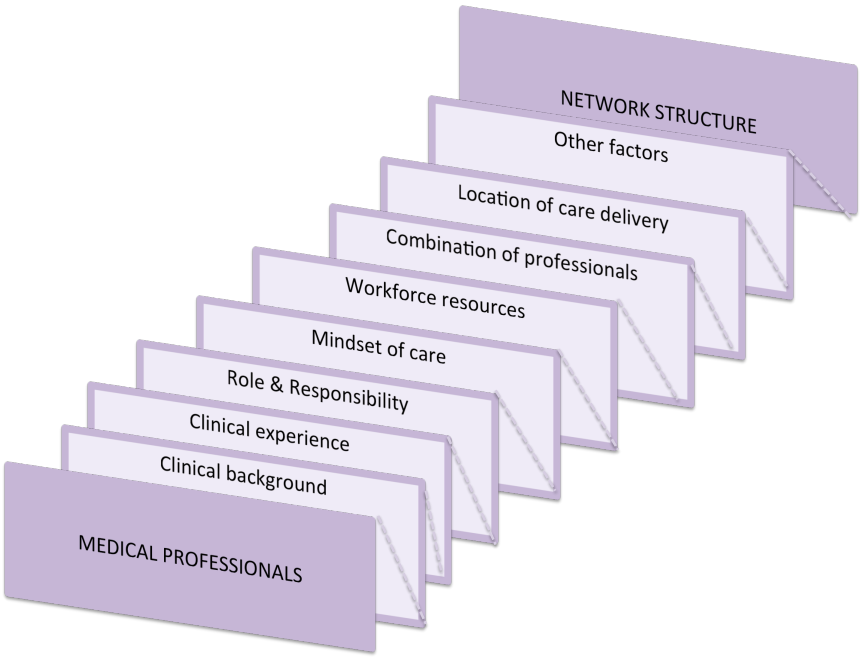


Figure 29 Outer layer factors

10.6 An Educational Framework to Provide Guidance for Medical Professionals Establishing Clinical Networks to Deliver Optimal Care for Children and Young People with JIA

In this section I present the content for the framework elements. In contrast to the visual boxes used by Dikjstra to summarise their programme parts I have used succinct statements in colour-coordinated tables to provide a more user-friendly way to visually present the findings of my study. I include an explanation of the *purpose of the guide (Section 10.6.1,* Table 15*)* and the context - outer layer concertina of interrelated factors relating to network structure and medical professionals) (Section 10.6.2, Table 16). I then present the guidance content for the inner layer elements; guidance in the form of *considerations* and *practical tips* for establishing links between professionals and their organisations (Section 10.6.3, Table 17) delivering care (Section 10.6.4, Table 18) and educating and training (Section 10.6.5, Table 19).

10.6.1 Purpose of the Guide

PURPOSE OF THE GUIDE	• The overall purpose of this guide is to provide guidance for medical professionals establishing clinical networks to deliver optimal care for children and young people with Juvenile Idiopathic Arthritis (JIA). • Clinical networks are defined as 'linked groups of healthcare professionals working in a coordinated manner, unconstrained by existing professional and organisational boundaries to ensure equitable provision of high quality effective services'. • Optimal care is care that is defined by the BSPAR/ARMA Standards of Care for children and young people with JIA.
	• The reason for the development of this guide is because medical professionals involved in establishing clinical networks to deliver optimal care for children and young people JIA have found the following interrelated processes challenging*:* - Linking professionals and their organisations together - Delivering care - Educating and Training
	• This guide has been developed and is intended for medical professionals – specifically paediatric rheumatologists (based at the tertiary centre) and linked clinicians - paediatricians and adult rheumatologists (based at local centres). • It has been devised from interviews and focus groups with a range health professionals from the MDT, young people with JIA and their families across the UK. • It may be of relevance to other medical professionals, members of the MDT and management involved in service delivery and care provision for children and young people with JIA in clinical networks.
	• This guide is in the form of *considerations and practical tips*. Due to the complexities of networks it is suggested that the user of the guide applies the 'fitness-for-purpose principle'. This principle allows the user to decide how relevant or important the guidance is depending on specific contextual circumstances.
	• It is hoped that this guide facilitates the establishment of clinical networks to deliver optimal care for children and young people with JIA, and provides a starting point for discussion between professionals and their organisations if challenges arise.

Table 15 Purpose of the Guide

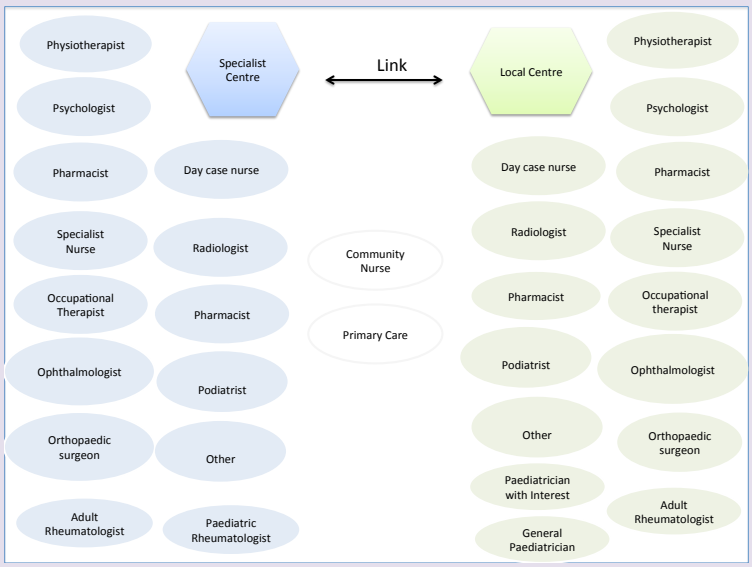
10.6.2 Context: Medical Professionals and Network Structure

MEDICAL PROFESSIONALS & NETWORK STRUCTURE

- The guidance for medical professionals establishing clinical networks to deliver optimal care for Children and Young People with JIA is complex as no clinical network is the same.
- There a number of interrelated factors – the context, which may influence the challenges encountered (and therefore the support required) whilst establishing links between professionals and their organisations, delivering care, and educating and training professionals involved.

PROFESSIONAL BACKGROUND

- Professionals come from different clinical backgrounds illustrated below.



- Clinical networks 'link' these professionals from different backgrounds together.
- These professionals from different professional backgrounds may be based at the specialist/ tertiary centre (tertiary hospital) and/or local centre (local hospital) or in the community (primary care).

CLINICAL EXPERIENCE

- Medical professionals who are managing the care of children and young people with JIA will have varying degrees of clinical experience.
- Some general paediatricians who take on being the 'link' clinician at the local centre may not have had any formal training in paediatric rheumatology, but there may be others who have had more experience, and have developed an 'interest' in the specialty.
- Many of the adult rheumatologists have generally been involved in the management of children and young people with JIA for a number of years.
- Paediatric rheumatologists may have only just been appointed to their first consultant post and others may have a number of consultant years of experience.

ROLE & RESPONSIBILITIES

- Depending on 'where' and 'how' the care is delivered, professionals may have different roles are responsibilities (and therefore influence the educational and training needs of professionals involved).
- Some locally based link clinicians may have responsibility for the all patients with JIA in their geographical region. The tertiary specialists support the management of the care of these patients. For others the responsibility may rest entirely with the paediatric rheumatology specialist team. For other the responsibility may be shared.
- Roles and responsibilities may changes over time, as service needs change and clinical experience is gained.

MIND SET OF CARE

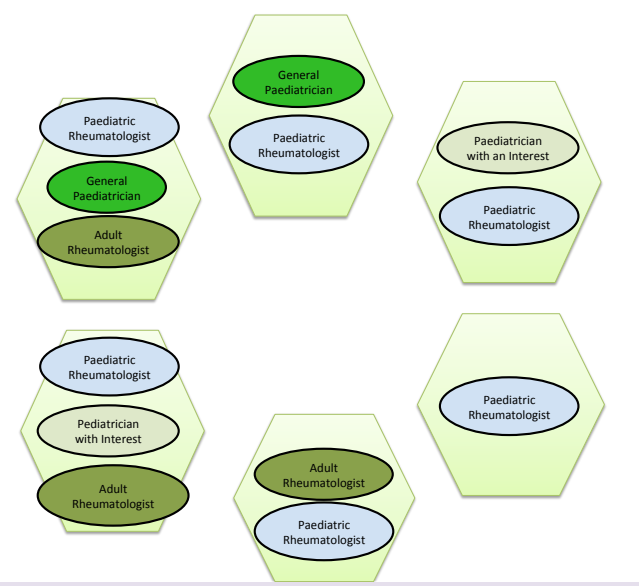
- There may be belief differences between professionals about the way that optimal care 'should' be delivered, and these differences in belief influence not only the role and responsibilities of professionals, but also the relationship between professionals and their organisations. For example a paediatric rheumatologist may believe that their role is to
  - Support local clinician(s) to deliver specialist care
  - Deliver specialist care locally with support from the local clinician(s)
  - Deliver specialist care at the tertiary centre, with support for part of their care from the local clinician(s):
- Tensions may be created if there are evident or perceived service standards or clinical practice differences between centres and professionals

WORKFORCE RESOURCES

- There may be differences in workforce resources, which influences the way that care is or can be delivered. Specialist and local centres need to be resourced. For example have professionals in post with time to establish links, develop relationships, deliver care and educate and train those involved.

