at the start of their journey with JIA, parents have no idea what good looks like. This issue is similar in regard to RA. It is only once you have engaged with the NHS systems for a period of time and had a chance to do some research, that you become aware of what services you should be entitled to receive.

The Project

Our intention, through an initial survey project which started in the autumn of 2012 and completed in late spring 2013, was to map as wide a selection of current services across the UK as possible, within the above timeframe, to identify unmet need in service provision and to document examples of gold standard care and good practice in accordance with ARMA/BSPAR Standards of Care. Simultaneously, we wanted to be able to identify challenges, opportunities and barriers to improving care for families and adolescents, as well as young people transitioning into adult care and to establish how NRAS could add value by providing patient and family services where unmet need exists, working collaboratively with other charities in the sector.

To our knowledge, this has not been done before. The findings of our visits and the results of our surveys (aggregated responses) across the UK are reported in full in this report, 'A focus on JIA'. This report will enable us to produce a business plan outlining an appropriately staged level of services going forward following recommendations from the families, young people and health professionals interviewed as to how they believe JIA-at-NRAS could help. This, in turn will enable our Fundraising Team to identify the level of funds needed to enable such services to be sustainable over the long term.

Department of Health (2004) 'National Service Framework for Children, Young People and Maternity Services' (key issues for primary care: core standards; standard for disabled children and young people and those with complex health needs)


Department of Health; UK Plan for Rare Diseases (2012)

STANDARDS OF CARE FOR CHILDREN AND YOUNG PEOPLE WITH JUVENILE IDIOPATHIC ARTHRITIS Prepared by the Clinical Affairs sub-committee of the BSPAR, and adapted from the British Society of Rheumatology Standards of Care for Rheumatoid Arthritis (1). The standards were ratified by the Executive Committee of BSPAR in January 2009.

The ARMA/BSPAR Standards of Care for Juvenile Idiopathic Arthritis (2010)

The ARMA/BSPAR standards of Care are considered to be the Gold Standard and many of the units visited have either already audited their service against these or are in the process of auditing their service. Cross cutting themes emerging from these standards include ensuring and improving the competencies and skills of all those treating children with JIA, a focus on early referral, diagnosis and treatment start (to minimise damage and disability, disruption to education and impact on social and family activities) and ensuring that all children have access to a specialist paediatric rheumatology team.

There is also, of course, an emphasis on families and young people having access to timely information and relevant support. There are 44 standards and you can access these via the BSPAR and ARMA websites for further information.

One of the reasons for undertaking the project to survey services for JIA across the UK (apart from wanting to identify areas where we could add value), was because we were aware that (similar to RA), there was inequality of access to good care and
Acknowledgements

It is important for me to pay particular tribute to Nicky Kennedy and to thank her on behalf of the team and the Board of Trustees at NRAS, for the dedication and passion she has brought to this project, the many extra hours she has worked and for her tireless enthusiasm for travelling the length and breadth of the UK to gather the data which forms the meat of this report.

Sincere thanks and appreciation also go to my PA, Deborah Flitter, for all the work she has done to support Nicky throughout the project and to both her and NRAS Membership Supervisor, Emma Seymour, for their great efforts in converting the hand-written questionnaires into excel spreadsheets which could be presented graphically within this report.

I am grateful to NRAS Government Affairs Manager, Jamie Hewitt, for working with us on the commissioning aspects of the project, and its equivalent in Scotland, Wales and Northern Ireland, and for contributing on this subject within the final report.

We are very grateful to Dr. Nick Wilkinison, paediatric rheumatologist and External Affairs Manager at BSPAR. He and his team at Oxford allowed me to sit in clinic and observe a busy JIA specialist team at work, for enabling us to attend one of their parent group evenings and for his and BSPAR’s enthusiastic support of this project.

I would also like to thank the health professionals involved in the treatment and care of children and young people in all the units we visited or spoke to, who took part in this work, for their time which they gave freely and openly and last but by no means least, to the many families and young people who sometimes travelled a significant distance to see Nicky and to tell their stories.

Thank you to everyone involved.

Ailsa Bosworth
CEO, NRAS
“I would like to be able to play football. I would like to get back to the person I was, to achieve me. I think I’m different in a good way, think I’m a better person and more understanding”

Boy, aged 15
Introduction to the Report
Ailsa Bosworth, CEO, NRAS

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- Aims of the project
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  - Delivery of services for JIA within paediatric rheumatology
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The findings compiled from discussions with:
- Parents of children and teenagers
- Young people
- Consultant paediatric rheumatologists
- Consultant paediatricians with or without a special interest in paediatric rheumatology
- Adult rheumatologists working with or without a paediatrician
- Members of multidisciplinary teams
- Advanced clinical pharmacist and one senior clinical psychologist
- Directorate and service managers
Discussion

The discussion on the findings within this report concentrates on those elements which inform and guide NRAS to plan both a service and an additional voice for the benefit of children, young people and families coping with JIA.

Appendices

1. Understanding specialised commissioning in England and the equivalent systems in Scotland, Wales and Northern Ireland
2. References to appendix 1
3. Team compositions and regional diagrams
4. Report questions
Introduction to the Report
by Ailsa Bosworth, CEO, NRAS

Background

It has always been our intention that the National Rheumatoid Arthritis Society (NRAS) provide a service for children, families and young people with JIA. That is why, when we launched in 2001, we had a number of Paediatric Rheumatologists as Medical Advisors from the outset. A visit to see Professor Taunton Southwood at Birmingham Children’s Hospital was the first hospital I visited to discuss services for children. However, our adult RA services took off and until recently, we have never had the funding or resources to move this area forward from the provision of simple, basic information, to something more valuable and needed by the families and young people affected.

More recently, Nicky Kennedy, JIA Project Advisor and I have been gradually taking part in activities relevant to JIA in the build up to the start of this work, as follows:

- For the past 2 years or so we have been working collaboratively with Kate Armon and colleagues in the East of England (on behalf of the ‘patient’ voice) as they move towards an informal Managed Clinical Network for paediatric rheumatology across the East of England region.
- In 2011, we collaborated with the British Society for Paediatric and Adolescent Rheumatology (BSPAR) on a project to seek views from families/young people with JIA in regard to putting the 44 standards featured in the (Arthritis and Musculoskeletal Alliance ) ARMA/BSPAR Standards of Care into order of priority from their perspectives.
- I have been the lay member on the BSPAR Juvenile Register (Etanercept) for a number of years.
- Both Nicky and I have been attending JIA sessions at the BSR and EULAR for the last two years or so.
- We have also attended relevant paediatric conferences at the Royal College of Paediatric and Child Health, a family network day in the West Midlands area, presented at the British Society for Paediatric and Adolescent Rheumatology annual conference in 2011 and participated in the 2012 conference.
- We have carried articles about JIA in our magazine.
- We have recently successfully applied for one of our young adult members with JIA to be a lay representative on the Clinical Reference Group (CRG)* for Specialised Rheumatology.

The above activities have contributed valuable background understanding of some of the key issues in service delivery for JIA prior to the commencement of the visits to units around the UK.
A FOCUS ON JUVENILE IDIOPATHIC ARTHRITIS

*(CRGs are responsible for providing NHS England with clinical advice regarding specialised services – which includes paediatric rheumatology – and for the delivery of key ‘products’, such as service specifications and commissioning policies, which enable NHS England to commission services from specialist service providers through the contracting arrangements overseen by its Area Teams).*

**The Evidence Base and Current Guidelines/Standards**

There are a number of national standards and guidelines which relate to paediatric rheumatology. A full list can be accessed within the service specification for Paediatric Medicine: Rheumatology (http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-medi-rheum.pdf), and on the BSPAR website, however some key ones to note are:


- Department of Health; UK Plan for Rare Diseases (2012).

- Standards of Care for Children and Young People with Juvenile Idiopathic Arthritis Prepared by the Clinical Affairs sub-committee of the BSPAR, and adapted from the British Society for Rheumatology Standards of Care for Rheumatoid Arthritis. The standards were ratified by the Executive Committee of BSPAR in January 2009.

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The ARMA/BSPAR Standards of Care are considered to be the gold standard and many of the units visited have either already audited their service against these or are in the process of auditing their service. Cross-cutting themes emerging from these standards include ensuring and improving the competencies and skills of all those treating children with JIA, a focus on early referral, diagnosis and treatment start (to minimise damage and disability, disruption to education and impact on social and family activities) and ensuring that all children have access to a specialist paediatric rheumatology team. There is also, of course, an emphasis on families and young people having access to timely information and relevant support. There are 44 standards and you can access these via the BSPAR and ARMA websites for further information.

One of the reasons for undertaking the project to survey services for JIA across the UK (apart from wanting to identify areas where we could add value), was because we were aware that there was inequality of access to good care and at the start of their journey with JIA, parents have no idea what ‘good’ looks like. This issue is similar in regard to RA. It is only once you have engaged with the NHS systems for a period of time and had a chance to do some research, that you become aware of what services you should be entitled to receive.

**The Project**

Our intention, through an initial survey project which started in the autumn of 2012 and completed in late spring 2013, was to map as wide a selection of current service models across the UK as possible, within the above timeframe, to identify unmet need in service provision and to document examples of gold standard care and good practice in accordance with ARMA/BSPAR Standards of Care.
Simultaneously, we wanted to be able to identify challenges, opportunities and barriers to improving care for families and adolescents, as well as for young people transitioning into adult care and to establish how NRAS could add value by providing patient and family services where unmet need exists, working collaboratively with other charities in the sector.

**To our knowledge, this has not been done before.**

The findings of our visits and the results of our surveys (aggregated responses) across the UK are reported in full in this report, ‘A focus on JIA’. This report will enable us to produce a business plan outlining an appropriately staged level of services going forward following recommendations from the families, young people and health professionals interviewed as to how they believe NRAS could help. This, in turn, will enable our fundraising team to identify the level of funds needed to enable such services to be sustainable over the long term. It’s important to note that the primary purpose of this work and the production of this report is for our own internal needs and for our Board of Directors to fully understand the paediatric rheumatology picture in the UK, in advance of our embarking upon a new direction for the charity.

Having said that, we understand that the wider paediatric rheumatology community is very interested in the findings and outcomes and we have therefore agreed with the British Society for Paediatric and Adolescent Rheumatology to share it widely and it will also be our intention to use it to raise public awareness of JIA which remains extremely low.

It is also very important to reiterate that we are keen to work with others as we have no desire to duplicate work already being done, and to that end have already met with some of the key charities in the field of JIA and there is a great appetite for all of us to work collaboratively.

**The Data**

It is hoped that the findings of this report will be genuinely useful to the health professionals involved in treating and caring for children with JIA. All the survey data has been anonymised. The data in the appendices which is not anonymised for obvious reasons, includes: pictorial and geographical inreach and outreach services including shared care and team compositions in the units visited, all of which are reported in a standardised format. The blank questionnaires used for the different types of health professional interviewed are also included in the appendices.

**Disclaimer**

This is not a research project. The methodology used has been as rigorous as we could make it and is described in section 2 in the report. However, we believe that the report presents an accurate reflection of the different types of services being delivered across the four different health economies in the UK.

Our goal is that this work will lead to the development of ‘JIA-at-NRAS’ and to being able to make a positive difference to the lives of all those affected by Juvenile Idiopathic Arthritis, and to support the health professionals who treat them.

Ailsa Bosworth
CEO, NRAS
The Report

- Aims of the project
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- Data presentation
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- Delivery of services for JIA within paediatric rheumatology
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The Report

Aims of the project

- To report on the varying systems and models of care for JIA in the UK provided by:
  - paediatric rheumatology specialist teams working in specialist (tertiary) centres
  - paediatricians with an interest working 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 in district general hospitals working alone but with good communication with local paediatricians

Methodology

- To arrange visits to a selection of hospital units working to the various differing models
- To meet as many of the team members as possible, consultants, multidisciplinary team (MDT) members, and where possible 1 or 2 parents and 1 or 2 young people cared for by each team
- To establish the main challenges, problems and issues arising around service delivery and transition of young people to adult services for the professionals; for parents, the problems, worries and emotional impact of caring for a child with JIA; for teenagers the impact of having JIA
- To meet with hospital managers having direct links with specialist commissioning
- To establish from all respondents advice and guidance on how NRAS might best focus effort towards improving identified unmet need
- To use semi-structured interviews, individually tailored for each group, with all willing participants. These were developed with lay and health professional input:
  1. Two semi-structured questionnaires compiled to guide discussion with consultants, one for paediatric rheumatologists and paediatricians; one for adult rheumatologists
  2. Semi-structured questionnaire compiled to guide discussion with clinical nurse specialists, physiotherapists, occupational therapists and other multidisciplinary team members as available
  3. Semi-structured questionnaire compiled to guide discussion with parents of children or teenagers
  4. Semi-structured questionnaire compiled to guide discussion with young people (age 10–25)
  5. Semi-structured questionnaire compiled to guide discussion with hospital managers having direct links to specialist commissioning (appendix 4)
- To collate all data collected on excel spreadsheets in order to analyse the findings, prepare a final report and present this for dissemination to NRAS and the Board of Trustees. Subsequently, copies to be sent to the BSPAR Executive and all participating units
- To establish the location of specialist centres and regional referring hospitals along with team composition of each specialist centre (appendix 3)
Data Presentation

Due to the considerable amount of data collected it has been challenging to ensure that the key messages and findings are clearly presented. Analysis of the data has been achieved by examining common themes from each separate set of questionnaires. The report is illustrated with charts and graphs of some of the key data. The scope of each service model has been described in order to highlight variations in access to services and care.

Acronyms used throughout the report:

AHP | Allied Health Professional
ARMA | Arthritis and Musculoskeletal Alliance
BSR | British Society for Rheumatology
BSPAR | British Society for Paediatric and Adolescent Rheumatology
CAMHS | Children and Adolescent Mental Health Service
CNS | Clinical Nurse Specialist
CRG | Clinical Reference Group
CSG | Clinical Studies Group
DBS | Disclosure and Barring Service
DGHs | District General Hospitals
GPs | General Practitioners
JIA | Juvenile Idiopathic Arthritis
MCN | Managed Clinical Network
MCRN | Medicines for Children Research Network
MDT | Multidisciplinary Team
NRAS | National Rheumatoid Arthritis Society
OT | Occupational Therapist
PCT | Primary Care Trust
PEARS | Paediatric East Anglian Rheumatology Society
pGALS | paediatric Gait Arms Legs Spine (physical assessment tool)
SNAC | Scottish Network for Arthritis in Children
SPARN | Scottish Paediatric and Adolescent Rheumatology Network
UK | United Kingdom
WHSSC | Welsh Health Specialised Services Committee

The following alphabetical list includes all units from which data was obtained in the compilation of this report. 30 centres were visited, 3 lead clinicians were interviewed at either the British Society for Rheumatology conference or the Scottish Paediatric and Adolescent Rheumatology Network annual meeting. One interview was conducted via teleconference and email.

Centres were chosen as potential examples that demonstrated varying models of paediatric rheumatological care. The aim was to give both good coverage of the UK and identify the variations in service delivery. Units were approached by email and an introduction made with a request to visit.

<table>
<thead>
<tr>
<th>Centre Name</th>
<th>Hospital Name</th>
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<tbody>
<tr>
<td>Belfast, N.Ireland. Musgrave Park Hospital</td>
<td>Luton, Luton and Dunstable Hospital</td>
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<tr>
<td>Birmingham, Birmingham Children's Hospital</td>
<td>Manchester, Royal Manchester Children's Hospital</td>
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<tr>
<td>Brighton, Royal Sussex County Hospital</td>
<td>Margate, Queen Elizabeth the Queen Mother Hospital</td>
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<tr>
<td>Bristol, Bristol Royal Hospital for Children</td>
<td>Milton Keynes, Milton Keynes Hospital *</td>
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<tr>
<td>Cambridge, Addenbrooke's Hospital</td>
<td>Newcastle, Great North Children's Hospital</td>
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<tr>
<td>Cardiff, Wales. University Hospital of Wales</td>
<td>Norwich, Norfolk and Norwich University Hospital</td>
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<td>Coventry, University Hospital</td>
<td>Oxford, Nuffield Orthopaedic Centre</td>
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<td>Derby, Royal Derby Hospital</td>
<td>Peterborough, Peterborough City Hospital</td>
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<td>Exeter, Royal Devon and Exeter Hospital</td>
<td>Plymouth, Derriford Hospital</td>
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<tr>
<td>Fife, Victoria Hospital</td>
<td>Portsmouth, Queen Alexandra Hospital</td>
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<td>Glasgow, Scotland. Royal Hospital for Sick Children</td>
<td>Sheffield, Sheffield Children's Hospital</td>
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<tr>
<td>Leeds, Leeds General Infirmary</td>
<td>Southampton, Southampton General Hospital</td>
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<tr>
<td>Lewisham, University Hospital</td>
<td>Stoke on Trent, Haywood Hospital</td>
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<td>Liverpool, Alder Hey Children's Hospital</td>
<td>Taunton, Musgrove Park Hospital</td>
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<td>Llandudno, Wales. Llandudno General Hospital</td>
<td>Truro, Royal Cornwall Hospital *</td>
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<tr>
<td>London, Great Ormond Street Children's Hospital</td>
<td>Wishaw, Scotland. Wishaw General Hospital</td>
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<tr>
<td>London, St. Mary's Hospital, Paddington</td>
<td>Wrexham, Wrexham Maelor Hospital</td>
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* Telephone interview
* Face to face interview at BSR Conference & SPARN meeting
Logistical issues

Visits were planned to a variety of settings within the UK where children with JIA are cared for, and included England, Wales, Scotland and Northern Ireland. It has not been possible to cover all units providing care for those with JIA but the geographical coverage has been as extensive as possible. Where possible, visits were grouped in regions to minimise travel and therefore cost.

Unexpectedly, there was often a significant wait to hear back from Consultants to arrange suitable dates/times to visit and this compounded the difficult task of co-ordinating sequential visits in nearby regions. Added to this was the request to meet the members of the MDT, some parents and young people and consequently the logistical challenges became difficult for not only the project leader, but the rheumatology teams as well. NRAS is extremely grateful for the support and co-operation received during all visits.

Delivery of services for JIA within paediatric rheumatology in England, Scotland, Wales and Northern Ireland

The timing of this project has coincided with significant reforms and changes for the delivery of services for JIA throughout the UK, but particularly in England. It is against this background of a continuum of change that the following short accounts of information gathered by NRAS on the overall picture of health provisions in the UK are reported.

Specialised Commissioning has been going through significant change in the current NHS reforms. It has therefore been helpful for NRAS to meet several influential paediatric rheumatologists, in order to specifically gain greater understanding of how the changes will affect the commissioning of paediatric rheumatology services in England going forward.

The reforms, in relation to paediatric rheumatology, currently underway in NHS England are clearly presented in Appendix I.

The population of Scotland is around 5 million and equates to one large regional area in England. Scotland covers a large and challenging geographical area. There are approximately 900 children and young people diagnosed with juvenile idiopathic arthritis, across Scotland, and there may be more, as yet, undiagnosed.

The country is divided into fourteen regional health boards, each responsible for delivery of local health care services. The National Services Division commissions specialist services, based on a number of factors including Deprivation and Poverty Indices. The paediatric rheumatology service for the country is managed as a clinical network called the Scottish Paediatric and Adolescent Rheumatology Network (SPARN) with the specialist centres based in Glasgow and Edinburgh. This was set up in 2009 with a three year funding programme from the Scottish Delivery Plan. At the end of this period each region was expected to take on the necessary funding. This is the only funded Managed Clinical Network in the UK. Within all regions there are now established links with one named unit responsible for delivery of care for those with JIA and their families.

SPARN has adopted the ARMA/BSPAR standards of care for the management of JIA with some minor modifications due to the fact that the health delivery system in Scotland is different. Common protocols and guidelines are in place across the country to drive
quality standards. There is evidence that there is good collaborative working with each region managing their own service, alongside regular network clinics when visiting paediatric rheumatologists attend from either Glasgow or Edinburgh.

There is a parent organisation called SNAC, a registered charity providing factual, practical and emotional support for children, young people and families. It holds parent and carer days rotated around Scotland; fund raising events; trains local contacts throughout Scotland so that they in turn can support other patients and families; organises a weekend event for 20 families each year; connects families through social media to BSPAR and current research and is developing its portfolio and growing constantly.

The position in Scotland, in relation to paediatric rheumatology, is clearly presented in Appendix I.

In Wales there is no specialist centre for paediatric rheumatology. However, at the University Hospital for Wales in Cardiff, the adult rheumatologist with very many years of experience in managing paediatric rheumatological conditions, is providing the specialist service for South Wales. This is delivered within one quarter of each week’s timetable.

Wales has geographical challenges, similar to Scotland, and can be divided into north, mid and south Wales. The total population is 3.1 million with 2 million concentrated in the south.

There is no formal managed clinical network (MCN) in Wales and all specialist services for critical paediatric rheumatology are accessed from England, either from Alderhey Children’s Hospital, Liverpool for those living in the north, Birmingham for families from mid Wales and Bristol for those located across the South. The team from Bristol also provides a regular outreach clinic in Swansea, for families in South Wales. It is acknowledged by most that the services for JIA in Wales are limited.

On this basis NRAS was approached to make links with regard to a national approach to specialist services for paediatric rheumatology. This was achieved by a visit to the Welsh Health Specialised Services Committee (WHSSC), which has responsibility for the joint planning of all specialised and tertiary services on behalf of the seven Local Health Boards (LHBs) in Wales. During our meeting, the extent of the limited resources across Wales was acknowledged. Currently, none of the seven Health Boards are prioritising paediatric rheumatology and it has been agreed that during July/August 2013, NRAS will write to all Local Health Boards on this subject. Discussions were also held as to how NRAS could positively influence the potential funding of a specialist service based in Cardiff to serve a population of 2 million. A new hospital for children is underway on the site of the University Hospital in Cardiff and is due to open in 2015.

The position in Wales, in relation to paediatric rheumatology, is clearly presented in Appendix I.

The specialist centre for Northern Ireland is based in Belfast and serves the total population of 1.8 million. There is a committed multidisciplinary team, all trained in paediatric rheumatology, supporting the paediatric rheumatologist who is employed in a 50% split role between the clinical service and 50% at the university. Although the service is not fully funded as a specialist centre, it is understood that the team will soon benefit from a second paediatric rheumatologist.

The region is sufficiently compact for the team to have good links and co-operation from the referring consultants at the district general hospitals and likewise from the adult rheumatologists taking over the care of young people at the time of transition.

It was possible, on a visit to the centre, to meet some of the parents and their teenagers. There is a parents’ group for mutual support and liaison and the praises of the representative for Arthritis Care who runs this group were applauded by everyone. This role is very highly regarded and valued by the families and professionals and includes face to face support offered to families in their own homes. NRAS welcomes the opportunity to share ideas and to work collaboratively with Arthritis Care for the benefit of families in Northern Ireland.

The position in Northern Ireland, in relation to paediatric rheumatology, is clearly presented in Appendix I.
Understanding specialised commissioning in England and the equivalent systems in Scotland, Wales and Northern Ireland

Health is a devolved matter, meaning that the respective governments of England (Westminster), Scotland, Wales and Northern Ireland each have the power to determine the configuration of their local health services. This in turn has led to different approaches being adopted in the planning and delivery of paediatric rheumatology services. (Greater detail on understanding specialist commissioning in the UK can be found in Appendix I)

The research agenda

This project did not set out to discuss access to research. However, it was reinforced, whilst visiting the specialist centres, that research is integral to maintaining and developing every aspect of care (biological, psychological and social) for the children, young people and families coping with JIA. Research is entirely dependent on sponsorship and recruitment in order to push the boundaries of knowledge forward. There is much hard work and many barriers to achieving these goals. At the request of Professor Michael Beresford, Professor in Child Health, Chair of Medicines for Children Research Network/Arthritis Research UK Paediatric Rheumatology CSG, Nicky Kennedy was invited to meet with him. This was to discuss how NRAS, as a patient organisation, might have influence with families and in addition, with policy makers, for the benefit of research. He highlighted that many children do not have access to clinical research even though they have the right to inclusion from JIA.

Aware of the reputation of NRAS as the ‘Voice of RA’ in the UK and the commitment the charity has to representation on decisions around the inclusion of drugs under NICE recommendations, Professor Beresford would welcome both the consumers’ and the charity’s voice in supporting initiatives for research and priorities in children.

(NRAS has provided the patient input to two relatively recent NICE single technology appraisals for the use of biologics in JIA)

The paediatric rheumatology service in Eire

Short report on the discussions held by phone with Dr Orla Killeen of The National Centre for Paediatric Rheumatology, Our Lady’s Children’s Hospital, Crumlin, Dublin 12.

The next BSPAR conference will be held in the autumn of 2013 and hosted by the paediatric rheumatology team in Dublin. At the request of Dr Nick Wilkinson, External Affairs Manager for BSPAR, it was suggested that it would be beneficial if contact could be made with the lead clinician at the National Centre for Paediatric Rheumatology to explain the JIA project being undertaken by NRAS. Dr Wilkinson made the initial introduction.

Dr Killeen willingly explained their service from Dublin and answered the preformatted questions put to consultants in the UK. NRAS is very grateful for this co-operation.

The total population in Eire is just under 5 million, with the projected number of JIA cases being around 1,000. Dr Killeen will see between 50-70 new diagnoses of JIA annually. There are no referral protocols set up with GPs, it is unlikely that they use the pGALs tool, but the majority of referrals come from general paediatricians, adult rheumatologists and orthopaedic teams from all over Eire. In spite of the referrals coming from secondary care, the quality of the letters is such that it is not possible to judge the level of need of the children referred. The sad consequence is that these children will not receive timely treatment, and it was very shocking to learn that the waiting list for children is two and a half years. Dr Killeen explained that between 6-8 children annually, will attend her new patient clinic with their joints already wrecked by inflammatory damage because of misdiagnosis. In Waterford and Galway there are adult rheumatologists who will see children, with the annual figures being 20-30 in Waterford, and 50 in Galway. Throughout Eire there are two paediatricians with an interest in paediatric rheumatology.
The local team in Dublin consists of 1.7 whole time equivalent (WTE) paediatric rheumatologists, 2 WTE clinical nurse specialists (1 post is currently sponsored), 1.2 WTE paediatric physiotherapists and 0.5 WTE occupational therapist. All other services have to be accessed by referral if available.

The waiting list for ophthalmology screening for uveitis is 12-14 months. The team try to achieve combined clinics when possible. There are no community nursing services. The two CNS and the OT attached to the hospital clinic will liaise with schools and may very occasionally do school visits in the immediate locality.

Support for families in the form of printed or web based information is provided by ARUK and Arthritis Ireland. Arthritis Ireland has a Parents’ Group which provides an educational weekend for families and teenagers. The research nurse on the team is sponsored by the pharmaceutical company sponsoring the research being undertaken at this centre. She is involved with the adolescents and is keen to set up a network for them. Transition clinics are held weekly and in this clinic the team work with an adult rheumatologist. There is also the benefit that the paediatric rheumatologist can continue to treat local teenagers until age 20. Outside the Dublin area much more needs to be done for adolescents.

Dr Killeen has audited their service against the ARMA/BSPAR Standards of Care for JIA as a basis for negotiation for recognition and therefore improvements to the service. She would welcome the benefits of working as a managed clinical network in Eire. At present there is a degree of informal clinical network co-operation. Asked if she had any issues with adult rheumatologists seeing and treating children, Dr Killeen said that she has an issue with these doctors not recognising JIA and consequently there are many cases where the children are clinically under treated.

Dr Killeen attended both conferences, BSPAR in 2012 and BSR in 2013. She praised the adolescent day organised at BSR.

The key issues and barriers to the delivery of the service in Dublin are the need for:

- Guideline development
- Access to care
- The problems that chronic pain and non-inflammatory conditions dominate the service
- The juvenile patient group needs organisation by an external provider
The findings
compiled from discussions with:

- Parents of children and teenagers
- Young people
- Consultant paediatric rheumatologists
- Consultant paediatricians with or without a special interest in paediatric rheumatology
- Adult rheumatologists working with or without a paediatrician
- Members of multidisciplinary teams
- Advanced clinical pharmacist and one senior clinical psychologist
- Directorate and service managers
The Findings

1. Overall findings from discussions with parents of children and teenagers

It is important to note that the majority of parents interviewed attend specialist tertiary centres (20:7) and as such will potentially skew the data.

In total 27 parents around the UK participated in a semi-structured interview, 20 whilst visiting 7 different specialist centres and 7 at 3 different District General Hospitals. There was overwhelming willingness to spend time ‘telling their own story’ and gratitude that their views were sought in order to have some influence on the development of the aims of the charity for the benefit of children with arthritis. Direct quotations are contained within inverted commas and recorded comments may have been précised by the interviewer.

1.1 Can you tell me about your experiences leading up to, and including, the diagnosis of JIA in your son/daughter?

The first 6 months of symptoms and the experiences encountered leading to the diagnosis are highlighted below.

Saw GP, who was not very helpful and “put them off” – the mother said “you trust the Doctors”

“If it will keep you quiet we will do some blood tests”
1.2 What happened at the time of the diagnosis?

10 out of 27 parents admitted to the assorted stresses of a delayed diagnosis and 5 resorted to attending A&E at some point and 1 to seeking an opinion privately. The categorisation of the parents’ experiences is entirely as a result of their own interpretations, for example, worrying symptoms having been dealt with promptly, ‘potentially urgent symptoms picked up’, or the parents’ interpretation of an acceptable timescale for referral and management, ‘timely referral and management’.

The emotionally traumatic experiences will be a lasting memory for this parent:

“The paediatrician was ‘horrendous’ and advised me it was arthritis, that my daughter would be in a wheelchair, may go blind and will be on treatment for the rest of her life”

This experience was only four years ago.

1.3 Where were you seen? Was this a specialist centre or your local hospital?

52% to Specialist Centres
11% to DGHs
33% to DGHs and subsequently Specialist Centres
4% Privately

1.4 Did you feel you were given sufficient information at the beginning?

YES 93%
NO 7%

The initial referral pathway was as follows:
- 52% to Specialist Centres
- 11% to DGHs
- 33% to DGHs and subsequently Specialist Centres
- 4% Privately

n=27
1.5 Were you offered the opportunity to see a Specialist Nurse, Physiotherapist or Occupational Therapist?

All but 11% saw a physiotherapist, not everyone saw a CNS and one third did not see an OT.

*Historically there were no specialist nurses; they were introduced during the ‘90s. Some parents would not have seen a CNS at the outset.

1.6 Did you feel supported and were you given a contact telephone number to call?

1.7 Have you felt that more should have been offered, and if so what might this be?

For most parents there was a universal feeling of support from the team together with a contact telephone number, although 3 of 27 parents reported more could have been offered and 1 parent, whilst positive, “only wanted information gradually”.