COMBINATION OF PROFESSIONALS at the local centre

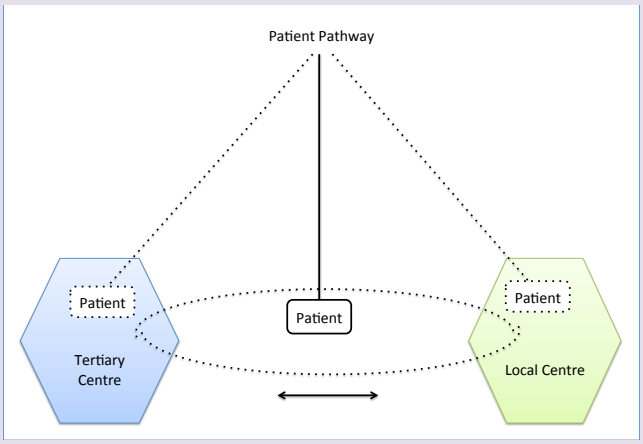
- Depending on whether or not the paediatric rheumatologist goes to the local centre or not, the combination of professionals 'doing clinic' or involved in the care locally varies, as illustrated below.



- These professionals may or may not be present in clinic, may all be in the same room, or running parallel clinics in adjacent rooms. There may be variability in who leads the consultations.

LOCATION OF CARE DELIVERY

- A patient's care pathway may swing, like a pendulum between the tertiary and local centre (or primary care/ in the community), at different points in time, and for different reasons. There will be different support and developmental needs of professionals required depending on 'where' care is delivered, and for 'what part of care'.



- The geography of the area, for example how far a patient has to travel, and local resources may influence 'where' care is delivered and for 'which part' of the care.

OTHER FACTORS

- Networks are dynamic entities, continually evolving and therefore users may encounter other issues.

Table 16 Context: Medical Professionals and Network Structure

10.6.3 Guidance Content for Establishing Links between Professionals and their Organisations

Establishing links between professionals and their organisations	***Considerations & Practical Tips***
• Involves first an engagement process to 'link' professionals together. These professionals may be based at the specialist centre (tertiary hospital) and/or local centre (local hospital – for example a district general hospital, closer to a patients home). The engagement process may involve creating new links or strengthening informal links. It may be a lengthy process.	• *Time put aside to develop relationships is essential. When time is limited, consider starting discussions with professionals and organisations that are most engaging and interested, or when a natural opportunity, such as a professional's retirement arises. Other professionals and organisation may join in discussions once benefits are shared.*
• Any professional involved in the care of children and young people with JIA should be working as part of a multidisciplinary team (MDT) and as part of a clinical network.	• *It may be helpful for the 'engagement process' to include not only medical professionals but also the MDT. Consider setting up a regional clinical network steering group with representation from different geographical areas and centres, with MDT professionals from different backgrounds, and patient/parent groups. This may facilitate the engagement process across different areas and disciplines.*
• Is an on-going process; clinical networks are dynamic entities.	• *Links may need to be re-established when personnel change, when professionals take on different roles or when service needs change.*
• The BSPAR/ ARMA Standards of Care for children and young people with JIA is a key document, which sets the standard of care to that which is now expected.	• *Consider referring to the BSPAR/ARMA Standards of Care during discussion with managers and professionals involved in the care of children and young people with JIA. Many have found it useful to support service development in clinical networks.*
• 'Linking' different centres (professionals and their organisations) may require different approaches – what works for one centre may not work for another. Between and within clinical networks, no 'link' is the same and different challenges may be encountered.	• *When establishing 'links' consider the historical basis for change and the impact of change for individuals and their organisation.*
• When health care organisation/ service delivery changes are discussed do not be surprised if resistance is encountered. Transforming resistance to engagement and commitment is important, as resistance can inhibit access to specialist care for children and young people with JIA.	• *An understanding, and appreciation of the background to the resistance, and addressing this through training/education programmes may help facilitate ways to overcome it.*

• The background to resistance may be related to a lack of information and clear vision, confusion over the reasons for the need to change, disagreement in principles behind delivering care in a network, or if there are financial implications.	• *Suggestions to overcome resistance:* - *Raising awareness of specialty of paediatric rheumatology, and providing information to those looking after children and young people JIA about the BSPAR/ARMA Standards of Care. For example, going to local centres and participating in local education programmes.* - *Allow time and facilitation for feedback to any suggested change, with opportunity for contribution to ideas, and perspective from all involved, with consideration of how change will impact* on them.
• The background to resistance may be related to the emotional effect of change. Some clinicians may have provided services when there was no alternative, with little resources. They may feel threatened if an enjoyable area of their clinical practice is taken away. There may be fear of losing control and of colleagues, and fear of being seen an incompetent. They may think that their service has been running well.	• *Suggestions to overcome resistance:* - *Be aware that organisational change may be a sensitive issue, and that strategies relating to just providing information may be insufficient. Consider exploring how involved professionals feel and why they feel that way.* - *Acknowledging the roles and contributions that clinicians have historically/currently play, and sharing experiences may be helpful.* - *Consider ways of meeting a common ground. For example maintaining involvement in service provision such as an adult rheumatologist role shifting towards adolescents and transitional care.*
• The background to resistance may be related to issues beyond the immediate situation. For example there may not be resistance to trying to improve services, but rather the resistance may stem from what the change represents to the individual or their organisation. It may encompass other differences (e.g. personal, cultural, historical factors).	• *Suggestions to overcome resistance:* - *Raising awareness and relationship building may be helpful.* - *Further information may be required with more convincing arguments and facts.* - *Change of personnel (from either the tertiary centre, local centre (or both) may be helpful.*

Table 17 Considerations and Practical Tips for Establishing Links between Professionals and their Organisations

10.6.4 Guidance Content for Delivering Care in Clinical Networks

Delivering optimal care	*Considerations & Tips*
• There are multiple ways of delivering care in a network – no one network is the same, and no one-way of working is necessarily 'better' than any other. There may be advantages, compromises and trade-offs to different 'ways of doing things'.	• *Consider ways to deliver are which are flexible and adaptive to the current situation, but centred on achieving the BSPAR/ARMA Standards of Care for children and young people with JIA.*
• Network terminology relating to the way that care is delivered may be confusing. For example 'outreach', 'shared care', 'network', 'doing clinics together' can mean different things to different people.	• *Consider a shared language or a detailed explanation within (and between) networks when network terms are used. Being specific about what the term means in clinical practice may prevent misunderstandings. For example 'outreach' clinic may construe a hierarchy, which may be inhibitory to developing relationships. An alternative suggestion may be to use the term 'network' clinic to overcome this.*
• Requires a critical workforce mass that is engaged to deliver care in a network.	• *Specialist and local centres need to be resourced, with professionals having allocated time in job plans to develop network activities otherwise links to deliver care may not be maintained. It is useful to document clinical workload to justify to managers service needs particularly around succession planning.*
• The GMC's guidance (Good Medical Practice, http://www.gmc-uk.org/guidance/good_medical_practice.asp) on communication, partnership, teamwork and collaboration is of particular relevance to care delivery in a clinical network. The guidance is reminder of the professional standards expected of medical professionals. For example - Communicating effectively (via phone, e-mail, letter etc.) - Respecting the skills and contributions of colleagues, and treating colleagues fairly	• *Consider how your behaviour may influence others within and outside the team of people involved in the care delivery within a network.* • *Consider having 'named' professionals (including the MDT) as this can facilitate collaborative working between centres. Consider getting together with all those involved to clarify vision, roles and responsibilities, expectations, to establish core values, and to ensure optimal clinical governance. Having an understanding of the level (practical aspects) of care that can be provided can prevent misunderstanding or problems arising from different expectations.*

• Delivering care in a network requires trusting colleagues. For some this may be difficult – and there may be a number of reasons for this. For example when professionals do not yet know each other or following historic events or encounters, which have not gone well. • Professionals may find it challenging to work together particularly when levels of specialist experience or 'number of consultant' years differ.	• *Trust may develop over time but can be enhanced by 'getting to know' each other during social events, educational activities, discussing clinical cases, working together or 'doing clinics together'* • *Consider being aware of this at the outset, and acknowledging it. Over time it frequently becomes easier. If tensions arise, consider the reason for it. For example it could be related to feeling undermined, or threatened. In some instances, a change in personnel may be required and this may allow established behaviours to be challenged and overcome historical problems.*
• May benefit patient and their families by providing care closer to home, and prevent additional travel time. However, sometimes network/ outreach clinics may mean a lot of people in the same room.	• *Parents have suggested that if it their first time to a 'network' or 'outreach' clinic they are pre-warned if there are going to lots of professionals there. Consider asking for a larger room if space is an issue.*
• Local care may prevent additional travel for patients and their families.	• *To prevent unnecessary repeat investigations (and travel) ensure similar protocols are used between centres. For example for MRI scans it is useful if radiologists at local and specialist centres link together to ensure that local imaging protocols match those at the specialist centre.* • *If specialists are asking local clinicians to organise local investigations, then ensure that the local clinician understands the background to the request, or any issues that may arise on the check lists (e.g. MRI check list screen). This may prevent misunderstandings or safety issues, or unnecessary repetition of tests.*