“Advice on benefits would have been helpful”

“Needed NRAS to have been able to help at the time and is delighted that this project is underway”

“School teacher who got the whole class to do the physio regularly that her son had to do”

“It was very scary but once the consultant took us on the team were fantastic”
1.8 Have you been offered the opportunity to meet any other parents?

1.9 Is this something that you would want to do?

Just over half the parents had been offered the chance to meet other parents, but 8 would not take up the offer. This was for a variety of reasons ranging from their child having been diagnosed many years previously to a complete lack of interest in that sort of contact with other parents.

1.10 Which websites have you used?

Websites that have been accessed are shown below:

(5) – Local Links
(3) – Google
(1) – NHS Direct
(2) – CCAA Kids with Arthritis
(2) – Arthritis Care
(7) – Arthritis Research UK

20 out of 27 responded
Website preferences indicated in brackets

More than half the parents would have welcomed a comprehensive website on JIA

If there had been a website with comprehensive information on juvenile arthritis at the time of diagnosis, would you have used it?

Have you used a social media site like Facebook?

<table>
<thead>
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<th>Parent Numbers</th>
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<th>No</th>
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<table>
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</tr>
<tr>
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<td>8</td>
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<td>2</td>
</tr>
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</table>
1.11 Are you willing to talk about the impact of your son or daughter’s arthritis on all family members (especially brothers, sisters, fathers)?

The impact on all family members of having one member with JIA has shown significant emotional, logistical and stressful issues but alongside these some added strengths are reported. The full impact data is detailed below:

**Impact on families:**
- Impact on family has increased with older teenager now needing surgery and 2 holidays have had to be cancelled
- Big impact on all family members compromising activities inside and outside the home
- Father has to take days off to attend tertiary centre
- Mother suffers from clinical depression, this worsens when daughter is unwell
- Daughter’s “symptoms and pain make everyone in the family worry”
- “Parenting a sick child is so difficult”

**Impact on fathers:**
- Father had trouble accepting the diagnosis
- Father was very upset at the diagnosis
- Parents split up 3 years ago
- “Father doesn’t understand at all”
- “Father was very upset and felt rather left out”
- Father was unbelieving and did not appreciate mother’s concerns

**Impact on siblings:**
- Tensions between siblings when sister in pain
- Older brother was jealous when he was younger and can still be at 19 years old
- Brother upset by experiences in hospital
- Older sister (with JIA) had to use little brother’s buggy when flaring, which was hard on him
- Brother has watched injections and these worry him
- 2 younger sisters have been affected, the middle child admiring her brother even though she was sidelined a little when growing up
- Sibling anxiety about her older sister
- “Life has been a living hell for him, as he has had to mature quickly” 2 year old younger brother
- Huge pressure on older 2 siblings as the child and her accompanying twin had to travel 200 miles to London for treatment and monitoring (22 years ago)

**Potentially positive outcomes mentioned by parents:**
- Older siblings (2) always involved in everything. Both have now become JIA patients
- Sister has a good grasp of the wider issues of disability
- Younger sister wants to be a nurse
- The parents have needed each other’s support

1.12 The final question to parents asked for their wish list of what they would have wanted to be different:

- Better awareness of JIA
- A sooner diagnosis
- 1 Stop Shop to reduce travelling
- Reducing emotional trauma
- Timely information
- Issues around medication
- Schooling problems
- “For my daughter to be healthy and well”
2. Overall findings from young people who have JIA

In total twelve young people were interviewed, seven receiving care from specialist centres and five from district general hospitals with the age range at the time of interview being 10–25 years between 6 young women and 6 young men. Generally, but not exclusively, the young people were seen on their own and an open discussion was centred around questions to prompt the various topics to be explored.

2.1 What is your earliest memory of arthritis?

Earliest memories of arthritis can be categorised into three main lasting impressions; pain in a joint(s) with or without stiffness; a strongly emotional memory; and physical limitations setting the child or young person apart from their peers in some way.

<table>
<thead>
<tr>
<th>Number of Young People</th>
<th>Pain with or without stiffness</th>
<th>Physical limitations setting child apart from others</th>
<th>Emotional response (Young person or parent)</th>
<th>No memory</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=12</td>
<td>5</td>
<td>4</td>
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</tr>
</tbody>
</table>

- Age 9-10 pain in ankles
- Complaining of aching in ankles
- 3 years ago complaining of stiffness

“At 13 my life falling apart”
“Really scary”
- Specialist Dr. who made him feel at ease and she understood “Initial diagnosis with the paediatrician and with my mother crying”

- In school in the infants class sitting at the side in assembly
  “I liked skipping but had pain in my ankle”
  “At 3 years in nursery had to sit on a chair when other children were on the floor”
- At school doing PE and Sports which led to lack of confidence and self esteem
2.2 What irritates you most about your treatment?

Many treatments prescribed are quite difficult for young people. Almost exclusively, the treatments require regular blood monitoring and many necessitate weekly injections. These are inherently intrusive on their lifestyles which cannot be as carefree as their peers. Methotrexate has several potentially unpleasant side effects, such as nausea, vomiting and others. Some have restrictions that can be irksome to teenagers and many may be unpleasant at the time they have to be swallowed or injected.

Selected quotations highlight some of the irritations:

“Having to have ongoing treatment”

“Blood tests and just having to remember to take it”

“Not the treatment, but the arthritis which limits me is irritating”

“Taking 6 tablets which make me feel sick for 10-20 minutes”

“I hate the colour yellow”

“The weight gain with steroids”

“Just having to have it”

“Injections”

“Having a sleep over and having to take tablets”

“Side effects of treatment especially methotrexate. I hate it”

“The last quote above is increasingly remarked upon by teenagers and parents in conversations”
2.3 Do you ever rebel against the treatment?

![Pie chart showing 58% Yes and 42% No with n=12]

2.4 Do you get fed up with your parents over the treatment?

Rebellion against treatment, feeling fed up with parents and refusal to adhere to regimens are known and understood during the teenage years. These young people were willing to discuss their feelings as shown below:

2.5 Have you ever refused to take your medication, an injection or a special test?

“Not rebelled against treatment “But I’ve had piercings”

“Yes, quite a lot – for infusions for a while, got really anxious but realised I’m fine because I’m getting better”

“Last infusion I said if you can’t get it in the vein I’m not having it”

KEY POINT

2.6 Do you feel your parents, brothers, sisters, friends, doctors, nurses, ever really understand what it is like to have JIA?

Developing the theme around the impact of JIA, the young people were asked if they felt that those around them ever really understood what it is like to have JIA. A mature young man of 15 comments “At the start they didn’t. Now they do especially my family and the team and that really helps”. He explained that he had had a group of friends who didn’t understand and were cruel. He deliberately distanced himself and now he has friends who are more understanding.

“Key Point

“They can’t really understand but try to. Little things in life change around you and for you”

“They don’t understand so I don’t try to explain. I just go off on my own”
2.7 What are you unable to do that you would really like to do?

- Used to play rugby but now doesn’t miss it
- “JIA has had a big impact. I was at county level for rugby and had planned a career in the Marines”
- “Stand for a long time”
- “It has stopped me doing ballet”
- “Be free of the restrictions of JIA”
- This young lady has not felt part of her peer group at school and now at college this is no better.
- “Go out to play and not feel too tired and fatigued”

The eldest young lady interviewed (25 years) felt she had achieved a lot, gained a degree and was able to do activities but has missed out on the physical aspects whilst growing up. She now works full time as a WRVS service manager.

2.8 Do your parents stop you doing things that you would like to do?

No one reported that their parents had stopped them doing things, although one said “they’ve tried but not succeeded”, but there did seem to be a typical adolescent lack of enthusiasm to helping with household chores!

2.9 Do you help with household chores?

Do you have an after school or Saturday job, or are you in full-time employment?

Two of those interviewed are in full-time employment. None of the others have a Saturday job but a lengthy discussion with one young lady (16 years) uncovered considerable adolescent anxieties about feeling unable to take any fulltime employment due to significant debilitating fatigue. In addition she was not wanting to contemplate going to university and was nervous about making a career choice.
2.10 Finally, the young people were asked if they ever had worries that no one asks them about.

“I don’t really worry. I leave that to Mum”
(M 15 yrs)

“Yes but I tell my pet dog”
(F 10 yrs)

“I had difficulties during transition to adult clinics. It was about knowing and understanding and coping with the system”
(F 25 yrs)

“Yes, and sometimes I lie to my parents saying I’m going out with my mates but in reality I’m just going down to the beach to try to sort my head out”
(M 18 yrs)

“Went to a psychologist, same stuff everyone worries about. Did look at stuff on web but not now. Don’t know about transition and this worries me”
(M 15 yrs)

“No, I just get on with things. I may keep pain to myself”
(M 11 yrs)

Just before leaving a 16 year old young lady asked “can I tell you the hardest part? The hardest part of it all is friends understanding JIA, they didn’t believe me; said I was attention seeking. I had a time without any friends. Had a psychologist, it helped for a little while. The whole ‘friends’ thing is VERY hard.”
(F 16 yrs)
3. Overall findings from consultant paediatric rheumatologists working at a specialist centre for paediatric rheumatology

Specialist (tertiary) centres for paediatric rheumatology are led by a consultant paediatric rheumatologist with a supporting team of doctors and a range of allied health professionals (who are specialists in paediatric rheumatology). Many members of the team will work full time within the speciality, although senior clinical posts may include research and teaching commitments at the local University. The essence of a specialist centre is that all possible clinical specialists are available should the complex management skills for very ill children be required.

Data was obtained from 13 specialist centres throughout the UK and included the only quaternary centre, Great Ormond Street Hospital, London. 12 centres were visited and information was obtained from an additional centre by email and teleconference.

Note: Identical questions were used in discussion with paediatric rheumatologists (section 3) and consultant paediatricians (section 4)

3.1 What is your total population?

The regional populations covered, range from 700,000 to 5.8 million but a figure is not quantifiable for the quaternary centre as referrals will come from within as well as outside the UK.

Total regional populations for each specialist centre

(no figure from quaternary centre)
3.3 Are there any posts that you need or wish to fill?

In every centre there is a shortfall of personnel to adequately cover the services required including paediatric rheumatology consultants and notably clinical nurse specialists, clinical psychologists, occupational therapists and physiotherapists.

The diagram below shows the total number of posts required across the 13 centres.

**WTE posts required**

- **Paediatric Rheumatologist** 8
- **Clinical Nurse Specialist** 10.5
- **Physiotherapist** 3.9
- **Occupational Therapist** 3.9
- **Psychologist** 6.1
- **Pharmacist** 1

One centre is in position to achieve a full team following a successful business plan. It is apparent that in most centres, paediatric rheumatology is not prioritised by those responsible for ‘commissioning’ their local services.
3.4 How many children with a new diagnosis of JIA do you see in a year?

All centres complain of inadequate databases to accurately report on the patient numbers and limited coding systems to give meaningful data. Newly diagnosed JIA cases range from approximately 30-100/annum.

Numbers of children with a new diagnosis of JIA/annum

3.5 Do you have any specific referral arrangements? For example, do your GPs use the pGALs tool?

3.6 What would be the pathway for a newly referred child?

3.7 Would this pathway be the same for any age up to 16 or do pathways differ for older children?

Referral patterns show a diversity of routes, from GPs directly if the symptoms have been recognised, but most commonly from general paediatricians or orthopaedic teams and from adult rheumatologists caring for children and sharing care or liaising on cases outside their expertise. Members of a trained multidisciplinary team may also refer children, not uncommonly from the physiotherapy services. Referrals may be received up to age 16 or 17 years dependent on the hospital but there is evidence of a softening of rigid guidelines in regard to age of transition to adult care.
3.8 What about access to ophthalmology? Do you work with someone specific and for example, do combined clinics?

**Silent Uveitis** refers to the condition of inflammation of the eye(s) which can occur in some forms of JIA but which may have no visual or painful symptoms. Regular routine checks must be made on these children and close working relationships with local ophthalmologists are very important. All specialist centres have good working relationships and in many there are regular combined clinics. The ophthalmology services in the areas around the district general hospitals, (served by the specialist centre outreach clinics), may be more of a concern and some are reporting that they are having problems when the BSPAR guidelines for ophthalmology screening in JIA are not being followed. In two centres ophthalmology specialist nurses screen all children alongside the ophthalmologist.

3.9 Can you tell me something about any services in the wider community? For example someone who liaises with schools?

**Services in the wider community** are extremely variable surrounding each specialist centre. For community nursing this may range from no service at all to a co-operative team of paediatric community nurses who will respond to requests, train their staff and provide regular treatment for the patients in their own homes. This is a massive help particularly for the administration of methotrexate injections.

One centre reports that the social worker, as part of the community liaison service, attends the regular multidisciplinary meetings in the hospital to take any appropriate referrals.

**School liaison** is undertaken from all centres, by letter or telephone contact. The opportunity to visit schools to advise directly on specific individual children’s needs would appear to be a diminishing service. Traditionally this has been the role of the OT but not exclusively. Of the 13 centres 6 were unable to visit schools or only provided an extremely limited service, or reported that a community OT might be asked to visit, (and there may be other unreported centres doing likewise), 2 centres did not reply to this query but 4 gave examples of admirable practice. One centre is able to offer visits to schools, in one all children starting methotrexate by injection will be visited by the CNS, in another the CNS will do school visits and will give talks if required, and one consultant will visit colleges for 16-19 year olds.
3.10 What resources would you typically use to provide information and support for families? Is there a local support group?

**Resources provided**

- [Chat](#)
- [Arthritis Research UK](#)
- [Olivia's Vision](#)
- [The Source](#)
- [Arthritis Care](#)
- [For Parents](#)
- [PRINTO](#)
- [BSPAR](#)
- [Consultant/CNS](#)

**Is there a local support group of any kind?**

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Yes – there is a local group</th>
<th>No local group but referred to national</th>
<th>No local group</th>
<th>Local group planned</th>
<th>No answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=13</td>
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<td>2</td>
<td>5</td>
<td>1</td>
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</tr>
</tbody>
</table>

3.11 At what age do children tend to transition from your department?

Teenage patients are gradually introduced to the process of transition from paediatric to adult services by being seen on their own when they are judged to be ready, often from secondary school age onwards. Each centre has differing approaches to preparing young people to be independent of their parents for their health needs and providing the opportunity to discuss ‘normal’ and disease related adolescent issues. Usually young people are seen in an adolescent clinic until they are either in employment or have completed full-time education, aged 16-18.
**3.13 What, do you find, are the typical issues for young people going through the process?**

Typical transitional issues (as expressed by paediatric rheumatologists)

- “They hate it”
- Culture shift from a caring, attentive and responsive paediatric team
- Young people find it hard to adjust to the adult systems
- Psychological issues – emotional anger, depression, mental health
- Body image issues
- Adherence to medication/rebellion
- Unhappy with the shift from entonox for joint injections to local anaesthesia only
- Finding an identity
- Concerns about future aspirations and worries
- Seeking independence
- Sexual health
- Parental changes
- Information seeking

**3.14 Have you or are you planning to audit your service against the standards of care?**

All specialist centres, bar one, said they had audited, or were planning to audit, the service against the standards. One centre did not answer the question.

**3.15 What is your opinion about moving to a Managed Clinical Network (MCN) Gold Standard approach to the management of JIA in the UK?**

All specialist centres are supportive, however, there are several concerns that the lack of allied health professionals in the spoke units means the hub is overloaded; it was expressed that MCNs are almost impossible in a large geographical area (the network for Scotland (SPARN) would counter this); there are concerns about lack of resources and two areas have, as yet, a hub but no spokes.
3.16 Are you operating either formally or informally as an MCN?

- Formally: 15%
- Informally: 16%
- No: 69%

n=13

3.17 How do you work with hospitals in your area where there is an adult rheumatologist who is seeing children?

3.19 Do you have any concerns about adult rheumatologists treating children?

In approximately half the total number of centres visited, an adult rheumatologist was the lead clinician for the care of children with rheumatological conditions. The paediatric rheumatologists were asked how they worked with these colleagues. This is variable. There are some good collaborative working patterns but also some evidence of delayed referral from the adult rheumatologists and ‘inappropriate management’ reported. Most young children will be referred and shared care initiated. Teenagers may be referred for diagnosis and then care maintained closer to home. Outreach clinics held regularly within an established network have the potential to work effectively and in a timely manner.

Close working relationships and trust by all parties will ensure satisfied families, educational opportunities for the teams and efficient use of resources.

In areas where there are no networks and the adult rheumatologists are isolated there may well be a limit to the involvement of any paediatric rheumatology trained MDT members. In some places adult rheumatologists may see younger teenagers privately (14 or 15 year olds). The specialist paediatric teams have concerns that teenagers should not be denied access to the paediatric care that covers the issues around adolescence, development and education. There are also queries made around child protection.
3.20 Were you able to attend the last BSPAR conference?

All specialist centres were represented by team members at the BSPAR conference in Edinburgh 2012.

3.21 Why do you think this conference doesn’t attract more adult rheumatologists who see children?

Paediatric rheumatologists were asked what they felt were the reasons why more adult rheumatologists did not attend the BSPAR Annual Conference:

- Limited funding
- Limited time
- Not seen as a priority
- Fewer rheumatologists seeing children
- “Maybe we’ve put them off”; “seen as a pals’ club”
- The programme needs to be produced 1 year ahead to attract more support
- Topics need to be more clinical; more adolescent based
- Conference may be seen as less scientific

3.22 A further discussion took place around the issues and barriers to the delivery of the service from the specialist centre, summarised below:

- Staffing shortages
- Community care
- Transitional/adolescent/vocational aspects
- Funding of drugs with limited research evidence
- Paediatric rheumatology not ‘emotive’ enough so suffers from low priority and inequitable funding
- More access and availability for research programme required
- Chronic pain is becoming a key coping issue including rising referrals
- Variable confidence in the management of services. Services need stability
- Commissioning/funding; the needs of services are not understood by commissioners
- Political tensions between competing Trusts jeopardising local DGH care
- Gradual privatisation of NHS to the detriment of networks
- Team strength is being part of a managed clinical network
4. Overall findings from Consultant Paediatricians with or without a special interest in paediatric rheumatology (5 units)

Consultant paediatricians caring for children with a rheumatological condition will not be involved full time in the speciality, but have an interest in musculoskeletal conditions, which may be recognised either formally as a special interest within their contract or informally when paediatric rheumatology is a small part of a demanding general paediatrician’s job specification. There are usually good communication links with the nearest specialist centre for advice and guidance. The expertise of the allied health professionals required for the care of the children may or may not include specific training in paediatric rheumatology and the staff may not be based at the same hospital.

The differences in service provision in these 5 units are quite marked.

4.1 Paediatrician – Local DGH catchment population

![Bar chart showing population distribution across different DGHs]

n=5

4.3 Are there any posts that you need or wish to fill?

All units have a shortfall in even a basic multidisciplinary team, and although access to allied health professionals is usually possible, there are no certainties that these staff have experience or training in paediatric rheumatology.

One of the ‘no’s indicated that improvements to the service and the team are “out of his control”’

One hospital said that there was “no OT on the team” and “no psychological support at all”
4.4 How many children with a new diagnosis of JIA do you see in a year?

4.5 Do you have any specific arrangements or referral protocols set up with local GPs? For example do your GPs use the pGALs tool?

4.6 Can you talk me through what the pathway would be for a newly diagnosed child?

4.7 Would this pathway be the same for any age up to 16 or do pathways differ for older presenting children or for different types of JIA?

Although there may be no specific referral protocols set up for GPs, some areas have developed good relationships and consequently receive appropriate referrals that can be followed up with minimal delay. The SPARN network is about to launch its referral standard for the whole of Scotland. Most units made reference to referrals being from various sources – paediatric colleagues, orthopaedic teams, physiotherapists or GPs. The referral pathway is the same for all, up to age 16, and for some it is the same up to ages 17 or 18.

New diagnoses made range between 6-20/annum across the 5 units.

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New diagnoses made range between 6-20/annum across the 5 units.

“We can offer a rapid response of the next clinic or to attend the ward for assessments, with a maximum of 1 week’s wait”

“In this area it can be a tortuous route to get to the right consultant”

“There is no split in the age groups: younger children and adolescents seen in the same clinic”

No available data from 1 DGH, n=5

Some younger referrals (approximately age 14) are being seen by adult rheumatologists, usually privately, but then they have to be referred to paediatric teams as they cannot be seen as part of the adult NHS service.

4.8 What about access to ophthalmology? Do you work with someone specific and for example do combined clinics?

Ophthalmology services do not allow for combined clinics as the numbers are too small. The regular service is variable, referrals may or may not be to known ophthalmology colleagues. One unit reports that their ophthalmology service is overwhelmed, and that they have had problems with non adherence to the BSPAR guidelines for uveitis screening.
4.9 Can you tell me something about any services that you have in the wider community? For example someone who liaises with schools?

Services in the wider community include examples of a social worker liaising with all outside agencies and good community nursing teams. Particularly valuable is the service from community nursing that will teach parents and support them with methotrexate or biologic injections. In one area, the physiotherapy services are out-sourced and consequently there are unknowns with regard to standards of care and staff training in the specialty.

School liaison is undertaken by community physiotherapists or occupational therapists. In one, “There is no school liaison other than by letter from the consultant”.

4.10 What resources would you typically use to provide support and information for families? Is there a local support group of any kind?

Resources provided

- New Patient Pack
- Parents Teaching Pack
- Scottish Network for Arthritis in Children

n=5
4.11 What do you provide for teenage patients? At what age do children tend to transition from your department?

4.12 Can you tell me a little about that process here?

There are many variations within the services for the transition phase of care. Generally it is not possible to offer separate adolescent clinics for the teenagers. In one unit they have developed links with the adult rheumatologists specifically to ease the transition process. The young person will transfer to the adult clinic when this is appropriate but usually between age 16-18 dependent on the local service. The transfer is more difficult when there are several adult rheumatologists locally, which is often the case. SPARN in Scotland is developing a transition document for the network.

4.13 What do you find are the typical issues for young people going through this process?

This list shows some of the typical issues that the young people experience as reported by the paediatricians and mirror those cited by the adult rheumatologists:

- How to manage; medication; lack of education; school issues/sympathy; general support
- Generally they cope well and the CNS has links for other aspects of care and help
- Anxiety around moving to adult services, care is different and there is less support
- Paediatricians treat patients differently in style of service, more relaxed and child friendly. The contrast between paediatric care and adult care is significant. The unit needs a process for transition

4.14 Have you or are you planning to audit your service against the Standards of Care for JIA?

4.15 What is your opinion about moving to a Managed Clinical Network Gold Standard approach to the management of JIA in the UK?

4.16 Are you operating either formally or informally as an MCN?

2 of the 5 units have audited their service against the Standards of Care. A further unit will do so when the Scottish version of the Standards of Care is in place.

There is good support for working within an informal or formally managed clinical network and only 1 unit does not have this opportunity.

4.17 How do you work with hospitals where there is an adult rheumatologist who is seeing children?

4.19 Do you have concerns about adult rheumatologists treating children?

The paediatricians were asked how they worked with an adult rheumatologist in their area. For 4 of the 5 this was not applicable (it may be pertinent to ask why) but one works well with the adult rheumatologist locally sharing the care. One unit has concerns about adult rheumatologists caring for children, reporting that the approach is quite different and they are not good at managing other issues like school or family concerns.
4.20 Were you able to attend the last BSPAR conference?

4.21 Why do you think this conference does not attract more adult rheumatologists who treat children?

2 of the 5 clinicians attended the last BSPAR conference but a realistic comment made is that for general paediatricians there are many calls on their limited time and funding for updating their clinical knowledge, and rheumatology cannot always take precedence. Asked why more adult rheumatologists do not attend conference, it was felt that some feel discouraged, and others may believe it is too specialist centre driven, rather than embracing the teams working from DGHs.

4.22 What do you see as the key issues or barriers that you have overcome or still need to address in the delivery of your service here?

Issues or barriers to be overcome:

- Lack of service recognition for both paediatric rheumatology and chronic pain and consequently inadequately funded provision
- Encroachment on staff’s own time
- Families denied equal opportunities to access the essential services of the multidisciplinary team
- “Winning hearts and minds” of the fund holders
5. Overall findings from adult rheumatologists working with a paediatrician or alone but with good communication with the local paediatricians (16 units)

There are many adult rheumatologists caring for children and young people with a rheumatological condition. Most, but not all, will work alongside a consultant paediatrician and have good links with the local specialist centre. The composition of the teams of allied health professionals will be variable. It is likely that these rheumatologists will have many years’ experience of caring for children and young people as historically arthritis in children was part of an adult rheumatologist’s role.

5.1 What is your total population?

Based on the information given at the interview the total estimated catchment population of the 16 District General Hospitals visited is approximately 8.8 million. The estimated numbers of new diagnoses of JIA reported from each unit totals approximately 200 per annum.

**KEY POINT**

<table>
<thead>
<tr>
<th>DGH</th>
<th>Catchment Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>500,000</td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>16</td>
<td>1,000,000</td>
</tr>
</tbody>
</table>

**Adult rheumatologists – Local DGH catchment population**

n=16
5.2 How many children with a new diagnosis of JIA might you see in a year?

**Adult rheumatologists – number of new diagnoses of JIA seen in a year**

![Bar chart showing number of new JIA diagnoses per annum](chart)

(1 DGH – no data available)  

5.3 Are there any children that you would refer on to a paediatric rheumatology specialist team straight away? If so, what sort of disease profile would prompt you to refer?

The degree to which a local team will need to call on the specialist centre for advice is variable. Seven units receive visiting teams from the regional specialist centre as a regular outreach service. This fosters good communication and the opportunity to discuss and plan best practice. In the remaining eight units some, but not all, rheumatologists have many years’ experience in caring for JIA patients and their families. Some may feel more isolated and although communication with the specialist centre may be excellent this is not always the case.

Dependent on the presenting symptoms to the rheumatologist some children will be referred directly to the specialist centre, for instance, all sick children, the very young or likely systemic onset JIA. In most cases the ongoing care will be ‘shared’ between the specialist centre and the DGH. Where outreach clinics from the specialist centre are in place locally, the children with more serious management problems will be reviewed regularly in those clinics. In the absence of outreach clinics the families will have to travel to the specialist centre for as long or as frequently as necessary.
5.4 Which is your local specialist centre?

The adult rheumatologists visited have links with the following specialist centres:
- Great Ormond Street Hospital, London
- Nottingham Children’s Hospital
- Bristol Royal Hospital for Children
- The Nuffield Orthopaedic Centre, Oxford
- Birmingham Children’s Hospital
- Alderhey Hospital for Children, Liverpool
- The University Hospital for Wales, Cardiff
- Royal Hospital for Sick Children, Edinburgh

5.5 Do you have any kind of referral pathway established with the surrounding GPs?

Referral pathways from local GPs to the adult rheumatologists who run clinics for paediatric patients may be dependent on the experience and expertise of the rheumatologist and therefore the known reputation of the clinician. As with any other referral to a service for paediatric rheumatology, there may be delays in these referrals. In one unit the local GPs are asked to refer all musculoskeletal problems promptly so that important diagnoses are not missed. A few units have established pathways and in Scotland it is reported that “GPs in Scotland will not follow pathways”. However, the majority of referrals will come via the general paediatricians.
5.6 Do you have a paediatric specialist nurse working with you or does your adult specialist nurse work with you and your JIA patients, and similarly physiotherapists and occupational therapists?

5.7 Do you work alongside a paediatrician and are they hospital or community based?

Ten adult rheumatologists run their clinics alongside the paediatrician and six have established links with the local paediatricians for advice or referral. The paediatricians are usually hospital based, two in this sample were community based.

The extent of the multidisciplinary teams attached to these consultants is very variable and not all members are paediatric trained or have specialist knowledge in rheumatological conditions in children, as shown below:

**Which team members work with you?**

<table>
<thead>
<tr>
<th>Unit</th>
<th>In Clinic</th>
<th>Advice Only</th>
<th>Paediatric Specialist Nurse</th>
<th>Paediatric Physio</th>
<th>Paediatric OT</th>
<th>Adult Specialist Nurse</th>
<th>Adult Physio</th>
<th>Adult OT</th>
</tr>
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<tbody>
<tr>
<td>1</td>
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<td>16</td>
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**SUMMARY**

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<table>
<thead>
<tr>
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<tr>
<td>Adult specialist nurse only</td>
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<tr>
<td>Paediatric MDT</td>
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<tr>
<td>Adult MDT</td>
<td>1</td>
</tr>
<tr>
<td>Adult CNS with paediatric assistance</td>
<td>7</td>
</tr>
<tr>
<td>Paediatric Physio only</td>
<td>1</td>
</tr>
</tbody>
</table>
5.8 Are there any services in the wider community? For example someone who liaises with schools?

All units, bar one, have systems in place to liaise with schools and many are able to offer visits. Community paediatric nurses, OTs and physiotherapists offer a service for these families but they are likely to be very stretched.

5.9 What about ophthalmology? Do you work with someone specific and do combined clinics?

Ophthalmology services are available to all units but there are no combined clinics.

5.10 What resources would you typically use to provide information and help for children and families? Is there a local support group?

A support group is only available locally from 1 unit and in this area there is also a support service for children with chronic diseases. Another unit benefits from the regular events and activities provided by Arthritis Care and these are much appreciated.
5.11 Have you got good co-operation with the local GPs and practice nurses?

This data suggests that there is room for improvement to achieve seamless services.

<table>
<thead>
<tr>
<th>Local PCT/CCG Co-operation</th>
<th>Satisfactory</th>
<th>Unsatisfactory</th>
<th>Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21%</td>
<td>36%</td>
<td>43%</td>
</tr>
</tbody>
</table>

The issues around this move are summarised below but generally the adult rheumatologists feel that the gradual process of helping young people to understand and cope with their long term condition is achievable.

5.14 What do you find are the typical issues for young people going through this process?

Transitional issues as reported by the adult rheumatologists:
- Move from paediatric service to perceived more intimidating adult service
- Loss of security from previous close links especially with the CNS
- Attendance for therapies
- Becoming independent from parents/conflict/parents letting go
- The less academically able need more support
- Pregnancy/contraception
- Alcohol/sex/sexuality and illegal drugs
- Taking control of their disease
- Schooling/bullying/social issues
- Coping with university/further education
- Not being like others
- Career choices
- High social deprivation is an additional challenge

5.12 Do you have different clinics for adolescents and their parents or are they seen in the same clinic as younger children?

5.13 How do you organise transition for teenagers or young adults. What age are they when they move to the adult clinic?

**Transition from the paediatric to the adult service** is universally between 16-18 years for all the units visited. 47% of the adult rheumatologists are able to provide separate adolescent clinics. The process is not seen to be a challenge, by the clinicians as often the care remains with the same adult rheumatologist. The environment will change, and so too, the culture within the adult service. Some multidisciplinary team members will be different.
5.15 Were you able to attend the last BSPAR conference?