Table 18 Considerations and Practical Tips for Delivering Care

10.6.5 Guidance Content for Educating and Training

Educating and Training	*Considerations & Tips*
• Clinical networks can provide an infrastructure to support education of health professionals. • Different network structures provide different training and learning opportunities. • There may be educational and training advantages, compromises and trade-offs to different 'ways of doing things'.	• *The regular physical presence of a paediatric rheumatologist in the local centre can facilitate education and training of local professionals, who then in turn can educate and train a wider audience. This may be helpful when there are limitations in workforce resources and professional's time.* • *Regulating the number of patients seen, when a paediatric rheumatologist & local clinician do 'clinics together' can ensure that time for education and training is not compromised.* • *Organised educational activities may facilitate opportunities for colleagues to get to know each other, for example during social events before, during or after meetings. These events can help develop relationships, which is important for collaborative working.* • *Organised educational events delivered by videoconferencing can still facilitate colleagues to get to know each other. Although, this format overcomes the issue of travel to meetings, attendance still depends on whether the topic is relevant and they have no other commitments. IT support is essential to help facilitate smooth running of meetings.* • *Network educational events often include a multidisciplinary audience –those organizing and delivering the education have found pitching the level to be challenging. Consider part of the programme to include parallel workshops for professionals of different backgrounds (if time, space and workforce resources allow). Attendance at educational events may be improved if catering supplied, and the educational event doesn't clash with others!*

• Professionals working in a clinical network and managing children and young people with JIA come from different clinical backgrounds with varying levels of exposure and experience. The educational and training needs of these professionals is likely to vary. • The educational needs of professionals working in the network are likely to change over time as the network evolves. .	• *Consider discussing individually or getting professionals together to identify educational needs. Suggestions include reviewing 'how care is (or could be) delivered – where and by whom, what people's interests are, their previous experience, their role and responsibilities in the clinical setting and what the local services needs are.* • *The RCPCH curriculum for post graduate training and special interest module (SPIN) in paediatric rheumatology provide references for knowledge, skills and behaviours, and may be helpful to identify education and training needs.* • *Consider reassessing the educational needs when new members of staff join or/and when the network evolves. Attendance at clinics the specialist centre can build up the confidence of local professionals, particularly if new in post.*
• Establishing clinical networks and delivering care in clinical networks involves a process of change – in the ways that services are run and also clinical practice.	• *Consider educational activities/ CPD programmes to include training in conflict, negotiation, team working, change management and implementation science.* • *When difficulties arise relating to changing clinical practice consider separate teaching clinics. Over time shift of management can happen.*

Table 19 Considerations and Tips for Educating and Training

10.7 Conclusion

This penultimate chapter has fulfilled the aim of this study. The findings from this study had fed into development of an educational framework to provide guidance for medical professionals, in the form of considerations and practical tips, establishing clinical networks to deliver optimal care for children and young people with JIA. In the next chapter I consider the implications of the study findings, and discuss the limitations of the study with implications for future areas of research.

Chapter 11. Conclusions

11.1 Introduction

In conclusion, over the course of this thesis the specific objectives of the study, which I outlined in Chapter Two, have been met:

- Chapter Five described the rationale for delivering care for children and young people with JIA with a clinical network.
- Chapters Six and Seven described how clinical networks for children and young people with JIA have been established, and described the associated challenges.
- Chapter Eight identified how care for children and young people with JIA is delivered within clinical networks.
- Chapters Seven, Eight and Nine described the challenges of delivering care for children and young people with JIA within clinical networks.
- Chapters Five to Nine identified and described the developmental needs of medical professionals involved in establishing clinical networks for children and young people with JIA, and delivering care within them.
- Chapter Nine described existing continued professional development and training within clinical networks for JIA, in terms of format, content, target audience, and how it is delivered.

The discussion generated by achieving these specific objectives resulted in the general objectives of the study being met:

- This thesis has added to the understanding of the evolution of clinical networks to deliver care for children and young people with JIA, and the relationship to the developmental needs of medical professionals.

Achieving the specific and general objectives of this study has facilitated the overall aim of this study:

- An educational framework has been developed to provide guidance for medical professionals involved in establishing clinical networks to deliver care for children and young people with JIA.

In this final chapter I bring together all the phases of my research and consider the implications of the study findings. I reflect upon the research methods used and

discuss the limitations of the study with implications for future areas of research. Finally, I discuss the wider relevance and how the study findings will be implemented.

11.2 Implications

In Chapter One of this thesis, I summarised and reviewed the literature that led to the development of this study. I explained that there had been a call from within the speciality of Paediatric Rheumatology to support medical professionals involved in establishing clinical networks to deliver care for children and young people with JIA, and to support the education and training of those involved. The optimal strategy, and the exact nature of support required had not been reported in the literature. By exploring the experience of those involved, this study reports and contributes to the understanding of this topic area. In this section I discuss the implications of the study findings, the conclusions and meaning that can be drawn from this study for medical professionals, and children and young people with JIA. I will consider the study's generalizability and what the findings mean for wider professionals groups.

11.2.1 Implications for Medical Professionals

The study has documented important issues that may be encountered by medical professionals during the processes of establishing a clinical network, such as linking professionals and their organisations together, delivering optimal care through collaborative working, and educating and training those involved (explored in detail in Chapters Five to Nine). It is apparent from my findings that clinical networks are best viewed as dynamic entities rather than a static structure to be aspired to. It is not possible to define a clear endpoint when a clinical network has become 'established,' and moves into the 'maintaining' phase. Instead establishing and maintaining clinical networks to deliver optimal care should be thought of as a continuous process. Changes in personnel or other circumstances require the parts of the network to be 're-established' to take account of the changes. This perspective of constant network evolution impresses on medical professionals the importance of recognising the many complicated interactions that define networks. None of the participants in this study described their network as being complete or 'fully established'. Recognising this is crucial for medical professionals to maintain flexibility and readiness to address and adapt to change. The framework for 'establishing' a network remains central to its on-going evolution.

This study has provided opportunity to document the key issues encountered during the processes of linking professional and organisations together, delivering optimal care, and educating and training professionals involved in clinical networks. In doing so it provides a unique starting point from which to be able to develop the required support for medical professionals to manage and overcome these challenges, and allows for open discussions to be had during different stages of network development. The guidance for medical professionals within the educational framework has specific implication for medical professionals who may encounter difficulties at the different stages of network development. The contextual considerations and practical tips described in Chapter Ten provides them with a reference point rather for them to just have to 'feel the way', and this offers potential solutions to the challenges that may arise. In doing so it is hoped that that the processes described as 'challenging' become easier.

11.2.2 Implications for Children and Young People with JIA

This whole study was predicated on understanding how to facilitate the delivery of optimal care in clinical networks for children and young people with JIA. A central finding of this study with implications for children and young people with JIA is the demonstration that professional and organisational boundaries exist. I observed that boundaries can have a profound influence on network establishment and therefore can limit the access to and level of specialist care that can be provided for these children and young people. Although this study does not prove that care delivery in clinical networks improves clinical outcomes and needs investigating separately, it is logical to extrapolate and conclude that barriers to access to specialist care (including organisational and professional boundaries) need to be overcome to optimise care for children and young people. This study raises awareness of this issue and the need to bring about effective organisational change. The educational framework offers some solutions to overcome these boundaries.

11.2.3 Implications for Wider Professional Groups

Although this study focused on the medical professional group involved in the care of children and young people with JIA in a clinical network, the issues relating to establishing links between professionals and their organisations, collaborative working and professional and organisational boundaries are not specific to just this

professional group. Professionals from the wider MDT, other medical or surgical specialities may relate to similar issues. For example, an integrative literature review by McInnes *et al.* (2015) identified similar facilitators and barriers that influenced collaboration and team work between general practioners and nurses. The potential solutions to the challenges encountered by participants from this study may be helpful to others who encounter similar issues.

The issues raised may have implications for wider professionals groups. Commissioners and policy makers will benefit from understanding the complexity of variables that impact on the effectiveness of care delivery, allowing them to target funding to maximise clinical utility. This study would suggest that commissioning which supports the central entities of the educational framework is likely to be effective at ensuring the long-term success of the network delivery of care. This support needs to be on-going. A short-term investment in education and training might facilitate the initial steps of establishing a network, but on-going financial support is likely to be needed to continue evolving the network as personnel and circumstances change. The findings specifically relating to the varied (and confusing) network terminology (described in Chapter Eight) has direct implications to commissioners, policy makers, college and societal bodies, particularly if there is a possibility that misunderstandings may occur if synonymous terms are used but what happens in clinical practice differ. This study highlights a call to be explicit when using such terms or for a shared common language to be used.

The issues raised in this study may have implications that extend beyond the UK. Over the course of the study period, the European Agency for Health and Consumers contracted a new initiative for children and young people with rheumatic disease: the Single Hub Access point for Paediatric Rheumatology in Europe (SHARE) (Wulffraat *et al.*, 2013). In short the aim of this project is to define what is required in order to provide optimal care to children with paediatric rheumatic disease in the European Union member and candidate member states. The detailed description of the how UK is attempting to address inequities in access to optimal care by developing clinical network is of interest to all the SHARE work packages who are trying to identify best practices across Europe.

11.3 Limitations and Implications for Future Research

In the following section I reflect upon the methods that I used in this study, acknowledge the study limitations and discuss the topic areas that I consider to be important for future research.