![Pie chart showing 69% Yes and 31% No.](chart.png)

n=16

5.16 What resources do you like to access for up to date clinical information?

- Information from GOSH
- Hospital library service provides bulletins by speciality
- BSPAR updates
- Paediatric network meetings
- Educational day in Bristol
- BSR
- Workshops
- Colleagues
- Regional adult rheumatologist meetings
- PEARs meetings
- Journals
- Paediatric international forum
- Online discussion boards
- e-learning
- SPARN

5.17 Do you feel that the BSPAR Conference caters sufficiently for the adult rheumatologists?

"Probably not" “Could be better” Reasons and suggestions are summarised below:

- Need a reasonably specific attraction to go
- Conference needs to change to accommodate all consultants, all AHPs and wider networks
- Suggested topics to include: pregnancy and care during labour/ surgery in young adults/long term complications eg Amyloidosis/young adult JIA issues
- Conference lacks scientific focus
- BSPAR is not seen to attract adult rheumatologists, non paediatricians are not made to feel welcome
- Conference must acknowledge that not all units can work to a Gold Standard in everything
- Significant concern that adult rheumatology trainees are not getting training in paediatric rheumatology, particularly issues around late adolescence and early adulthood
### 5.18 Are you familiar with the ARMA/BSPAR Standards of Care?

### 5.19 Do you agree with and support these standards?

### 5.20 Have you, or will you plan to audit your service against the standards?

All adult rheumatologists, bar one, were familiar with and supported the Standards of Care. Eight units have already audited their service, three will undertake this as part of their plan, from one the response is unknown and the remaining four units have no plans to do an audit but one rheumatologist replied “Perhaps we should think about this”.

### 5.22 Do you see any issues or barriers to the delivery of your service here?

- Lack of money
- Lack of time for additional clinics
- Lack of adequate knowledgeable teams, particularly serious lack of CNS time
- Needing to ‘Future Proof’ the service
- Geographical issues disadvantaging the most disabled children and compromising care for the remainder
- Divided responsibilities between the acute Trust and the Community Trust compromising the care and stability of the MDT
- Contracts of employment not accommodating service delivery in paediatric rheumatology leading to funding and communication issues

### Comment on access to research

Given the picture that has emerged from this group of units it has to be acknowledged that even with the best efforts, access to research programmes is potentially difficult or very unlikely. The key issues are lack of funding, recognition of the importance of, and the will to support research by the management structure and the available time of clinicians and families.
6. Overall findings from members of the multidisciplinary teams from 10 specialist centres and 9 other units where the lead clinician is either an adult rheumatologist or a general paediatrician:

Clinical Nurse Specialists

The survey with the members of the multidisciplinary team was reliant on the availability of as many team members as possible on the day of the visit. This was often quite challenging. In all, 19 clinical nurse specialists were interviewed and of these 10 were attached to specialist centres and 9 to DGHs. 9 occupational therapists were seen, 6 at specialist centres and 3 at DGHs and 13 physiotherapists, 7 at specialist centres, 6 at DGHs. Finally 2 podiatrists, 1 at a specialist centre, 1 at a DGH and 1 pharmacist and 1 clinical psychologist at specialist centres.

6.1 Do the clinics run as a ‘One Stop Shop’?

6.2 Which healthcare professionals are available in every clinic?
6.3 Do you run nurse led clinics? Which aspects of care do these cover?

The CNS role is multifaceted and whether working from a specialist centre or a DGH the nurses manage the education, support, advice line and urgent access for the patients and families, with the majority running their own nurse-led clinics. Patient assessment is not undertaken by all, and is dependent on the experience of the nurses and the clinic structures within each unit.

Aspects of care which the nurse led clinics offer

There are no CNS led clinics in 4 units, 2 at specialist centres and 2 at DGHs, so they are not included in this data.

6.4 How is the advice/helpline organised and are you overwhelmed? Can you book urgent reviews easily?

All units offer access for parents to the advice or helpline service. This is managed by the majority as direct calls or emails to the department. The remaining nurses have an answerphone, but one nurse is reliant on calls redirected from the consultant’s secretary (this was because, at the time of interview, the CNS was still waiting for an office, a desk and a phone in spite of being in post for 2 years).

Many nurses can find themselves overwhelmed by the numbers of calls and emails. Where there is an adult CNS covering the paediatric service there will be additional pressures on their time and any nurse only working part time will have issues with returning calls at an appropriate point in their working week.

Encouraging examples were also given of a very comprehensive service where new patients are followed up with a phone call; where young people at the point of transition are encouraged to call in to the nurse to maintain continuity of care; where families who are not managing well are contacted regularly and more. Urgent access to the team, for review, is managed in various ways but all units can offer a timely response.
6.5 What are some of the reasons for calling the advice/helpline?

**Common reasons for calling advice line**

<table>
<thead>
<tr>
<th>Reason</th>
<th>CNS Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side effects/medication</td>
<td>7</td>
</tr>
<tr>
<td>Flare/Pain</td>
<td>6</td>
</tr>
<tr>
<td>Unwell children/general advice</td>
<td>4</td>
</tr>
<tr>
<td>Psychological/social support</td>
<td>3</td>
</tr>
<tr>
<td>Blood tests</td>
<td>2</td>
</tr>
<tr>
<td>Immunisation/chickenpox queries</td>
<td>2</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>1</td>
</tr>
<tr>
<td>Psychological/social support</td>
<td>3</td>
</tr>
<tr>
<td>Blood tests</td>
<td>2</td>
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<tr>
<td>Immunisation/chickenpox queries</td>
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<td>Prescriptions</td>
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<td>Psychological/social support</td>
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<td>Immunisation/chickenpox queries</td>
<td>2</td>
</tr>
<tr>
<td>Prescriptions</td>
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</tbody>
</table>

n=19

6.6 Are you involved in outreach clinics, liaising with colleagues in other units?

8 CNS are involved in outreach clinics, either as part of the team visiting DGHs or receiving the outreach advice from the specialist centre. All but 3 CNS felt that their work was not threatened but there is a general sense of insecurity at present which was raised during discussions.

6.7 Are you able to deliver the service you need or want to?

There were a raft of suggestions to this question as detailed below:

- Frustrated by lack of time to develop the services
- The patient load is overwhelming
- The complexity of cases is challenging
- There are not sufficient staff, particularly need psychologist, dietician, social worker
- Continually in crisis management
- Significant number of hours worked as extra hours
- Aware that not all patients are accessing the care they need because they are less educated, not ‘savvy’ enough
- Real concern that the role is not ‘visible’ to management/commissioners
6.9 What would you change if you could?

Developing the conversations further by asking “What would you change if you could?” there is a universal sense of diminishing job satisfaction because everything is becoming an overwhelming struggle to cover the basic service.

On a more positive note the discussions led to a desire to develop the services, to have more face to face time with families, to establish drop in clinics for teenagers, for more child friendly areas in clinic for informal education and links with families, to have a realistic annual review and transition programme, to have a defined multidisciplinary team approach to care and liaison. The suggestion was also made that there might be advantages in having a defined specialist role in nursing that is pertinent to DGHs and not necessarily the same as for specialist centres.
7. Overall findings from members of the multidisciplinary teams from 10 specialist centres and 9 other units where the lead clinician is either an adult rheumatologist or a general paediatrician:

**Physiotherapists, Occupational Therapists and Podiatrists**

**KEY POINT**

7.1 Are you available for every clinic, in the clinic or elsewhere?

7.2 Can parents contact you directly?

It emerges from the data that many families have to be referred to these professionals as they are not part of clinics providing a ‘1 stop shop’ approach to care. This necessitates a return visit to the hospital, either specialist centre or DGH with compounding disruption to schooling, employment and the possibility of having to call on the good will of relatives or friends again. In some hospitals physiotherapy services are only available in the locality and these staff may not have had specific training in paediatric rheumatology. However, in all but one unit, all therapists and the 2 podiatrists interviewed can be contacted directly by parents and all can book patients to their own clinics for review.

**Availability of therapy services**

<table>
<thead>
<tr>
<th>Availability of Therapy Services</th>
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</thead>
<tbody>
<tr>
<td>Physiotherapists, OTs &amp; Podiatrists</td>
</tr>
<tr>
<td>Available</td>
</tr>
<tr>
<td>Physio n=13</td>
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</table>

7.4 Are you able to deliver the service you need or want?

7.5 Is your work with JIA under threat?

‘Are you able to deliver the service you need or want?’ was asked of these MDT members and as shown in the data some services are compromised. From some tertiary centres it was admitted that the service ‘was less than ideal’, that it is difficult for ‘out of area children’ as the OT service is not part of the outreach clinics. In one centre physiotherapy has been halved in paediatric rheumatology in favour of the orthopaedic team’s needs. In another the demands of non-inflammatory pain is taking more of the service to the detriment of the surveillance of the JIA population, for example the loss of end of range movement in joints needs timely scrutiny. Positive comments are also made, “it is a very integrated professional team”; “appointments are quite structured; OTs are working towards active screening”; and “local provision for JIA is improving”.

In the DGHs the provision of MDT services is variable with centres reporting a variety of issues, “aware that the children do not get the best service”; “only local children can be seen, up to 40% are outside the area, there is no recognition of the service and no funding”. But here too, there are also good reports “generally both the physiotherapist and OT can deliver the services they need and want to and both are experienced and have autonomy”; one podiatrist interviewed felt “able to deliver the service she was happy with, but extra time for joint working with the physiotherapist would be good”; in another unit physiotherapy can offer a significant hydrotherapy service.
THE FINDINGS FROM MEMBERS OF THE MULTIDISCIPLINARY TEAMS FROM 10 SPECIALIST CENTRES AND 9 OTHER UNITS WHERE THE LEAD CLINICIAN IS EITHER AN ADULT RHEUMATOLOGIST OR A GENERAL PAEDIATRICIAN CONT.

7.4 Are you able to deliver the service that you need/want to?

All MDT members were asked if their service for JIA was under threat. Happily 16 did not feel threatened. A few had concerns, some have an uncertain future dependent on the decisions around commissioning, others the possibility of having to support alternative clinical needs, and also mentioned was the changing nature of the work in JIA. There may be less splinting but more secondary problems such as writing fatigue requiring hand exercises.

7.5 Is your work with JIA under threat?
7.6 Do you visit children and teachers in schools?

7.7 Are you involved in outreach clinics, liaising with colleagues in other centres?

From this group of 24 MDT members, 2 physiotherapists and 1 occupational therapist are involved in outreach clinics. Liaison is undertaken by 8 physiotherapists, 6 OTs and 1 podiatrist.

7.8 What would you change if you could?

- More investment in professional staff, therapists, psychologists
- Investment in administrative assistants and clerical staff
- Better treatment areas
- Better availability of physiotherapy services ‘out of area’
- Improved peer support around transition issues
- Improved communication between tertiary centre and DGH
- A reduction in the numbers attending each clinic
- Achieving a dedicated rheumatology unit
8. Findings from 1 Advanced Clinical Pharmacist and 1 Senior Clinical Psychologist

Discussions were held with both health professionals attached to the multidisciplinary team for paediatric rheumatology at one specialist centre.

**Advanced Clinical Pharmacist**

Within paediatric rheumatology the post is 0.1 WTE which equates to one half day weekly.

**The scope of the role includes:**
- Pharmacist prescriber for rheumatology
- Organisation of home care delivery for methotrexate and biologic medication
- All methotrexate monitoring, checking relevant blood test results
- Reporting on relevant NICE reviews
- Undertakes clinical reviews on evidence for differing indications for special cases; case study evidence and adult random controlled trial data
- Develops child/young person friendly versions of information leaflets
  (Feedback would be welcomed on these leaflets from patients and families via NRAS)
- Working towards resolving the anomalies between areas on the categorisation of many drugs used in rheumatology (amber/red categories which influence prescribing by GPs)
- Investigation into the problems and issues around biologic medication records in medical notes, particularly in primary care when all prescribing and monitoring is undertaken in secondary care

**Senior Clinical Psychologist**

Within paediatric rheumatology the post is 0.2 WTE which equates to 1 day/week

**The scope of the role and some implications include:**
- Teaching/supporting/training the paediatric rheumatology team
- Developing good working relationships with team members
- Taking referrals for psychological support for patients/families (the waiting time reported at the time of interview was 4-5 months with no other psychological support for JIA within the entire region)
- Local CAMHS teams do not accept referrals for psychological stress due to treatments
- Huge NHS pressures
- “The reality of provision of psychological support is good in theory but not easy in practice”
9. Discussions with Directorate and Service Managers on services for JIA

One aim of this survey was to meet managers in a variety of centres having direct links and influence with specialist commissioning in order to understand the organisation within the hospitals for the implementation of specially commissioned services.

In spite of requests made to several specialist centres only three managers were available. The pre-prepared questions for discussion proved difficult to comment on given the uncertainties that have existed and continue to exist in the NHS, particularly around specialist commissioning.

Two service managers in England and one in Wales were interviewed.

There were no definitive answers on how they saw their role in relation to specialist commissioning for paediatric rheumatology services. One felt that the senior consultant would interface with commissioners and that the aim needs to be for ‘Best Practice Tariff’. The recurring obstacle remains in that “there will probably not be enough money to meet service specification”. A second manager had been working on NHS contracts and was confident that his role would have some influence locally. The consultant adult rheumatologist for the paediatric service in Wales has been appointed as gatekeeper for services and referrals going outside Wales. This will necessitate development of services within Wales.

There is concern that nationally commissioned services will be so big and have such a wide portfolio that there may continue to be ‘winners and losers’ in the apportioning of funds. However, specialist commissioning is expected to raise the profile of paediatric rheumatology. This system will not apply in Wales.

None of the managers were aware of the Standards of Care for children and young people with JIA and no mechanisms are in place to capture feedback from families coping with JIA.

To the question, how well do you feel paediatric rheumatology is financed in your hospital, one manager believed it was reasonable and in Wales that this may involve ‘spending to save’ and the work underway to build a children’s hospital should ultimately bring the saving from not needing to refer to services outside the country. The remaining manager was probably not aware of this detailed breakdown in funding needs but felt peer review and benchmarking give important evidence for change.

It was possible to leave a portfolio from NRAS on the nature of JIA, some important statistics, the locations of specialist centres and the NRAS Annual Review 2011/12. In addition, with our thanks to the paediatric rheumatology team at Birmingham Children’s Hospital, three copies of DVDs were included in this pack, two covering young peoples’ views and comments on their care and one of parents talking to camera of the stresses and problems of getting to the correct consultant in a timely way and coping with a diagnosis of JIA in their child.
Discussion

The discussion on the findings within this report concentrates on those elements which inform and guide NRAS to plan both a service and an additional voice for the benefit of children, young people and families coping with JIA.
Discussion

The discussion on the findings within this report concentrates on those elements which inform and guide NRAS to plan both a service and an additional voice for the benefit of children, young people and families coping with JIA. In addition the varying systems in the UK for managing this condition will be compared to the extent that inequalities where apparent, can be highlighted in order to provide a knowledge base towards lobbying for access to equitable care for all.

The impact of JIA is felt long before the opportunity for any diagnosis is made. Delayed referral to the right clinician has been reported for many years. It is still the cause of anguish, frustration, false hopes and suffering for all family members. This is an educational issue for all students of medicine and the allied health professions. Once diagnosed the pathway of care differs dependent on the families’ geographical location. For those living in the North of England and the Midlands, a specialist centre is usually available within a reasonable distance from home and care is likely to be shared with the local DGH, many of which offer a fully trained MDT. Areas with very limited and distant access to specialist centres are the South West, South East, East Anglia, parts of Lincolnshire, Cumbria and the far North. In these areas the breadth and the scope of the service beyond the specialist centre may be fragmented.

In Wales there is no specialist centre (as discussed). In Scotland the SPARN network has allowed the country to develop a comprehensive co-ordinated approach to care and management and in Northern Ireland the specialist centre is expanding and has the will to develop.

It is clear that having good local shared care between specialist centres and DGH teams is important for families. A priority must be to ensure that the local teams currently delivering care are supported in every way possible to develop and improve their service. One of the difficult issues is to establish the best solution for families where there is no outreach (or network) clinic and the specialist hub is far distant. Also, local societal problems, complex families, cultural barriers, poverty and deprivation will be best served locally. In some areas where the service is limited there are signs that people are ‘voting with their feet’ once they are aware of the level of service they should be able to access.

Notably in some DGH units the care and support for families is very comprehensive whether the lead clinician is a paediatrician or an adult rheumatologist. The teams are passionate about their clinical roles, about delivering an excellent service in all aspects and as a consequence the parents may well decline to visit the specialist centre. This can also be because of other factors, often economic, with families unable to afford or to organise themselves to travel a significant distance. There are many large areas in the UK trapped in significant poverty and deprivation. This not only refers to economic factors but educational, social and emotional issues. These families particularly, will bond with their local team, build relationships of trust and dependency and find it hard to imagine that another hospital will deliver any greater benefit.

The families in areas a long way from the specialist centre may also find that there is no outreach provision of specialist teams visiting. In these cases they have no option but to travel themselves to the specialist centre when the clinical need cannot be met locally.
There are some units, however, where the lead clinician is an adult rheumatologist with no named MDT members other than the limited support of their adult clinical nurse specialist. All therapy needs have to be organised by referral and the opportunity for ‘team’ building, close working and co-operation, are potentially compromised. It has to be questioned whether the bio-psycho-social needs, particularly in relation to developmental and educational issues, parental and sibling stresses, can be addressed by these units when there would appear to be limited opportunity for intercommunication between the professionals. The paediatrician working alongside these rheumatologists, although this is not the case in every unit, will add their professional expertise but the tasks of support, education and regular assessment of family need is best placed with the MDT and without this, some problems will not be addressed in a timely way.

The experienced knowledgeable teams and those clinicians working at a distance from the specialist centre are apprehensive of the future, fearing that specialist commissioning will direct all funding to the specialist (tertiary) centres. These clinicians are protective of the families in their care, aware of the stresses and strains, the travel problems, understand the impact for parental wage earners and the loss of schooling for the children and young people. Also, in many areas there are significant cultural and ethnic variations, complex families and language difficulties. Local experience and expertise are invaluable. Many adult rheumatologist-led units are providing a service which would appear to be meeting the needs of the families and young people admirably and it is a service close to home. This situation would appear to be contrary to some generally held assumptions.

Like other members of the MDT, clinical nurse specialists are overburdened and frustrated. This is uncomfortable for any health professional, indeed for any committed employee and saps energy, vision and drive for improvements. Why does this state remain invisible? Simple changes could solve some problems immediately, for instance administrative help and more junior staff to assist in day to day tasks. The expertise of any specialist nurse, physiotherapist or occupational therapist is an expensive asset that at present is inappropriately squandered in many locations. The desire to develop services is very evident with a whole range of ideas from each centre and every MDT member but it is very telling that many of these aspirations have been passed to NRAS in the hope that the charity can begin to meet some of these goals.

Physiotherapists, OTs and podiatrists are working in a range of differing organisational structures. Some jobs are secure, some threatened by cuts in favour of other services. Does this reflect invisibility or simply lack of systems to accurately code activities against diagnoses? Physiotherapists and OTs are the specialists in liaison and advice whilst visiting schools. This service has been reducing over recent years and may be a factor in the limited knowledge and understanding that is reported amongst teachers by parents and young people. A letter is no substitute to an experienced professional’s visit to school. Without good communication the burden for the young person is increased, there is likely to be a sense of guilt that they may be jeopardising the school’s reputation because of absenteeism outside their control and there is less understanding throughout the school population.

All centres were acutely aware that the support and expertise of clinical psychology was exceedingly limited. Where business plans have been successful in this and other needs being acknowledged, it would be beneficial to be able to share their strategy. There will be other examples of sharing good practice and this should be encouraged for the benefit of all. There is neither the time nor the funding to expect every region to reinvent service specifications. The consultants in each centre were asked, from their perspective, what they considered to be the issues and barriers they faced in the development of a truly gold standard service. The lists of responses are recorded in sections 3, 4 and 5.

It has been unfortunate that the timing of this project has coincided with changes and uncertainties in the NHS. It has meant that an attempt to meet managers with direct links to specialist commissioning has been thwarted.
No real findings can be drawn from the three interviews conducted as these managers remained uncertain as to their role in influencing the provision of specialist rheumatology in their centres. The overall impression gained was that this speciality, whilst acknowledged, was not one that attracted much energy, drive or, importantly, funding.

This project was undertaken with some background knowledge of the varying models of paediatric rheumatology care and services and together with this, a vision of what a gold standard service should constitute. Indeed, this is set out in the ARMA/BSPAR Standards of Care for Juvenile Idiopathic Arthritis. This survey, covering 18 paediatric rheumatologist or paediatric led services and 16 adult rheumatologist led services, has highlighted some important findings.

The conclusions that may be drawn from these are that there must surely be wasted time, effort and considerable money in not standardising the systems for the delivery of services. This is reflected particularly in the employment of all staff required, in the directorates to which they are attached, the variations in the ‘allowed’ activities that team members can undertake, the unrealistic volume of work versus available time and the expectation that all professionals will ‘give’ time because there is no other solution.

Many centres are struggling, in spite of providing a comprehensive committed service. This is the case in both the specialist centres and many DGHs. However, it appears that there is a considerable divide between the specialist centres together with several DGHs and the remaining units where the service is limited in breadth and depth of provision.

There are goals which NRAS would want to promote by lobbying at Government level in order to advance the services for JIA. Regional networks with nationally driven guidelines should be encouraged so that any clinician responsible for a paediatric rheumatology service is required to join. Robust coding and data gathering are necessary so that comprehensive information can inform service planning and delivery. Paediatric rheumatology has been a ‘Cinderella’ service for too long.

The expanding drug budget alone cannot be ignored nor the consequences that this brings in terms of necessary staffing.

NRAS has received a wealth of information to support the development of a good service for young people and families. These observations represent not only the vision and aspirations of the teams to achieve a service they can have pride in but also uncover the frustrations and disappointments that make up their daily experience. The guiding principles must be an equitable service for all, knowledgeable support, timely and appropriate information, signposting to a range of websites and lobbying to raise awareness of the problems and challenges in the management of JIA. In collaboration with BSPAR and other charitable organisations, NRAS can strive to be not only a ‘Voice for the People’ receiving the care, support and management of JIA, but importantly a ‘Voice for the Professionals’ striving to deliver that service, care and management.

The real picture of JIA for families is one of physical and emotional pain, a disease that impacts on every family member and alters lives, a disease that may set the child and young person apart from their peer group, that can compromise ‘childhood’ and change hopes and dreams for the future. BUT, with the scientific expertise, research programmes, targeted treatments, committed clinical teams and a variety of support and information services, a positive difference CAN be made for the next generation growing up with arthritis.
Appendices

1. Understanding specialised commissioning in England and the equivalent systems in Scotland, Wales and Northern Ireland
2. References to appendix 1
3. Team compositions and regional diagrams
4. Report questions
Understanding specialised commissioning in England and the equivalent systems in Scotland, Wales and Northern Ireland

This appendix seeks to outline the main differences in the approaches to developing and delivering specialised services across the four nations and to indicate the relative priority given to the development of paediatric rheumatology services.

Before 1 April 2013, specialised services in England used to be commissioned by ten regional Specialised Commissioning Groups (SCGs) and a National Specialised Commissioning Team, with the London Strategic Health Authority hosting national specialised services on behalf of all the Strategic Health Authorities from 2007-08.

An Advisory Group for National Specialised Services was also established to advise Ministers on which highly specialised services, products and health technologies should be nationally commissioned, which centres should be designated as providers for specialised services, the annual budget for new and existing specialised services and the contribution required from Primary Care Trusts (PCTs)1.

This overall approach led to variation in the way that SCGs operated. This resulted in different arrangements being struck between SCGs and their PCTs and created variation in access to specialised services, the standards and specifications for these services, as well as the underlying contractual arrangements2.

The government subsequently acknowledged that without a national strategy, decisions were taken locally that ultimately resulted in inconsistent implementation of the 34 Specialised Services National Definition Sets3, which were supposed to define service expectations for given disease areas – including Definition no. 26, which had been developed for Specialised Rheumatology Services and covered JIA4.

When an attempt to formulate priorities was eventually made through the publication of the National Specialised Commissioning Priorities 2011/12 no mention was made of paediatric rheumatology services5.

With the passage of the Health and Social Care Act 2012, NHS England is now responsible for developing national policies, undertaking commissioning and determining which high cost treatments will be funded across specialised services – controlling a budget of around £12 billion.

The vision is to create an equitable service for specialised services across England. Priority setting and strategic direction is conducted nationally, with 10 of NHS England’s 27 Local Area Teams being responsible for local implementation and managing contracts with service providers.

To advise on service specifications and to provide assistance with ongoing policy development for conditions within the domain of specialised commissioning, NHS England’s Medical Directorate has created 74 advisory bodies called Clinical Reference Groups (CRGs). Membership of these CRGs comprises clinicians, commissioners, professional organisations and patients6.

A specific CRG for paediatric medicine has been created which covers specialised elements of children’s care including diabetes, rheumatology,
immunology, and endocrinology. The CRG has created a service specification for paediatric medicine rheumatology, which attempts to define the features of an evidence-based, safe and effective service for this domain.

The new paediatric medicine rheumatology service specification sets out the following objectives:

- To correctly diagnose the condition in a timely and efficient manner
- To achieve and maintain remission of disease, minimise disability and deformity, and preserve normal physical, social, and emotional growth and development
- To optimise patient related outcomes, by providing the most appropriate care for children and young people with rheumatic diseases
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children and young people with rheumatic diseases
- Ensure that all children and young people have timely access to services for appropriate diagnosis and on-going care which minimises travelling and disruption to family life
- To ensure that children and young people have their health, education and any social care plans coordinated
- To ensure children and young people with rheumatic conditions are treated in line with national guidelines and agreed local pathways
- To ensure that children and young people have optimal opportunity to take part in clinical research and clinical trials as part of National Institute for Health Research (NIHR) portfolio activity
- To ensure optimal age-appropriate care and transition into adult services

Key features mentioned in the service specification include the need to:

- Provide a robust system for information sharing across a pathway of care and shared care guidelines and protocols to deliver good practice
- Ensure there is one consultant paediatric rheumatologist, two nurse specialists and one physiotherapist and occupational therapist, per 200,000 children
- Meet BSPAR recommendations for the wide range of expertise available through specialist multidisciplinary teams and ensure this service is available 24 hours/seven days a week
- Give access to diagnostic services with rapid access to services such as laboratory and radiological investigations and expert interpretation, when required
- Undertake transitional care planning that involves adult rheumatology teams and local hospitals under a shared care arrangement
- Ensure a consultant paediatric rheumatologist will be available to give advice 24/7 including new patients and acute referrals of on-going problems

The service specification was put out for public consultation between 12 December 2012 and 22 February 2013 and the finalised version of the document has been published on the NHS England website. Providers are expected to start implementing the service specification from 1 October 2013.

As part of the process of establishing effective lay representation for JIA, NRAS helped to successfully recruit a patient with the disease to the CRG for paediatric medicine.
It used to be the responsibility of the National Services Division (NSD), working on behalf of NHS Scotland, to commission and performance manage specialised services and National Managed Clinical Networks. As a division of NHS National Services Scotland it receives ring-fenced funding from the Scottish Government Health Directorates (SGHD) to perform these roles.

NSD develops service agreements for each nationally designated service. These agreements cover service specifications, expected levels of quality and activity. Regular meetings between clinicians and managers from NSD and the services are then held to discuss issues relating to audit, clinical outcome and other service issues.

In January 2013 it was announced that a new decision-making framework would be introduced for making recommendations on national commissioning, commencing in the 2013/14 national commissioning cycle. A new committee called the National Specialised Services Committee (NSSC) has taken over responsibility from the multidisciplinary National Services Advisory Group within the NSD for making recommendations to the NHS Board Chief Executives’ Group and to the Scottish Government Health and Social Care Directorates about the commissioning of highly specialised services. The NSSC’s remit includes considering proposals for the commissioning of new specialised services, providing oversight of existing nationally commissioned services, and reviewing these every 3-5 years.

Specialised services in Scotland are concentrated in a small number of locations to encourage the creation of centres of excellence. In certain circumstances in the past, when these centres of excellence have not able to provide a particular service, the NSD has opted to fund a shared service with the English NHS. NSD did this through contributing to the now defunct National Specialised Commissioning Team (NSCT) in England and by pooling funds on behalf of NHS Boards for non-nationally designated specialised services. In the case of JIA, stem cell transplantation is a service that has been provided by Great Ormond Street Hospital for Children NHS Trust and Newcastle Upon Tyne NHS Foundation Trust.

As mentioned previously, NSD also commissioned a limited number of National Managed Clinical Networks (MCNs) on behalf of NHS Scotland. These MCNs are ‘virtual’ groups of health professionals and representatives from primary secondary and tertiary care organisations that work together across Health Board boundaries to improve standards via establishing quality improvement systems and processes. MCN work typically involves conducting service mapping exercises to identify demand, developing care pathways and parent networks, and creating education strategies to meet any identified needs.

As the MCNs are nationally designated the NSD is required to review them every 3-5 years to assess whether they are surplus to requirement. Of particular relevance to JIA, the Scottish Paediatric and Adolescent Rheumatology Network (SPARN) was created in 2009 in response to a recommendation arising from the Better Health, Better Care: National Delivery Plan for Children and Young People’s Specialist Services in Scotland that was published in the same year and, importantly, was centrally funded for 3 years. No official review has been published by the NSD on the work of SPARN so far.

The Better Health, Better Care plan had £32 million of funding attached to help deliver its recommendations, which also included the aim to create an additional consultant post to support networked paediatric rheumatology services across Scotland. The accompanying justification tacitly acknowledged that paediatric rheumatology services had lagged behind other areas of the UK and that the specialist workforce had been very small up to this point with input from consultants frequently from general paediatricians or adult rheumatology specialists with little direct paediatric rheumatology training.
An initial public consultation on the proposals outlined in the plan conducted in 2008 also yielded the fact that many respondents requested additional investment in Allied Health Professionals and physiotherapy services, and flagged the need for greater outreach and local service provision.

To co-ordinate and drive forward the final recommendations, a National Delivery Plan Implementation Group (NDPIG) was established. The Group comprised of Directors of Planning from each region, clinicians, voluntary sector representatives and others. Officially it was a sub-group of the Children and Young People’s Health Support Group, which is an expert Ministerial advisory group on children and young people’s health in Scotland.