11.3.1 Population and Sampling

The methodology necessitated capturing perspective and opinion from a wide range of people who had experiences of clinical network establishment, care delivery and education and training within networks for children and young people with JIA. Purposive sampling from networks across the UK allowed participants to be identified and specifically invited to attend the serial focus groups and interviews. It is possible that those who agreed to be interviewed had differing perspectives from those who did not attend. However, overall I feel that the methods chosen were effective in facilitating the study's objectives and overall aim, because the purposive sampling strategy used was able to maximise the opportunity to explore the research question in depth. By the end of the recruitment and analysis period similar themes were emerging.

The total number of health professionals involved in looking after children and young people with JIA is unknown in the UK. It is recognised that not all are members of BSPAR, and therefore the latest membership figure of BSPAR - 249 - is likely to be an underestimation (British Society for Rheumatology Data Source 2015). Without knowing the total number of people involved in clinical networks it is difficult to know whether the number recruited represented or underrepresented a particular group within the medical and allied health profession. This is an inherent problem with this type of research; but by using purposive sampling I have tried to keep the study population as representative as possible. Nevertheless, in comparison to the number of professionals recruited from a paediatric background, there was a relative under representation of adult rheumatologists. This was recognised during the study recruitment period, and increased efforts were made to try to recruit more professionals from this group. Unfortunately, this was unsuccessful and not everyone who was invited to participate in this study responded to the invitation. The input of the adult rheumatologists who did participate and the history of the evolution of provision of care that I discussed in Chapter One, with care provision being shifted away from adult rheumatologists identified some antagonism toward the paediatric

rheumatology-led networks that may have disengaged some adult rheumatologists from taking part. For future research, liaison with the British Society of Rheumatology to facilitate recruitment of adult rheumatologists may be more successful.

Another limiting aspect of the study population to highlight is that the young people and parents of children with JIA who were interviewed all lived in Scotland. Whilst there was variation in terms of which hospital they attended, and their care provided by professionals from differing professionals backgrounds, a national perspective cannot be completely discounted. Interviewing young people and parents of children with JIA from other regions of the UK may offer additional perspective, for example offering ethnicity or cultural issues that were not explored in this study.

It is important to bear in mind though that with a project of this nature there will always be some group (speciality, age or geography) that appears relatively under-represented. Crucially, I have not in general made claims in this study about one particular medical professional group or specific 'way of working'. I would expect that interviewing more people from any given interest group would highlight different experiences and perspectives, but that the solutions I have proposed in the educational framework would remain relevant.

11.3.2 Other Medical and Non-Medical Professionals

The perspectives of 'other' professionals groups, for example from primary care, orthopaedics and ophthalmology were not sought in this project. These professionals are important care providers and their work interacts with that of the network. I took the decision to focus on the relationship between paediatric and adult rheumatology professionals collaborating between the tertiary and the local centre as part of this study because of the practicalities of the time constraint of the study and to avoid further complicating the network analysis. Increasing the number of professional groups would have invariably have increased the number of people in each group. There will be specific challenges to how these other professional groups interact with networks and it would be an interesting topic for future research to explore and compare their perspectives. Fundamentally I would expect that the issues addressed in the educational framework would be relevant to these professional groups as well, in particular the themes around collaborative working.

There was a necessity to constrain the research area to a 'workable' topic area, to make the study 'manageable' in a specific time frame. As a result, this study and thesis have focused upon a specific group - 'medical professionals'. However, a recurrent theme that arose during the analysis of the data related to the importance of the role of local nurses in facilitating care delivery across boundaries. This finding went beyond the study aim and research question. There was a suggestion from the analysis that this would be an interesting and important area to explore further as 'local' nurse specialists may facilitate specialist care closer to a child or young person's home, and there may be financial implications relevant to the commissioning process.

11.3.3 Other Conditions

Although the study design allowed the specific objectives and aims to be achieved by focusing on a single patient condition, it is worth considering additional complexities of every day clinical network practice. In reality clinical networks are actually '*paediatric rheumatology clinical networks'*; the same group of professionals not only manage children and young people with JIA but also manage a number of other rheumatological conditions. Future research may consider exploring the implications of clinical networks for these other conditions.

11.3.4 Content of the Guidance

The guidance produced from the educational framework has limitations (or, potentially, advantages), as it is context dependent. The 'fitness to purpose' principle of a framework of context layers attempted to overcome this. However, a potential drawback of this principle is that those who use the framework may not have insight into whether or not it is applicable to them. Suggestions for future work include evaluation of the content of the framework by medical professionals in other networks to aid its refinement and contextualisation, and exploring how medical professionals relate to the guidance offered.

The guidance produced by the framework needs to be considered in light of changing governmental funding streams for specialist services. For example, during the study period, NHS England introduced strategic clinical networks (SCNs), as engines for change within the modernising NHS (Department of Health, 2012) and specialist services for children and young people underwent a commissioning review.

Currently, the exact flow of finance remains unclear. How the SCNs will work and their relevance to paediatric rheumatology clinical networks remains unclear.

11.4 Study Relevance and Implementing the Findings

In this section I discuss the wider relevance of the study and discuss how some of the findings are already in the process of being implemented.

11.4.1 GMC's Agenda on Professionalism and Collaboration

The study findings are currently very topical. For example, over the past year the GMC launched a programme of events and online discussions for health professionals entitled *Medical Professional Matters*, which has allowed clinicians to discuss the challenges of professionalism in every day clinical practice (GMC, 2015). The aim of the programme has been to encourage collaboration between those on the frontline – doctors, students, educators, other health professionals and key sector organisations. The findings are to be presented later in 2016, but a key theme in the draft report relates to the extent to which professionals interact with each other – termed as medical 'tribalism'. Similar to the findings from my study, this behaviour crucially prevents collaboration. In addition the annual RCPCH conference keynote talk (April 2016) to delivered by Professor Terence Stephenson, Chair of the GMC and past President of the RCPCH is about '*Working with doctors for patients across boundaries of care'*. As the GMC encourages a rethink of how health professionals collaborate to deliver care, it is timely to publish the findings of this study to raise awareness of these issues further, and provide some practical solutions to the issues encountered.

11.4.2 Research Study Design

This study described the specific variation of clinical network structures and what that means in clinical practice. The specific details of the way that care is delivered across the UK (who is involved and where care is delivered) is of relevance to other research projects relating to treatment and care pathways for children and young people with JIA. For example, in recent discussions about a trial set up, which aims to look at a treatment intervention compared to 'standard clinical care' across a number of centres, I was able to explain in detail some of the variations and practicalities that need to be considered. Publications from this thesis will be able to

provide the evidence base for the observed difference in the way that care in delivered across the UK.

11.4.3 Postgraduate Training Curricula

The findings from this study relating to professionalism have already fed into the open consultation process to develop a new framework for generic professional capabilities for post graduate training that are common to doctors across all medical specialists, and are essential for safe, high quality clinical care (an on line survey organised by the GMC and Academy of Medical Royal Colleges between1 July 2015 and 27 September 2015). In addition some of the findings from my study have provided content for the RCPCH 2016 curriculum revision, via my role as RCPCH Paediatric Rheumatology College Specialist Advisory Committee Assessment Advisor. For example the development of skills of 'doing clinic together' with another consultant within a network is now included. Similarly, this study has provided content for the RCPCH Specialty Trainee Assessment of Readiness of Tenure (START) scenarios. Due to RCPCH exam board confidentially issues I am unable to give examples of the START scenarios that I have developed from the findings of this study, as they will be used over the next few years in the START assessments.

11.5 Conclusion

This study has mapped out the support required for medical professionals establishing and maintaining clinical networks to deliver optimal care for children and young people with JIA. I acknowledge that are many questions still to be answered surrounding this complex area. However, I hope that my observations, theories and the development of an educational framework provides the basis for future research and begins to facilitate change to improve care for children and young people with JIA.

Personally, the past four years has resulted in much learning and discovery whilst undertaking this research study. It has been a privilege to get to know so many people, whilst exploring different 'ways of working' across the UK. Over the course of this study my ideas have changed as I uncovered and got to grips with the complexities involved in delivering care across boundaries. Pausing my clinical career, and stepping off the NHS ladder has allowed time for reflection. As I return to clinical medicine as a new consultant, I am more aware about the importance (and

challenges) of collaboration, and ultimately how I want to practice as a paediatric rheumatologist.

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Appendix 1 Consent Forms

Consent Form for Parent Discussion Group

Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

'What does your child's doctor need to know in order to provide the best possible care within a clinical network for JIA?'

Research consent form: Discussion group (parents)

Centre number:	Study number:
Participant Identification Number:	Name of researcher(s):

I confirm that: ***(Please initial each box)***

1. I have read and understood the information sheet (version 1, 22/07/12) for the research project named above. I have had enough time to think the information through, and a chance to ask questions. I am happy with any answers I have been given. ☐

2. I understand that I do not have to take part in this research. I can withdraw from it at any time, without giving a reason. I know this will not affect my child's medical care or legal rights. ☐

3. I allow the researchers to audio-record the discussion group I take part in. I understand that these recordings will be transcribed. The recordings will be destroyed six months after the researchers have finished analysing and writing up the data. ☐

4. I understand that the transcripts will be stored in line with the Data Protection Act. Any paper copies will be kept in a locked filing cabinet in the Institute of Health and Society at Newcastle University. Electronic versions will be kept in a password-protected area of a secure server for a period of ten years. ☐

5. I understand that information identifying me, my family, or any other individuals (e.g. health professionals) will be removed from the transcripts. I know that once this has been done, Arthritis Research UK (the charity which is funding this project) may see the transcripts. ☐

6. I understand that research records and data may also be inspected by regulatory bodies for audit purposes. ☐

7. I understand that things I say may be used in the final report and/or scientific publications, but that any quotes will be anonymous. No information identifying me, my family, or any other individuals (e.g. health professionals) will appear in any report or publication. ☐

8. I understand that in almost all circumstances, the data collected will be treated as confidential. However, if any statements are made during a discussion group that suggest malpractice, misconduct, or that someone is in danger of harm, this information will be shared with the appropriate professionals. ☐

9. I agree to take part in this research project. ☐

10. I would like to receive feedback on the findings of the research. ☐

.....	.....	.....
Name of Participant	Date	Signature
.....	.....	.....
Name of Person taking consent	Date	Signature

(One copy for participant and one for project file) *Version1 22/7/2012*

Consent Form for Young Person Discussion Group

Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

'What does your doctor need to know in order to provide the best possible care for you within a clinical network for JIA?'