In 2007 the National Steering Group for Specialist Children’s Services produced its final draft report on Paediatric Rheumatology which also gave insight into particular challenges faced in Scotland in relation to JIA service provision, noting that there were estimated to be over 900 children with JIA although clinicians working within the informal network for paediatric rheumatology at the time said they were aware of only around 500 affected children – suggesting that several hundred more children were not receiving appropriate care.

The report went on to conclude that paediatric rheumatology service provision and best practice use of some medicines (including Etanercept) was patchy, with the only centre offering timely access to sufficient multidisciplinary expertise being at RHSC, Glasgow. It also noted that there were only 1.5 specialist nurses in Scotland who supported local services but had insufficient time to provide backup and support for other units.

From the service user perspective, the report found that most parents supported locally based care and also identified the need for more specialist expertise. Some parents said they would be prepared to travel to access this expertise, although many also said they would find it extremely difficult to do so. Parents also said they noted benefits when their children were seen in a specialist clinic, while others said they were frustrated at not being given this opportunity, or felt it had simply come too late in their child’s illness after irreversible joint damage had occurred.

In Wales JIA services are commissioned by the Welsh Health Specialised Services Committee (WHSSC), which has responsibility for the joint planning of all specialised and tertiary services on behalf of the seven Local Health Boards (LHBs) in Wales and controls a budget of around £574 million.

WHSSC is a relatively new entity having only been established on 1 April 2010. It is hosted by Cwm Taf Local Health Board and was set up following a consultation on specialised services for Wales in 2009, which made recommendations over how the Welsh NHS could better plan and deliver specialised services through joined up working to reduce duplication and increase consistency.

The stated aim of the WHSSC was therefore to ensure equitable access to safe, effective and sustainable specialist services in Wales, as close to people’s homes as possible within available resources. WHSSC pursues this aim by:

- Planning, procuring and performance monitoring specialised services in Wales
- Developing, negotiating, agreeing and monitoring contracts with providers of specialised services
- Undertaking reviews of specialised services and new drugs and technologies
- Co-ordinating the approach towards planning specialised services
- Managing the pooled budget for specialised services and ensuring that financial risk management is in place
- Establishing clear processes for the designation of specialised service providers and ensuring ongoing clinical quality through a rolling process of service review
- Ensuring a process of patient and public involvement underpins this work
Although WHSSC acts on behalf of the LHBs, each LHB is still responsible to their local population for the provision of specialised and tertiary services. WHSSC is therefore a statutory sub-committee of each LHB. It is led by an independent chair appointed by the Health Minister, and three independent members, one of whom is the Vice Chair, the chief executives of the local health boards, associate members and a number of officers. The relationship between WHSSC and its constituent LHBs means that in some circumstances there is potential conflict of interest as a number of LHBs act as both providers and commissioners of specialised services.

There are a large number of sub-committees and advisory bodies at WHSSC which feed into the decision-making process including one on Quality and Patient Safety, which has responsibility for improving quality within the remit of the committee.

A number of Service Programme Planning Teams have also been established to take forward particular programmes of work identified by WHSSC, including one on Women and Children’s Services, which includes paediatric rheumatology.

A Planning and Prioritisation Advisory Group gives advice to the Director of Specialised Services on issues relating to clinical priority and the Annual Plan Oversight Group provides additional advice to the Director of Specialised Services on financial planning, risk management and choices for the planning of specialised services.

WHSSC obtains clinical advice from a wide range of people and organisations including: clinical leads, National Specialist Advisory Group, clinical networks, All Wales Medicines Advisory Group/ Welsh Medicines Partnership, professional bodies (e.g. Royal Colleges), and Local Health Board Clinical Directors. Along with the clinical leads, the WHSSC has a Medical Director, Deputy Medical Director and a Lead Nurse who help to filter this advice.

In 2011, an Epidemiology and Evidence Support Team (EEST) was established by WHSSC to improve evidence based decision-making, policy development and service development. According to the WHSSC website the EEST has only completed a very small number of reviews so far, none of which relate to paediatric rheumatology or JIA.

In 2012-13 the WHSSC published its first ‘Annual Plan’ setting out clinical priorities going forward, with no reference to work around paediatric rheumatology.

There are also no mentions of achievements relating to paediatric rheumatology in the first two annual reports, which do cite progress made against other strategic priorities.

The WHSSC also publishes a series of ‘Policies and Procedures’ which are short documents setting out advice about what should happen in certain clinical areas and medical procedures. There are no proper processes for developing these documents, although once developed they are mandatory and audited by WHSSC programme teams. There are no published policies relating to paediatric rheumatology or juvenile idiopathic arthritis.

NRAS is aware of discussions to set up a clinical network for paediatric rheumatology, which would require support from the Welsh Assembly Government and the WHSSC. The charity is also aware of discussions about the possibility of creating a series of Clinical Reference Groups in Wales to help advise on aspects of specialised commissioning, which might perform a similar role to those created by NHS England.

The Tertiary Review of Children’s Services for Wales report conducted in 2002 noted that therapy input for children with rheumatological conditions is very different to those with disability from other conditions, and that tertiary specialist services are needed for this as well as good local physiotherapy.

The report went on to say that consultant rheumatologists with a special interest in children provided most of the services for the children of Wales at the time and that it expected specialised paediatric rheumatology services to develop and expand, with expected usage set to increase.
Of note, the report also said the population size in South Wales was too small at the time to justify the service of a full time paediatric rheumatologist, and would be best served by clinicians with a special interest in children working in conjunction with specialised centres. Overall, the report concluded that paediatric rheumatology was an ‘above average’ priority for improvement compared to other specialised services for children.

Also published in 2002, A Special Service: The Future of Specialised Healthcare for the Children of Wales ranked paediatric rheumatology as the fifth largest cause of specialised service episodes in under 16 year olds and noted a significant discrepancy between the number of rheumatology outreach clinics being run in South Wales compared to North Wales. The report also contained comments from clinicians and the managers providing, and referring to, specialised children’s services in Wales who called for the development of a more local specialised service in South Wales.

One of the main frameworks setting out the vision for paediatrics in Wales is the National Service Framework for Children, Young People and Maternity Services. The document, which was published in 2005, did not specifically mention paediatric rheumatology, but it did set out the following relevant aspirations:

- LHBs and NHS trusts have a medicines strategy that includes a named pharmacist with expertise in paediatric medicine
- Children and young people have access to a full range of appropriately trained Paediatric Allied Health Professionals according to their specific needs. If provided by generic services, it is provided in partnership with specialist paediatric colleagues
- Every lead health professional has adequate arrangements for transfer of young people to adult services, preferably via specific transition clinics involving staff from both paediatric and adult services

More recently, in December 2012, the Chair of the Welsh Medical Committee wrote to the Minister for Health and Social Care Services to present a report on Improving Paediatric Services in Wales. The report made a number of recommendations for how paediatric acute care could be remodelled, how primary care could be improved and how paediatric care could be shared with organisations outside of health, promoting networks, improving transitioning arrangements and information sharing. However, there were no suggestions made specifically in relation to paediatric rheumatology.

Research conducted by the Welsh Paediatric Surveillance Unit that completed in 2006 hinted at some of the challenges facing JIA services in Wales. Camilleri and Amos concluded that the incidence of the disease based on reporting to the WPSU suggested a frequency of 5.0 per 100,000 population under the age of 16 years, which was at the low end of the expected range seen in the previous studies. They speculated that this may be due to under-reporting although it could be due to the rigorous system of case verification that better excluded other causes of joint pain or inflammation. The report also noted that the numbers of children referred for physiotherapy, occupational therapy and orthotics was lower than expected.

The process culminates in the publication of an annual Commissioning Plan that is produced in collaboration with the Public Health Agency (PHA). The plan is developed through a comprehensive commissioning cycle that involves undertaking a needs assessment, priority setting, gaining
agreements with providers, monitoring and evaluating delivery and impact, and ensuring that the services meet Department of Health, Social Services and Public Safety (DHSSPS) and other recognised standards.

Regional commissioning is undertaken via multidisciplinary Commissioning Service Teams (CSTs), which include input from local commissioning, primary care, social care, pharmacy, finance, information, public health, nursing and Allied Health Professionals from the Public Health Agency.

CSTs develop evidence-based service models and service specifications with input from clinicians, service managers and service users and consider the whole patient pathway together with cross-cutting issues such as life stage and workforce needs. The service specifications they produce are ‘live’ documents that are reviewed on an on-going basis as needs change. The CSTs make efforts to horizon scan to try and future-proof these services. The CSTs report to a Commissioning Programme Board which is chaired by the Board’s Director of Commissioning.

There are five LCGs that officially serve as committees of the HSCB. The LCGs assess local health and social care needs and undertake requisite planning to meet the needs of the local population. They also support the HSCB and the CSTs to deliver against identified strategic priorities, but have the power to amend regional priorities and objectives to take account of local context. LCGs also conduct local needs assessments upwards to inform the regional objectives and each LCG has a Commissioning Lead who sits on the Commissioning Programme Board and a member of their local team feeds into the regional CSTs.

Since its inception in 2009, the HSCB has not published any public documents relating to service models or service specifications for paediatric rheumatology in Northern Ireland.

However, the Health and Social Care Board and Public Health Agency Commissioning Plan 2013/14, final draft published in 2013, does note that due to Northern Ireland’s small population the more specialist services are becoming increasingly difficult to sustain. Opportunities to link clinical teams to larger centres in Great Britain and the Republic of Ireland in a network arrangement are essential to supporting long term sustainability.

Furthermore, under the heading ‘Successes for 2012/13’, the plan also noted investment in a range of specialist services including paediatric rheumatology to ensure that waiting times fell in line with agreed standards. Although under the section on ‘Key Challenges for 2013/14 and beyond’, the same plan also noted challenges around elective investment in specialist services – with additional infrastructure and activity required to support the delivery of targets and ensure effective management of emergency and elective care for areas including paediatric rheumatology.

Prior to this, the Health and Social Care Board and Public Health Agency Commissioning Plan 2010/11 noted a commissioning priority to ensure that paediatric inpatient services provided appropriate staffing and expertise in line with best clinical practice.

The Health and Social Care Board and Public Health Agency Commissioning Plan 2011/12 also committed the organisations to reviewing the arrangements for the provision of paediatric inpatient services taking account of the recommendations of the DHSSPS Maternity Review and other relevant considerations. The 2011/12 plan also made commitments to develop clinical networks with providers in the Republic of Ireland and Great Britain with a focus on specialist paediatric specialties and to invest in infrastructure and support for highly specialist paediatric services.

In Transforming Your Care – Vision to Action: A Post Consultation Report published in 2013 the Health and Social Care Board summarised proposals for the future health and social care system in Northern Ireland. Key recommendations of note to JIA patients were the insistence that it would not be possible to provide a full range of paediatric sub specialties for a population the size of Northern Ireland and the HSCB would therefore continue to ensure arrangements were put in place for when families have to access services in other parts of the UK or when services are not available locally.
The report also committed HSCB to move towards admitting all children under the age of 16 to age appropriate paediatric settings with a number of forthcoming DHSSPS reviews on acute paediatric services, paediatric palliative and end of life care services. The report stated its belief this would facilitate a regional approach to how services should be organised in future, including agreement on the age of transfer from paediatric to adult services. Finally, the report noted that the DHSSPS would start to carry out a review of paediatric services focusing on the commissioning and provision of effective and sustainable hospital and community services, with a view to beginning consultation within 6 months of the Transforming Your Care – Vision into Action report, which was published in March 2013.

The earlier Transforming Your Care – A Review of Health and Social Care in Northern Ireland consultation document published in 2011 noted challenges in providing a full range of paediatric sub specialities to a population of 1.8 million and the consequent need to have clear pathways and consistency of treatment. The document also noted that:

- Communities and the independent sector should be enabled to support families with ill children where appropriate
- Workforce issues and multiple service locations have the potential to threaten service resilience
- Single handed specialties will be difficult to sustain unless networked with other centres, whilst scarce skilled resources need to be carefully managed in the hospital setting
- Paediatrics should become a key resource working alongside integrated care partnerships enabling most care to be provided at or closer to home
- There is the potential for more formal links to larger centres in the UK or Republic of Ireland for paediatrics
- There is a case for establishing formal partnerships outside the jurisdiction for very specialist paediatric services
References


3 | Team compositions and regional diagrams

The centres shown on the map below are those units classified by BSPAR as ‘Specialist Paediatric Rheumatology Centres’. Not every centre shown was included in the project owing to the constraints of the available time and resources for the survey and the need to include a broad picture of the varying models of care.

The maps and charts in this appendix show the details (as reported by the centres themselves) of each of the specialist centres which NRAS either visited or interviewed.
North West Location around Liverpool including North Wales

Legend:
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

Alder Hey Children’s Hospital, Liverpool

ALDER HEY CHILDREN’S HOSPITAL CORE TEAM

<table>
<thead>
<tr>
<th>Position</th>
<th>Yes (Whole time equivalent)</th>
<th>No</th>
<th>Is referral required?</th>
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<tbody>
<tr>
<td>Paediatric rheumatologist</td>
<td>3.7</td>
<td></td>
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<tr>
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<td>1.5</td>
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<tr>
<td>Paediatric physiotherapist</td>
<td>1.5</td>
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<tr>
<td>Paediatric clinical psychologist</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Paediatric occupational therapist</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Podiatrist or orthotist</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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West Midlands Location around Birmingham

**BIRMINGHAM CHILDREN’S HOSPITAL CORE TEAM**

<table>
<thead>
<tr>
<th>Role in Paediatric Rheumatology</th>
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<td>Paediatric occupational therapist</td>
<td>1</td>
<td>Yes</td>
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<td>Podiatrist or orthotist</td>
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<td>Yes</td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
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<td>Yes</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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</tbody>
</table>
South West Location around Bristol and Bath

**Legend**
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

**BRISTOL ROYAL CHILDREN’S HOSPITAL CORE TEAM**

<table>
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<td>Paediatric rheumatology clinical nurse specialist</td>
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<td>Paediatric physiotherapist</td>
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<tr>
<td>Paediatric occupational therapist</td>
<td>0.6</td>
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<td></td>
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<tr>
<td>Podiatrist or orthotist</td>
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<td></td>
<td>✓</td>
</tr>
<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
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</tr>
<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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Bristol Royal Children’s Hospital

Legend:
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement
Great North Children’s Hospital Core Team

<table>
<thead>
<tr>
<th>Role</th>
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<tbody>
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<tr>
<td>Paediatric clinical psychologist</td>
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<td>Paediatric occupational therapist</td>
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<tr>
<td>Podiatrist or orthotist</td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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Legend:
- Specialist Centre
- District General Hospital
- Paediatric Rheumatologist
- Paediatric Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

North East Location around Newcastle
London and the South East Location and outside the UK

Great Ormond Street Hospital, Central London
(Paediatric patients)

University College Hospital, Central London
(Adolescents)

Legend
- Specialist Centre
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

Inner London
- Paddington
- Chelsea & Westminster
- Waterloo
- Archway
- Whitechapel
- Hammersmith
- Tooting
- Denmark Hill
- Hackney

Greater London
- Central Middlesex
- West Middlesex
- North Middlesex
- Hillingdon
- Barnet & Chase Farm
- Epsom
- Kingston
- Northwick Park
- Lewisham
- Leytonstone
- Ealing

Around London
- Cambridge
- Colchester
- Ipswich
- Southend
- Welwyn Garden City
- Luton & Dunstable
- Watford
- Bedford
- East Surrey
- Guildford
- Eastbourne
- Brighton
- Woolwich
- Farnborough
- East Kent
- And MORE...