Research consent form: Discussion group (young people)

Centre number:	Study number:
Participant Identification Number:	Name of researcher(s):

I confirm that: ***(Please initial each box)***

1. I have read and understood the information sheet (version 1, 24/07/12) for the research project named above. I have had enough time to think the information through, and a chance to ask questions. I am happy with any answers I have been given. ☐

2. I understand that I do not have to take part in this research. I can withdraw from it at any time, without giving a reason. I know this will not affect my medical care or legal rights. ☐

3. I allow the researchers to audio-record the discussion group I take part in. I understand that these recordings will be transcribed. The recordings will be destroyed six months after the researchers have finished analysing and writing up the data. ☐

4. I understand that the transcripts will be stored in line with the Data Protection Act. Any paper copies will be kept in a locked filing cabinet in the Institute of Health and Society at Newcastle University. Electronic versions will be kept in a password-protected area of a secure server for a period of ten years. ☐

5. I understand that information identifying me, my family, or any other individuals (e.g. health professionals (doctors, nurses, physiotherapist etc.)) will be removed from the transcripts. I know that once this has been done, Arthritis Research UK (the charity which is funding this project) may see the transcripts. ☐

6. I understand that research records and data may also be inspected by regulatory bodies for audit purposes. ☐

7. I understand that things I say may be used in the final report and/or scientific publications, but that any quotes will be anonymous. No information identifying me, my family, or any other individuals (e.g. health professionals) will appear in any report or publication. ☐

8. I understand that in almost all circumstances, the data collected will be treated as confidential. However, if any statements are made during a discussion group that suggest malpractice, misconduct, or that someone is in danger of harm, this information will be shared with the appropriate professionals. ☐

9. I agree to take part in this research project. ☐

10. I would like to receive feedback on the findings of the research. ☐

.....	.....	.....
Name of Participant	Date	Signature
.....	.....	.....
Name of Person taking consent	Date	Signature

(One copy for participant and one for project file) *Version1 24/7/2012*

Consent Form for Professional Discussion Group

Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks '

Research consent form: Discussion Groups (health professionals)

Centre number:	Study number:
Participant Identification Number:	Name of researcher(s):

I confirm that: ***(Please initial each box)***

1. I have read and understood the information sheet (version 1, 22/07/12) for the research project named above. I have had enough time to think the information through, and a chance to ask questions. I am happy with any answers I have been given. ☐

2. I understand that I do not have to take part in this research. I can withdraw from it at any time, without giving a reason. I know this will not affect my employment status or legal rights. ☐

3. I allow the researchers to audio-record the discussion group I am taking part in. I understand that these recordings will be transcribed. The recordings will be destroyed six months after the researchers have finished analysing and writing up the data. ☐

4. I understand that the transcripts will be stored in line with the Data Protection Act. Any paper copies will be kept in a locked filing cabinet in the Institute of Health and Society at Newcastle University. Electronic versions will be kept in a password-protected area of a secure server for a period of ten years. ☐

5. I understand that information identifying me, my patients, or any other individuals (e.g. or other health professionals) will be removed from the transcripts. I know that once this has been done, Arthritis Research UK (the charity which is funding this project) may see the transcripts. ☐

6. I understand that research records and data may also be inspected by regulatory bodies for audit purposes. ☐

7. I understand that things I say may be used in the final report and/or scientific publications, but that if so, these quotes will be anonymous. No information identifying me, my patients, or any other individuals (e.g. other health professionals) will appear in any report or publication. ☐

8. I understand that in almost all circumstances, the data collected will be treated as confidential. However, if any statements are made during a discussion group that suggest malpractice, misconduct, or that someone is in danger of harm, this information will be shared with the appropriate professionals. ☐

9. I agree to take part in this research project. ☐

10. I would like to receive feedback on the findings of the research. ☐

.....	.....	.....
Name of Participant	Date	Signature
.....	.....	.....
Name of Person taking consent	Date	Signature

(One copy for participant and one for project file) *Version1 22/7/2012*

Consent Form for Professional 1-1 Interview

Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

Research consent form: Interviews with key professionals

Centre number:	Study number:
Participant Identification Number:	Name of researcher(s):

I confirm that: ***(Please initial each box)***

1. I have read and understood the information sheet (version 1, 22/07/12) for the research project named above. I have had enough time to think the information through, and a chance to ask questions. I am happy with any answers I have been given. ☐

2. I understand that I do not have to take part in this research. I can withdraw from it at any time, without giving a reason. I know this will not affect my employment status or legal rights. ☐

3. I allow the researchers to audio-record the interviews I take part in. I understand that these recordings will be transcribed. The recordings will be destroyed six months after the researchers have finished analysing and writing up the data. ☐

4. I understand that the transcripts will be stored in line with the Data Protection Act. Any paper copies will be kept in a locked filing cabinet in the Institute of Health and Society at Newcastle University. Electronic versions will be kept in a password-protected area of a secure server for a period of ten years. ☐

5. I understand that information identifying me, my patients, or any other individuals (e.g. family members or health professionals) will be removed from the transcripts. I know that once this has been done, Arthritis Research UK (the charity which is funding this project) may see the transcripts. ☐

6. I understand that research records and data may also be inspected by regulatory bodies for audit purposes. ☐

7. I understand that things I say may be used in the final report and/or scientific publications, but that any quotes will be anonymous. No information identifying me, my patients, or any other individuals (e.g. health professionals) will appear in any report or publication. ☐

8. I understand that in almost all circumstances, the data collected will be treated as confidential. However, if any statements are made during an interview that suggest malpractice, misconduct, or that someone is in danger of harm, this information will be shared with the appropriate professionals. ☐

9. I agree to take part in this research project. ☐

10. I would like to receive feedback on the findings of the research. ☐

.....	.....	.....
Name of Participant	Date	Signature
.....	.....	.....
Name of Person taking consent	Date	Signature

(One copy for participant and one for project file) Version1 22/7/2012

Appendix 2 Information Sheets

Information Sheet for Parent Discussion Group

'What does your child's doctor need to know in order to provide the best possible care within a clinical network for JIA? '

Research project information sheet

Introduction

We would like you to help us with our research project. This information sheet explains why and how. We have tried to guess what questions you will have and to answer them clearly. If there is anything else you would like to know about the study, please get in touch with us. Our contact details are at the end of this information sheet.

Who are you?

We are a group of researchers and doctors from Newcastle University. Our names are:
Dr. Mary Cruikshank, Prof. Helen Foster, Dr.Tim Rapley and Dr. Jane Stewart.

What is your research about?

Our research is about postgraduate educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network. A clinical network is a linked group of health care professionals who are all working in a coordinated manner to ensure that patients all receive high quality care, irrespective of where they live.

Our aims are to

1. To identify, describe and understand the educational needs of doctors working within a clinical network, to enable them to deliver best possible care for children and young people with JIA

2. To explore barriers and challenges to addressing these needs

3. To describe strategies to deliver these needs within post graduate educational training programmes

Why are you doing this research?

Juvenile Idiopathic Arthritis (JIA) affects approximately 12,000 children and young people in the UK. The management of this condition has changed in recent decades, with best possible care focussing on early diagnosis, management by specialist teams and earlier treatment. There is accruing evidence that the earlier the intervention, the better the outcome. Clinical networks are developing as a means of sharing expertise and improving

the quality of care that your child receives. Paediatric rheumatology is a relatively young speciality and the doctors delivering care will bring various experiences and expertise to the speciality. Previous research suggests that these doctors would value support and training to develop the quality of paediatric rheumatology care.

Why are you asking me to take part?

You have been contacted as parent of a child or young people with JIA. We are keen to talk to **a selection of parents** who have experience of healthcare within a clinical network for JIA.

Do I have to take part?

No. We hope you will be interested in helping us with this study, but you do not have to. If you decide to take part, you will be asked to sign a form confirming you are happy to do this. However, this decision is not final. You are free to change your mind at any time and you do not need to give us a reason. Your decision will not affect the treatment or care that your child needs.

What will taking part involve, and how long will it take?

We are inviting you to take part in a one-off discussion group lasting around an hour. This discussion group will be facilitated by Dr. Mary Cruikshank. It will be recorded, and – we hope – involve a number of parents. It will take place in a quiet area of the [public place].

What will you do with the information from the focus group?