Quaternary Centre:
complex patients from UK

Patients from outside UK

GREAT ORMOND STREET HOSPITAL FOR CHILDREN CORE TEAM

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<td>Paediatric clinical psychologist</td>
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<tr>
<td>Paediatric occupational therapist</td>
<td>1.8</td>
<td></td>
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<td>Shared care</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
<td>Shared care</td>
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Yorkshire Location around Leeds

Legend
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

<table>
<thead>
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<th>LEEDS GENERAL INFIRMARY CORE TEAM</th>
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<td>Close link &amp; combined clinic every 2 weeks</td>
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<tr>
<td>Paediatric clinical psychologist</td>
<td>0.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paediatric occupational therapist</td>
<td>0.6</td>
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<tr>
<td>Podiatrist or orthotist</td>
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</table>
North West Location around Manchester

Legend
- District General Hospital
- Paediatric Rheumatologist
- Specialist Rheumatology Clinical Nurse Specialist
- Paediatric Physiotherapist
- Paediatric Occupational Therapist
- Paediatric Podiatrist or Orthotist
- Paediatrician with an interest in Paediatric Rheumatology
- Adult Rheumatologist with an interest in Paediatric Rheumatology
- Specialist Centre
- Specialist Team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

Manchester Children’s Hospital

MANCHESTER CHILDREN’S HOSPITAL CORE TEAM

<table>
<thead>
<tr>
<th>Position</th>
<th>Whole time equivalent</th>
<th>Is referral required?</th>
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<tr>
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<tr>
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<tr>
<td>Paediatric clinical psychologist</td>
<td></td>
<td>✓</td>
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<tr>
<td>Paediatric occupational therapist</td>
<td>0.6+0.5</td>
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<tr>
<td>Podiatrist or orthotist</td>
<td>0.1</td>
<td></td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
<td>0.1</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
<td></td>
<td>✓</td>
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</table>
East Anglia Location around Norwich

**Legend**
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

<table>
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<tr>
<th>NORFOLK AND NORWICH UNIVERSITY HOSPITAL CORE TEAM</th>
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<tr>
<td>Paediatric rheumatology clinical nurse specialist</td>
<td>1.0</td>
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<td></td>
</tr>
<tr>
<td>Paediatric physiotherapist</td>
<td>0.5</td>
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<td></td>
</tr>
<tr>
<td>Paediatric clinical psychologist</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Paediatric occupational therapist</td>
<td></td>
<td>✓</td>
<td></td>
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<tr>
<td>Podiatrist or orthotist</td>
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<td>Paediatrician with an interest in paediatric rheumatology</td>
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<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
<td>Transition</td>
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</table>
## East Midlands Location around Nottingham

### Nottingham Children’s Hospital Core Team

<table>
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<tr>
<th>Role in Rheumatology</th>
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<th>Required Referral?</th>
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<td>Ophthalmologist</td>
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<td>Paediatric physiotherapist</td>
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<td>Yes</td>
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<tr>
<td>Paediatric clinical psychologist</td>
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<td>Paediatric occupational therapist</td>
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<tr>
<td>Podiatrist or orthotist</td>
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<td>Yes</td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
<td>1</td>
<td>Yes</td>
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</table>

### Legend
- **District General Hospital**
- **Paediatric Rheumatologist**
- **Specialist Multidisciplinary Team**
- **Paediatrician with an interest in paediatric rheumatology**
- **Adult rheumatologist with an interest in paediatric rheumatology**
- **Specialist Centre**
- **Specialist team attends outreach clinics**
- **Referral and management to specialist centre**
- **Shared care arrangement**

---

### Shared Care Arrangements

- **Nottingham**
  - **Nottingham Treatment Centre, Nottingham**
  - **Mansfield**
  - **Burton Upon Trent**
  - **Boston**

- **Lincoln**
  - **Lincoln**

- **Peterborough**
  - **Peterborough**

- **Grantham**
  - **Grantham**

- **Derby**
  - **Derby**

- **Burton Upon Trent**
  - **Burton Upon Trent**

- **Boston**
  - **Boston**

- **Peterborough**
  - **Peterborough**
Northern Location of South Central region around Oxford

---

**THE NUFFIELD ORTHOPAEDIC CENTRE CORE TEAM**

<table>
<thead>
<tr>
<th>Role</th>
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<td>Paediatric occupational therapist</td>
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<tr>
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South Yorkshire Location around Sheffield

**Legend**
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

<table>
<thead>
<tr>
<th>SHEFFIELD CHILDREN’S HOSPITAL CORE TEAM</th>
<th>Yes Whole time equivalent</th>
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<th>Is referral required?</th>
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<tr>
<td>Paediatric occupational therapist</td>
<td>0.6</td>
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<tr>
<td>Podiatrist or orthotist</td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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</table>

**Note:**
- Sheffield Children’s Hospital
- Sheffield Children’s Hospital Core Team
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement

**Locations:**
- Chesterfield
- Barnsley
- Rotherham
- Doncaster
- Grimsby
- Scunthorpe
- Bridlington (occasional referrals)
- Wakefield
- Bridlington (occasional referrals)
- Wakefield
South Central Location around Southampton and Portsmouth

THE WESSEX AND SOUTH COAST PAEDIATRIC RHEUMATOLOGY CENTRE CORE TEAM

<table>
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<th>Position</th>
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<tr>
<td>Paediatric rheumatology clinical nurse specialist</td>
<td>0.8 + 0.2</td>
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<tr>
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<tr>
<td>Paediatric clinical psychologist</td>
<td>0.4 (Southampton)</td>
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<tr>
<td>Paediatric occupational therapist</td>
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<td>Podiatrist or orthotist</td>
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Legend
- Specialist Centre
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist team attends outreach clinics
- Referral and management to specialist centre
- Shared care arrangement
Northern Ireland

**BELFAST HOSPITAL TRUST CORE TEAM**

<table>
<thead>
<tr>
<th>Role</th>
<th>Yes Whole time equivalent</th>
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<tr>
<td>Paediatric physiotherapist</td>
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<td>Paediatric clinical psychologist</td>
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<tr>
<td>Paediatric rheumatology nurse</td>
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Scotland – Scottish Paediatric and Adolescent Rheumatology Network (SPARN)

**Health Boards**
- Ayrshire and Arran
- Borders
- Dumfries and Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow and Clyde
- Highland
- Lanarkshire
- Lothian
- Orkney
- Shetland
- Tayside
- Western Isles

**Legend**
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology

**SPARN Centres and Network Clinics**

**GLASGOW AND EDINBURGH CORE TEAMS**

<table>
<thead>
<tr>
<th>Paediatric rheumatologist</th>
<th>Whole time equivalent</th>
<th>No</th>
<th>Is referral required?</th>
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<tbody>
<tr>
<td>Glasgow</td>
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<tr>
<td>Edinburgh</td>
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<table>
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<tr>
<th>Ophthalmologist</th>
<th>Glasgow: 0.1 Edinburgh: 0.1</th>
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<tbody>
<tr>
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<tr>
<td>Paediatric physiotherapist</td>
<td>Glasgow: 1.0 Edinburgh: 0.5</td>
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<tr>
<td>Paediatric clinical psychologist</td>
<td>Glasgow: 0.2 Edinburgh: 0.05</td>
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<tr>
<td>Paediatric occupational therapist</td>
<td>Glasgow: 0.5 Edinburgh: 0.5</td>
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<tr>
<td>Podiatrist or orthotist</td>
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<tr>
<td>Paediatrician with an interest in paediatric rheumatology</td>
<td>Edinburgh: 0.2</td>
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<tr>
<td>Adult rheumatologist with an interest in paediatric rheumatology</td>
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</table>

- **Shared care arrangement**
- **Referral and management to specialist centre**

**Health Boards**
- Ayrshire and Arran
- Borders
- Dumfries and Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow and Clyde
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- Orkney
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Wales

Health Boards
Abertawe Bro University
Aneurin Bevan
Betsi Cadwaladr University
Cardiff and Vale University
Cwm Taf
Hywel Dda
Powys Teaching

Refer to Alder Hey for details of outreach clinics in North Wales.

Referals from mid Wales may go to Birmingham or Cardiff.

Legend
- District General Hospital
- Paediatric Rheumatologist
- Specialist Multidisciplinary Team
- Paediatrician with an interest in paediatric rheumatology
- Adult rheumatologist with an interest in paediatric rheumatology
- Specialist Centre
- Specialist team attends outreach clinics
- Referral and management to
- Shared care arrangement

UNIVERSITY HOSPITAL OF WALES, CORE TEAM

<table>
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<th>Role</th>
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<tr>
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<td>0.25</td>
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Report Questions

Questions for discussion with parents:

1. Can you tell me a little about your experiences (maybe during the first 6 months) leading up to the diagnosis of JIA in your son/daughter?
2. What happened at the time of diagnosis?
3. Where were you seen? Was this a specialist centre or your local hospital?
4. Did you feel you were given sufficient information at the beginning?
5. Were you offered the opportunity to see a specialist nurse, physio and OT?
6. Did you feel supported and were you given a contact telephone number to call?
7. Have you felt that more should have been offered, and if so what might this be?
8. Have you been offered the opportunity to meet any other parents?
9. Is that something that you would want to do?
10. If there had been a website with comprehensive information on juvenile arthritis at the time of diagnosis, would you have used it? Which websites have you used? Have you used a social media site like Facebook?
11. Are you willing to talk about the impact on all the family members (especially brothers, sisters, fathers) of your son/daughter’s arthritis?
12. If you could wish for 1 thing to be different (of course, apart from the obvious answer that arthritis had not been diagnosed) what would it be?

Questions for discussion with paediatric rheumatologists and paediatricians:

1. What is your total population?
2. TEAM COMPOSITION. Would you kindly check that this data is correct and fill in any gaps?
3. Are there any posts that you need or wish to fill? If so, are you likely to be successful in filling these?
4. How many children with a new diagnosis of JIA do you see in a year?
5. Do you have any specific arrangements or referral protocols set up with local GPs? For example do your GPs use the pGALs tool?
6. Can you talk me through what the pathway would be for a newly referred child?
7. Would this pathway be the same for any age up to 16 or do pathways differ for older presenting children or for different types of JIA?

Questions for discussion with older teenagers/young adults:

1. What is your earliest memory of arthritis?
2. What irritates you most about your treatment?
3. Do you ever rebel against the treatment?
4. Do you get fed up with your parents over the treatment?
5. Have you ever refused to take your medication, or an injection, or a special test?
6. Do you feel your parents, brothers and sisters, friends, doctors, nurses, ever really understand what it is like to have arthritis?
7. What are you unable to do that you would really like to do?
8. Do your parents stop you doing things that you would like to do?
9. Do you help with household chores? Do you have an after school or Saturday job or are you in full time employment?
10. Do you ever have worries that no one asks you about?
8. What about access to Ophthalmology? Do you work with someone specific and, for example, do combined clinics?

9. Can you tell me something about any services you have in the wider community? For example, someone who liaises with schools?

10. What resources would you typically use to provide information and support for families? Is there a local support group of any kind?

11. What do you provide for teenage patients? At what age do children transition from your department?

12. Can you tell me a little about that process here?

13. What, do you find, are the typical issues for young people going through this process?

14. Have you or are you planning to audit your service against the standards?

15. What is your opinion about moving to a managed clinical network (MCN) gold standard approach to the management of JIA in the UK?

16. Are you operating either formally or informally as an MCN?

17. How do you work with hospitals in your area where there is an adult rheumatologist who is seeing children?

18. Would you be kind enough to fill in the gaps and links in this template for the services for JIA in this area?

19. Do you have any concerns about adult rheumatologists treating children?

20. Were you able to attend the BSPAR conference in Edinburgh last year?

21. Why do you think this conference doesn’t attract more adult rheumatologists who see children?

22. What do you see as the key issues or barriers that you have overcome or still need to address in the delivery of your service here?

Questions for adult rheumatologists who see children with or without a paediatrician:

1. What is your total population?

2. How many children with a new diagnosis of JIA might you see in a year?

3. Are there any children that you would refer on to a Paediatric Rheumatology Specialist team straight away? If so, what sort of disease profile would prompt you to refer?

4. Which is your local tertiary centre? Is it able to offer shared care for JIA or a full MDT annual review or both?

5. Do you have any kind of referral pathway established with the surrounding GPs?

6. Do you have a paediatric specialist nurse working with you or does your adult specialist nurse work with you and your JIA patients? And paediatric physio and OT?

7. Presumably you work alongside a Paediatrician? Are they based here in the hospital or are they community based?

8. Are there any services in the wider community? For example, someone who liaises with schools where children may be having difficulties?

9. What about access to Ophthalmology? Do you work with someone specific and, for example, do combined clinics?

10. What resources would you typically use to provide information and help for children and teenagers and their families? For instance is there a local support group of any kind?

11. Have you got good co-operation with the local GPs and practice nurses?
12. Do you have different clinics for adolescents and their parents or are they seen in the same clinic as younger children?

13. How do you organise transition for the teenagers or young adults? What age are they when they move to the adult clinic?

14. What, do you find, are the typical issues for young people going through this process?

15. Were you able to attend the BSPAR conference this year?

16. What resources do you like to access for up to date clinical information?

17. Do you feel that the BSPAR conference caters sufficiently for the adult rheumatologists who care for children and young people? How could this be improved?

18. Maybe you were part of the ARMA/BSPAR team contributing to the Standards of Care but if not, are you familiar with them?

19. Do you agree with and support these new standards?

20. Have you or will you plan to audit your service against the standards?

21. Do you support the government initiatives towards Managed Clinical Networks, particularly for juvenile arthritis?

22. Do you see any issues or barriers to the delivery of your service here?

Questions for discussion with clinical nurse Specialists:

1. Do the clinics run as a ‘One Stop Shop’ for families?

2. Which health care professionals are available in every clinic?

3. Do you run nurse led clinics? Which aspects of care do these cover? eg: assessment, patient/parent education, support, urgent access, biologics review, other?

4. Advice/Helpline. How is this organised and are you overwhelmed? Can you book urgent reviews easily?

5. What are some of the common reasons for calling?

6. Are you involved in outreach clinics, liaising with colleagues in other centres?

7. Are you able to deliver the service you need/want to?

8. Is your work for JIA under threat? Can you give details (anonymously)?

9. What would you change if you could?

Questions for discussion with physiotherapists, occupational therapists and other MDT members:

1. Are you available for every clinic, in the clinic or elsewhere?

2. Can parents contact you directly?

3. If they need to be seen can you organise this in your own clinic?

4. Are you able to deliver the service you need/want to?

5. Is your work with JIA under threat? Can you give details (anonymously)?

6. Do you visit children and teachers in schools?

7. Are you involved in outreach clinics, liaising with colleagues in other centres?

8. What would you change if you could?
Questions for discussion with managers involved in commissioning paediatric rheumatology services:

1. What is your role in relation to commissioning paediatric rheumatology services?

2. Which NHS Commissioning Board Local Area Team do you fall within? Are they responsible for leading on specialist commissioning?

3. Are you aware of the ‘Standards of Care’ for children and young people with juvenile idiopathic arthritis published by ARMA/BSPAR 2010?

4. How do you capture feedback from the families coping with JIA?

5. How well do you feel paediatric rheumatology is financed in your hospital?
Contact us...

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Email: enquiries@nras.org.uk
National Rheumatoid Arthritis Society
Ground Floor
4 The Switchback
Gardner Road
Maidenhead
Berkshire
SL6 7RJ

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Twitter@helpline_NRAS

For up to date membership information follow
Twitter@members_NRAS