We will listen to and transcribe the discussion group recording. The recording will be destroyed six months after we have analysed and written up the data. The research team will keep copies of the transcript for ten years in a locked filing cabinet at Newcastle University (in the Institute of Health and Society) and/or in a password-protected area of the University's secure server. Information identifying you, or any other individuals (e.g. your child or doctor) will be removed from the transcript. After this has been done, Arthritis Research UK (the charity which is funding this project) may see the anonymised transcript. Things you say may be used in reports and publications, but all quotes will be anonymous. The data collected will be treated as confidential unless it suggests malpractice, misconduct, or that someone is in danger of harm. In this situation, we'd need to share the information with appropriate professionals.

Are there any disadvantages to taking part?

There is no risk to you or your child, if you take part.

Are there any advantages to taking part?

We cannot promise that your child will benefit personally, though some people find it helpful and/or enjoyable to talk about their experiences and feelings with an independent researcher. The treatment and care your child will receive will be the same whether or not you take part. However, we hope that the research will help children and young people with JIA in the future, by improving our understanding of the information and support that doctors need to make good treatment decisions.

What if something goes wrong?

If you are unhappy about how the research is conducted, you can contact [INSERT NAME OF SITE LEAD] or the lead researcher, Dr Mary Cruikshank, details are at the end of this information sheet.

Who's funding this research?

Arthritis Research UK is funding this research project.

Who's authorised this research?

This study has been reviewed and approved by the [NAME OF LREC] and the [NAME OF HOSPITAL TRUST].

Who can give me more information?

If you would like more information about the research project, please contact the lead researcher, Dr. Mary Cruikshank [insert email address] or her colleague Dr Tim Rapley (tim.rapley@newcastle.ac.uk). They are both based at the:

Institute of Health and Society,
Baddiley-Clark Building,
Richardson Road,
Newcastle-Upon-Tyne,
NE2 4AX
Tel. 0191 222 7045
www.ncl.ac.uk/ihs

Information Sheet for Young Person Discussion Group

'What does your doctor need to know in order to provide the best possible care for you within a clinical network for JIA? '

Research project information sheet

Introduction

We would like you to help us with our research project. This information sheet explains why and how. We have tried to guess what questions you will have and to answer them clearly. If there is anything else you would like to know about the study, please get in touch with us. Our contact details are at the end of this information sheet.

Who are you?

We are a group of researchers and doctors from Newcastle University. Our names are:
Dr. Mary Cruikshank, Prof. Helen Foster, Dr.Tim Rapley and Dr. Jane Stewart.

What is your research about?

Our research is about the educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network. A clinical network is a linked group of health care professionals (doctors, nurses, physiotherapists, occupational therapists etc.) who are all working in a coordinated manner to ensure that patients all receive high quality care, irrespective of where they live.

Our aims are to

1. To identify, describe and understand the educational needs of doctors working within a clinical network, to enable them to deliver best possible care for children and young people with JIA

2. To explore barriers and challenges to addressing these needs

3. To describe strategies to deliver these needs within post graduate educational training programmes

Why are you doing this research?

Juvenile Idiopathic Arthritis (JIA) affects approximately 12,000 children and young people in the UK. The management of this condition has changed in recent decades, with best possible care focussing on early diagnosis, management by specialist teams and earlier treatment. There is accruing evidence that the earlier the intervention, the better the outcome. Clinical networks are developing as a means of sharing expertise and improving

the quality of care that you receive. Paediatric rheumatology is a relatively young speciality and the doctors delivering care will bring various experiences and expertise to the speciality. Previous research suggests that these doctors would value support and training to develop the quality of paediatric rheumatology care.

Why are you asking me to take part?

You have been contacted as a young person who has JIA. We are keen to talk to **a selection of young people** who have experience of healthcare within a clinical network for JIA.

Do I have to take part?

No. We hope you will be interested in helping us with this study, but you do not have to. If you decide to take part, you will be asked to sign a form confirming you are happy to do this. However, this decision is not final. You are free to change your mind at any time and you do not need to give us a reason. Your decision will not affect the treatment or care that you receive.

What will taking part involve, and how long will it take?

We are inviting you to take part in a one-off discussion group lasting around an hour. This discussion group will be facilitated by Dr. Mary Cruikshank. It will be recorded, and – we hope – involve a number of young people. It will take place in a quiet area of the [public place].

What will you do with the information from the focus group?

We will listen to and transcribe the discussion group recording. The recording will be destroyed six months after we have analysed and written up the data. The research team will keep copies of the transcript for ten years in a locked filing cabinet at Newcastle University (in the Institute of Health and Society) and/or in a password-protected area of the University's secure server. Information identifying you, or any other individuals (e.g. your doctor) will be removed from the transcript. After this has been done, Arthritis Research UK (the charity which is funding this project) may see the anonymised transcript. Things you say may be used in reports and publications, but all quotes will be anonymous. The data collected will be treated as confidential unless it suggests malpractice, misconduct, or that someone is in danger of harm. In this situation, we'd need to share the information with appropriate professionals.

Are there any disadvantages to taking part?

There is no risk to you if you take part.

Are there any advantages to taking part?

We cannot promise that you will benefit personally, though some people find it helpful and/or enjoyable to talk about their experiences and feelings with an independent researcher. The treatment and care you will receive will be the same whether or not you take part. However, we hope that the research will help children and young people with JIA in the future, by improving our understanding of the information and support that doctors need to make good treatment decisions.

What if something goes wrong?

If you are unhappy about how the research is conducted, you can contact [INSERT NAME OF SITE LEAD] or the lead researcher, Dr Mary Cruikshank, details are at the end of this information sheet.

Who's funding this research?

Arthritis Research UK is funding this research project.

Who's authorised this research?

This study has been reviewed and approved by the [NAME OF LREC] and the [NAME OF HOSPITAL TRUST].

Who can give me more information?

If you would like more information about the research project, please contact the lead researcher, Dr. Mary Cruikshank [insert email address] or her colleague Dr Tim Rapley (tim.rapley@newcastle.ac.uk). They are both based at the:

Institute of Health and Society,
Baddiley-Clark Building,
Richardson Road,
Newcastle-Upon-Tyne,
NE2 4AX
Tel. 0191 222 7045
www.ncl.ac.uk/ihs

Information Sheet for Professional Discussion Group

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

Research project information sheet for discussion groups

Introduction

We would like you to help us with our research project. This information sheet explains why and how. We have tried to guess what questions you will have and to answer them clearly. If there is anything else you would like to know about the study, please get in touch with us. Our contact details are at the end of this information sheet.

Who are you?

We are a group of researchers and doctors from Newcastle University. Our names are:
Dr. Mary Cruikshank, Prof. Helen Foster, Dr.Tim Rapley and Dr. Jane Stewart.

What is your research about?

Our research is about postgraduate educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network.
Our aims are to

1. To identify, describe and understand the educational needs of doctors working within a clinical network, to enable them to deliver optimal clinical care for children and young people with JIA

2. To explore barriers and challenges to addressing these needs

3. To describe strategies to deliver these needs within post graduate educational training programmes

Why are you doing this research?

JIA affects approximately 12,000 children and young people in the UK. Within the UK, widely differing standards of care exist. Clinical networks have the potential to address inequities in clinical care within paediatric rheumatology. This is acknowledged in the consensus derived British Society for Paediatric and Adolescent Rheumatology (BSPAR) and Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care (SOC) for Juvenile Idiopathic Arthritis (JIA). These SOC set out minimum requirements for a quality clinical service to include "*access to specialist multidisciplinary teams working within identifiable clinical networks, and with appropriate skills and experience for managing children and young people with arthritis".*

The number of paediatric rheumatology clinical networks is increasing, and are a various stages of development, and involve clinicians with variable expertise and training. Pilot data demonstrates a self-perceived unmet need for postgraduate training amongst clinicians working in such networks and a need for further training and support.

Why are you asking me to take part?

You have been contacted as a health care professional involved in the delivery of care to children and young people with JIA. We are keen to talk to **a selection of key professionals** like you.

Do I have to take part?

No. We hope you will be interested in helping us with this study, but you do not have to. If you decide to take part, you will be asked to sign a form confirming you are happy to do this. However, this decision is not final. You are free to change your mind at any time and you do not need to give us a reason. Your decision will not affect your employment status or legal rights.

What will taking part involve, and how long will it take?

We are inviting you to take part in a one-off discussion group lasting around between 45 minutes and 1.5 hours. This discussion group will be facilitated by Dr Mary Cruikshank. It will be recorded, and – we hope – involve the range of professionals involved in the delivery of care for children and young people from your service. It will take place in a quiet area of the [NAME OF HOSPITAL or private room in public place].

What will you do with the information from the discussion group?

We will listen to and transcribe the discussion group recording. The recording will be destroyed six months after we have analysed and written up the data. The research team will keep copies of the transcript for ten years in a locked filing cabinet at Newcastle University (in the Institute of Health and Society) and/or in a password-protected area of the University's secure server. Information identifying you, or any other individuals (e.g. other health professionals that you work with) will be removed from the transcript. After this has been done, Arthritis Research UK (the charity which is funding this project) may see the anonymised transcript. Things you say may be used in reports and publications, but all quotes will be anonymous. The data collected will be treated as confidential unless it suggests malpractice, misconduct, or that someone is in danger of harm. In this situation, we'd need to share the information with appropriate professionals.

Are there any disadvantages to taking part?

There is no risk to you in taking part. It will not affect your employment status or legal rights.

Are there any advantages to taking part?

Though some people enjoy talking with an independent researcher about their educational experiences, we cannot guarantee this will be the case for you. In other respects you will not benefit personally from taking part in the research. However, we hope that the research will help health care professionals in the future, by improving our understanding of the educational needs required in order to facilitate optimal care delivery for JIA within a clinical network.

What if something goes wrong?

If you are unhappy about how the research is conducted, you can contact [INSERT NAME OF SITE LEAD] or the lead researcher, Dr Mary Cruikshank, details are at the end of this information sheet.

Who's funding this research?

Arthritis Research UK is funding this research project.

Who's authorised this research?

This study has been reviewed and approved by the [NAME OF LREC] and the [NAME OF HOSPITAL TRUST].

Who can give me more information?

If you would like more information about the research project, please contact the lead researcher, Dr. Mary Cruikshank [insert email address] or her colleague Dr Tim Rapley (tim.rapley@newcastle.ac.uk). They are both based at the:

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NE2 4AX
Tel. 0191 222 7045
www.ncl.ac.uk/ihs

Information Sheet for Professional 1-1 Interviews

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

Research project information sheet for 1-1 interviews

Introduction

We would like you to help us with our research project. This information sheet explains why and how. We have tried to guess what questions you will have and to answer them clearly. If there is anything else you would like to know about the study, please get in touch with us. Our contact details are at the end of this information sheet.

Who are you?

We are a group of researchers and doctors from Newcastle University. Our names are:
Dr. Mary Cruikshank, Prof. Helen Foster, Dr.Tim Rapley and Dr. Jane Stewart.

What is your research about?

Our research is about postgraduate educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network.
Our aims are to

1. To identify, describe and understand the educational needs of doctors working within a clinical network, to enable them to deliver optimal clinical care for children and young people with JIA

2. To explore barriers and challenges to addressing these needs

3. To describe strategies to deliver these needs within post graduate educational training programmes

Why are you doing this research?

JIA affects approximately 12,000 children and young people in the UK. Within the UK, widely differing standards of care exist. Clinical networks have the potential to address inequities in clinical care within paediatric rheumatology. This is acknowledged in the consensus derived British Society for Paediatric and Adolescent Rheumatology (BSPAR) and Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care (SOC) for Juvenile Idiopathic Arthritis (JIA). These SOC set out minimum requirements for a quality clinical service to include "*access to specialist multidisciplinary teams working within identifiable clinical networks, and with appropriate skills and experience for managing children and young people with arthritis".*

The number of paediatric rheumatology clinical networks is increasing, and are a various stages of development, and involve clinicians with variable expertise and training. Pilot data demonstrates a self-perceived unmet need for postgraduate training amongst clinicians working in such networks and a need for further training and support.

Why are you asking me to take part?

You have been contacted as a health care professional involved in the delivery of care to children and young people with JIA. We are keen to talk to **a selection of key professionals** like you. You may have already attended a discussion group and we would like to explore further some of the issues you raised. Or you may have been unable to attend a discussion group, but have had experiences that would be contributory towards this project.

Do I have to take part?

No. We hope you will be interested in helping us with this study, but you do not have to. If you decide to take part, you will be asked to sign a form confirming you are happy to do this. However, this decision is not final. You are free to change your mind at any time and you do not need to give us a reason. Your decision will not affect your employment status or legal rights.

What will taking part involve, and how long will it take?

We want to understand more about doctors educational experiences within your current service. To do this we need to talk to you, as a health professional involved in the delivery of care to young people and people with JIA. We are asking you to take part in a one-off interview lasting around an hour. This could take place in a quiet area of your [NAME OF HOSPITAL], or other public place, if that suits you better. We would like to record the interview.

What will you do with the information from my interviews?

We will listen to and transcribe the interview recording. The recording will be destroyed six months after we have analysed and written up the data. The research team will keep copies of the transcript for ten years in a locked filing cabinet at Newcastle University (in the Institute of Health and Society) and/or in a password-protected area of the University's secure server. Information identifying you, or any other individuals (e.g. other health professionals that you work with) will be removed from the transcript. After this has been done, Arthritis Research UK (the charity which is funding this project) may see the anonymised transcript. Things you say may be used in reports and publications, but all quotes will be anonymous. The data collected will be treated as confidential unless it

suggests malpractice, misconduct, or that someone is in danger of harm. In this situation, we'd need to share the information with appropriate professionals.

Are there any disadvantages to taking part?

There is no risk to you in taking part. It will not affect your employment status or legal rights.

Are there any advantages to taking part?

Though some people enjoy talking with an independent researcher about their educational experiences, we cannot guarantee this will be the case for you. In other respects you will not benefit personally from taking part in the research. However, we hope that the research will help health care professionals in the future, by improving our understanding of the educational needs required in order to facilitate optimal care delivery for JIA within a clinical network.

What if something goes wrong?

If you are unhappy about how the research is conducted, you can contact [INSERT NAME OF SITE LEAD] or the lead researcher, Dr Mary Cruikshank, details are at the end of this information sheet.

Who's funding this research?

Arthritis Research UK is funding this research project.

Who's authorised this research?

This study has been reviewed and approved by the [NAME OF LREC] and the [NAME OF HOSPITAL TRUST].

Who can give me more information?

If you would like more information about the research project, please contact the lead researcher, Dr. Mary Cruikshank (marycruikshank@doctors.org.uk) or her colleague Dr Tim Rapley (tim.rapley@newcastle.ac.uk). They are both based at the:

Institute of Health and Society,
Baddiley-Clark Building,
Richardson Road,
Newcastle-Upon-Tyne,
NE2 4AX
Tel. 0191 222 7045
www.ncl.ac.uk/ihs

Appendix 3 Cover Letters and Expression of Interest Form

Cover Letter for Parents Discussion Group

Institute of Health and Society
Baddiley-Clark Building
Richardson Road
Newcastle-Upon-Tyne
NE2 4AX

[Date]

Dear Parent,

What does your child's doctor need to know in order to provide the best possible care within a clinical network for JIA?

I'm writing to tell you about a new research project funded by Arthritis Research UK, which looks at educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network.

As part of the project we want to speak to parents who have child with JIA and have had experience of healthcare delivery within a clinical network. We'd really like to learn about your experience. So **we're inviting you to take part in a discussion group** (conducted by me). The discussion group would take place during [insert event] and would take approximately an hour of your time.

I've enclosed an information sheet telling you more about the project. I'd be really grateful if you'd read it. Then, if it's OK for me to call or email you about the research, either return the enclosed 'Expression of Interest' form to the person who gave it to you, or you can contact me via e-mail.

Contacting me doesn't commit you to anything and though it would be great if you could take part, it's totally your choice. Your decision won't make any difference at all to the medical care your child receives.

With very best wishes,

Dr Mary Cruikshank
Arthritis Research UK Educational Research Fellow
[insert e-mail address]

Cover Letter for Young Persons Discussion Group

Institute of Health and Society
Baddiley-Clark Building
Richardson Road
Newcastle-Upon-Tyne
NE2 4AX

[Date]

Dear [name],

What does your doctor need to know in order to provide the best possible care for you within a clinical network for JIA?

I'm writing to tell you about a new research project funded by Arthritis Research UK, which looks at educational needs of doctors who are looking after children and young people with Juvenile Idiopathic Arthritis (JIA), within a clinical network.

As part of the project we want to speak to young people with JIA and have had experience of healthcare delivery within a clinical network. We'd really like to learn about your experience. So **we're inviting you to take part in a discussion group** (conducted by me). The discussion group would take place during [insert event] and would take approximately an hour of your time.

I've enclosed an information sheet telling you more about the project. I'd be really grateful if you'd read it. Then, if it's OK for me to call or email you about the research, either return the enclosed 'Expression of Interest' form to the person who gave it to you, or you can contact me via e-mail.

Contacting me doesn't commit you to anything and though it would be great if you could take part, it's totally your choice. Your decision won't make any difference at all to the medical care you receive.

With very best wishes,

Dr Mary Cruikshank
Arthritis Research UK Educational Research Fellow
[insert e-mail address]

Cover Letter for Professionals Discussion Group

Institute of Health and Society
Baddiley-Clark Building
Richardson Road
Newcastle-Upon-Tyne
NE2 4AX
[Date]

Dear Colleague,

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

I'm writing to tell you about our research project, funded by Arthritis Research UK, which is looking at the postgraduate education of doctors who are involved in looking after children and young people with Juvenile Idiopathic Arthritis (JIA) within a clinical network. The research aims develop strategies to support clinical networks

In the early stages of the project we performed a national email survey of current clinical networks and postgraduate teaching.

We are now inviting you to take part in a one-off 'discussion group' to explore further opinion on teaching and training methodologies in different clinical contexts. We are keen to identify and describe examples of what has worked well and not so well, and why. We will ask what teaching resources are used and where possible examples of teaching methodologies will be collated (with appropriate consent). The group will involve six to eight relevant professionals and will meet for around an hour at [NAME OF HOSPITAL OR UNIVERSITY]. The discussion will be quite informal and we'll provide some refreshments.

I've enclosed an information sheet telling you more about the project. I'd be really grateful if you'd read it (feel free to discuss it with other people before responding). If it's OK for me to call or email you about the research, then either complete and return the enclosed 'Expression of Interest' form or e-mail me directly.

Contacting me doesn't commit you to anything and though it would be great if you could take part, it's completely your choice. Your decision won't affect your employment status or legal rights in any way.

With very best wishes,

Dr Mary Cruikshank

Arthritis Research Educational Research Fellow

[insert email address]

Expression of Interest Form

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

Expression of Interest to participate in further research

Contacting me doesn't commit you to anything and though it would be great if you could take part, it's completely your choice.

Name……

Occupation……

Hospital……..

E-mail address……..

Please send (preferably via email) [insert email address]

Alternatively send via post to

Dr Mary Cruikshank

Arthritis Research UK Educational Research Fellow

Institute of Cellular Medicine, Newcastle University

Musculoskeletal Research Group

Framlington Place

Newcastle University

NE2 4HH

Version1 22/7/2012

Appendix 4 Topic Guides

Topic Guide for Parents Discussion Group

'What does your child's doctor need to know to provide the best possible care for them within a clinical network for JIA?'

Aims

- To identify and describe educational needs of doctors' groups working in clinical networks for JIA, from parents perspective.

By the end of the discussion group the researcher will have:

- Gathered opinion from families with JIA, as to what doctors working within a clinical network for JIA should know, in order to provide the best possible care for their child.

Introduction

To start, would everyone mind introducing themselves?

Procedure

This discussion will be recorded and then transcribed; all contributions are treated as anonymous. The discussion group will last 1 hour; I may have to move things on as we have several areas to cover.

	Objective(s)	Sample questions/probes
Background 0-10mins	Basic information	-Tell me about your child: age and how long has he/she has had arthritis
Interactions with doctors 10-25mins	Account of all doctors involved with child since diagnosis	-Let's create a "master list" [network diagram] of all the types of doctors that you've seen.
	Whether parent perceives a "core care provider" who oversees all the care for their condition (reason for identifying this person/organisation)	-Is there one doctor/organisation in this diagram who is most involved with your child? Tell me about that person/organisation.
Interactions between doctors working in a network 25-40mins	Perceptions of information sharing and knowledge between Doctors	Which Drs communicate with each other? How do they communicate? (E.g. by talking/writing etc.) -How informed is/was Dr Y about your child? How did you know this?
	Perceptions of extent to which Drs share common understanding of condition/plan to address child's needs	-Do your Drs share a plan to address your child's needs? Do they recognize the same problems/symptoms? -Do they share treatment plans with each other? How?
Parents' overall evaluation of continuity of care within a network 40-55mins	Evaluation of care and coherency in care	-Are there links in this network that are strong/weak? Why?

	Objective(s)	Sample questions/probes
	Meaning of “continuity of care” to parents	-There’s been a lot of “continuity of care”. What does “continuity” mean to you? Why?
Concluding questions 55-60mins	Biggest challenges	-Are there areas of your child’s care that you feel your doctor could benefit from knowing more about? Which ones? Why?
	Comparison of experience to others	-Do you think your experience has been typical of others? Why/why not?
	Other topics that may not have been covered	-Is there anything that is important to you that I haven’t asked about?

NOTE: Questions and probes are abbreviated to provide an overall sense of subject matter covered.

Closure

We seem to have reached the end of our time today. We have heard many different opinions today and had very productive discussion and I thank you for that. Some conclusions we can draw are that your experiences of care delivery within a clinical network are ____, and that we should be including education areas focusing on_____. Thank you for your time and participation. Your contributions are invaluable.

Topic Guide for Young Persons Discussion Group

'What does your doctor need to know to provide the best possible care for you within a clinical network for JIA?'

Aims

- To identify and describe educational needs of doctors' groups working in clinical networks for JIA, from the perspective of young people with arthritis.

By the end of the discussion group the researcher will have:

- Gathered opinion from young people with arthritis, as to what doctors working within a clinical network for JIA should know, in order to provide best possible care for them.

Introduction

To start, would everyone mind introducing themselves?

Procedure

This discussion will be recorded and then transcribed; all contributions are treated as anonymous. The discussion group will last 1 hour; I may have to move things on as we have several areas to cover.

Overview of Discussion Group (young people) Questions and Probes

	Objective(s)	Sample questions/probes
Background 0-10mins	Basic information	-Tell me about yourself: age and how long you have had arthritis
Interactions with doctors 10-25mins	Account of all doctors involved with child since diagnosis	-Let's create a "master list" [network diagram] of all the types of doctors that you've seen.
	Whether young person perceives a "core care provider" who oversees all the care for their condition (reason for identifying this person/organisation)	-Is there one doctor/organisation in this diagram who is most involved with your care? Tell me about that person/organisation.
Interactions between doctors working in a network 25-40mins	Perceptions of information sharing and knowledge between Doctors	Which Drs communicate with each other? How do they communicate? (E.g. by talking/writing etc.) -How informed is/was Dr Y about you? How did you know this?
	Perceptions of extent to which Drs share common understanding of condition/plan to address child's needs	-Do your Drs share a plan to address your needs? Do they recognize the same problems/symptoms? -Do they share treatment plans with each other? How?
Young person's overall evaluation of care within a network 40-55mins	Evaluation of care and coherency in care	- What are the most important things that a doctor should know about when you go and see them at a clinic appointment?

	Objective(s)	Sample questions/probes
Concluding questions 55-60mins	Biggest challenges	-Are there areas of your care that you feel your doctor could benefit from knowing more about? Which ones? Why?
	Comparison of experience to others	-Do you think your experience has been typical of others? Why/why not?
	Other topics that may not have been covered	-Is there anything that is important to you that I haven't asked about?

NOTE: Questions and probes are abbreviated to provide an overall sense of subject matter covered.

Closure

We seem to have reached the end of our time today. We have heard many different opinions today and had very productive discussion and I thank you for that. Some conclusions we can draw are that your experiences of care delivery within a clinical network are ____, and that we should be including education areas focusing on_____. Thank you for your time and participation. Your contributions are invaluable.

Topic Guide for Professionals Discussion Group

'Developing an educational framework to facilitate optimal care delivery for Juvenile Idiopathic Arthritis within clinical networks'

Aims

- To identify and describe educational needs of doctors' groups working in clinical networks, and describe what teaching methods work well within clinical contexts.
- To identify, describe and understand challenges to developing (and delivering) an educational programme whilst working within a clinical network.

Objectives

By the end of the discussion group the researcher will have:

- Identified the ways in which doctor groups are currently being taught
- Distinguished between teaching methods that have worked well, and why this could be, and methods that have work less well, and explore why this could be the case.
- Gathered opinion from professionals as to what a teaching package for doctors within networks should comprise of.

Potential Questions
Tell me about postgraduate teaching for paediatric rheumatology. How would you describe your teaching experiences? Do you have any experiences of teaching within a clinical network?
What works well when teaching? And what doesn't?
What factors prevent you teaching? How do you think these could be overcome?
What do you think a general paediatrician working in a clinical network should know about JIA?
What do you think is essential?
How do you think this could and should be taught?
Are there educational materials you would like to help you deliver the standards of care? What formats?

General outline for discussion group		
0-10 mins	Introduction, background and objectives	
10 – 25 mins	Current practice	*What works well?*
		What doesn't?
25 - 40 mins	Proposed content	*What should be included?*
	[Rank content in relation to priority to generate discussion]	
40 – 55 mins	Proposed method	*How should the above be taught?*
		What would help you?
55 - 60 mins	Summary, conclusions and thanks	

Introduction

Good afternoon and thank you for participating. The aim of this discussion group is to produce relaxed discussion around postgraduate paediatric rheumatology teaching within a clinical network, and your opinion and participation is very much appreciated and valued.

Purpose

We are here to get your experiences of teaching within paediatric rheumatology surrounding the skills, knowledge required to delivery optimal care for Juvenile Idiopathic Arthritis. I would like to explore your good, and not so good, experiences, and find out works well and what doesn't. I would also like to hear your view on what you think you need/ needed to know, and in what ways that could be taught. The outcomes of this discussion will help in the development of an educational framework to deliver optimal care within a clinical network. There is no right or wrong, and I hope you will feel comfortable to say what you think.

Procedure

This discussion will be recorded and then transcribed; all contributions are treated as anonymous. The focus group will last 1 hour; I may have to move things on as we have several areas to cover.

Introduction

To start, would everyone mind introducing themselves, and say where they work (study) at present

Current practice

Can you tell me about your current experiences of postgraduate teaching within a clinical network?

Probes

If not – why

If so – do you enjoy it? What works well? What do you find difficult?

What are the good things about teaching? What are the barriers?

Prompts

Time, Knowledge, Curriculum, Learning outcomes

What kind of experience did you find that? In particular, what worked well and what didn't?

Proposed content

What do you think doctors need to know in order to deliver optimal care for JIA?

What is a realistic? What are the boundaries? Essential vs desirable?

What do you expect a general paediatrician working in a clinical network to know and do? Relationship to RCPCH core competencies?

Prompts

Learning outcome, Core presentation, Red flags, Clinical skills – history and examination, MSK knowledge, Skills of networking

Teaching aids

What would help you to deliver education within a clinical network, particularly those aspects we have just been talking about?

Probes

Are there things that would enable you to teach …overcome those barriers already explored

Have you examples from teaching other systems of things that help?

Prompts

What formats would you like these to be in?

Closure

We seem to have reached the end of our time today. We have heard many different opinions today and had very productive discussion and I thank you for that. Some conclusions we can draw are that your experiences of teaching within a clinical network are in general ____, and that we should be including _____.

Is there anything else that anyone would like to ask or add before we finish?

Thank you for your time and participation. Your contributions are invaluable in the construction of this teaching package.