#  History of BANNAR

Thank you for your interest in BANNAR. Whether you are a long-standing member of our network, or an interested individual who wishes to know a little more about us, we have collated a selection of information, papers and materials telling the *‘History of BANNAR’*.

## The BANNAR Story

There has been a long history of Arthritis Care, Arthritis Research UK (now merged to form Versus Arthritis) and current members of BANNAR working to improve Adolescent and Young Adult (AYA) rheumatology.

BANNAR formed in 2012 with the hard work of a few interested and dedicated rheumatologists. Since then, the membership has grown to over 110 members. Key areas of BANNAR work include advising and supporting current research in AYA Musculoskeletal (MSK) conditions, conducting and writing up AYA research and clinical healthcare guidelines, and being an advisory and conversational space for many professionals working in AYA MSK clinical care.

The Versus Arthritis/BANNAR partnership was formed in 2020 in order to help sustain BANNAR and fulfil Versus Arthritis’ remit of reaching every child and young person. Currently the collaboration assists Versus Arthritis with the Deliver, Demand, and Discover strategy by bringing together top professionals in rheumatology to provide excellent clinical care and the most up to date research for young people living with MSK conditions in the UK, in addition to hearing the thoughts and recommendations from the young people themselves.

### Pre-BANNAR

Before the emergence of BANNAR, our members were already working hard on establishing the wants and needs of young people, especially in the area of healthcare transition.

In 2000 a survey of service provision for young people in the transition from paediatric to adult rheumatology care was undertaken:

[Audit of rheumatology services for adolescents and young adults in the UK | Rheumatology | Oxford Academic (oup.com)](https://academic.oup.com/rheumatology/article/39/6/596/1783890?login=false)

It was established that young people needed their own care which was different to that of adults. There was a growing recognition that rheumatologists specialising in adult care, also needed to gain experience in paediatric care to assist young people with rheumatic conditions during adolescence and young adulthood.

In the UK organisations such as the British Paediatric Rheumatology Group (BPRG), were formed in the early 1980s and consisted of members from across the UK. It was subsequently renamed the British Society for Paediatric and Adolescent Rheumatology (BSPAR) (<http://www.bspar.org.uk/>) and included specific services for younger people.

As such, it comprised of nurses, physiotherapists, occupational therapists, physicians, paediatric rheumatologists, paediatricians, adult rheumatologists, and basic scientists. Paediatric rheumatology was becoming a recognised speciality and qualification on the specialist register. Academic and research-active centres focusing on paediatric rheumatology started to thrive along with generating a rational evidence-based approach to the treatment and management of rheumatological conditions of children, adolescents, and young adults. In 2015, BSPAR was formally integrated with the British society of Rheumatology.

[Paediatric rheumatology: a bright future in the UK and Europe | Rheumatology | Oxford Academic (oup.com)](https://academic.oup.com/rheumatology/article/44/4/423/2899400?login=false)

### BANNAR – 2012 onwards

The health needs specific to adolescence and young adulthood including developmentally appropriate care were being explored. Existing health models and barriers to care needed to be scrutinised and debated. Research agendas were recognising the need to optimise the best clinical outcomes for this specific age group, who were going through many changes; physically, emotionally, and mentally at this stage of their lives.

Rheumatology care irrespective of setting needed to be developmentally appropriate and acknowledge the multiple transitions in this life stage including healthcare, educational, pubertal, and social factors.

Research was highlighted as an integral part of the development of such service provision.

An integrated research initiative was required to look at the multiplicity of interactions between behaviours of young people with rheumatic conditions, and their close networks (friends, family, care providers etc), the variation of healthcare settings, and the lack of standardised evaluation tools.

As such, a research initiative was developed - a UK‑wide network of clinicians and researchers with expertise in paediatric and adult rheumatic diseases. The Barbara Ansell National Network of Adolescent Rheumatology (BANNAR) was established, with the primary goal of furthering research within the area of adolescent rheumatology.

[The coming of age of adolescent rheumatology | Nature Reviews Rheumatology](https://www.nature.com/articles/nrrheum.2013.202)

### 2014 - Getting Young People involved in our research

Young people are at the heart of everything we do. It is therefore important to understand how young people are involved in research and service evaluation as well as what services are provided to support such involvement.

In 2014 BANNAR members were surveyed, and it was identified that there was under involvement of young people in rheumatology research beyond the role of research participants, especially when compared to their involvement in service development.

### The YOURR Research Project 2014-2016

As a result of the above survey, one of the most important tasks for BANNAR was to listen to young people with MSK and rheumatic conditions about what they felt was important from research. The Young people Underpinning Rheumatology Research (the YOURR project) was therefore funded:

[Study protocol: Determining what young people with rheumatic disease consider important to research (the Young People’s Opinions Underpinning Rheumatology Research - YOURR project) | Research Involvement and Engagement | Full Text (biomedcentral.com)](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0037-8)

The YOURR Project was a qualitative, UK wide study conducted in 2014 -2016 funded by BANNAR. Focus groups allowed 63 young people (aged 10-24) to talk to researchers about what they felt were important research priorities.

Young people were recruited from our BANNAR members and relevant national charities. Following completion of the research, a national youth advisory panel was established – Your Rheum: [YOUR RHEUM | Welcome to YOUR RHEUM!](https://yourrheum.org/)

[What do young people with rheumatic disease believe to be important to research about their condition? A UK-wide study | SpringerLink](https://link.springer.com/article/10.1186/s12969-017-0181-1)

[What do young people with rheumatic conditions in the UK think about research involvement? A qualitative study | SpringerLink](https://link.springer.com/article/10.1186/s12969-018-0251-z)

[Research priority setting by young people with rheumatic musculoskeletal disease | Archives of Disease in Childhood (bmj.com)](https://adc.bmj.com/content/104/2/204.1)

### BeTAR Toolkit Project

In 2019 the development of a benchmarking toolkit for adolescent and young adult rheumatology services began. This enabled comparative evaluation of young people’s (YP) services to promote best practice and reduce variation in service delivery.

[Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR) | Pediatric Rheumatology | Full Text (biomedcentral.com)](https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-019-0323-8)

The overall focus of this project was to improve the care service provision for YP with JIA in both paediatric and adult services and ultimately their quality of life through driving service improvement. The aim of this project was to develop composite measures of optimal care in the form of a benchmarking toolkit that will allow comparative evaluation of clinical service performance in rheumatology YP friendly services across the country – applicable to both paediatric and adult rheumatology services delivering care to young people.

The initial phase of this project was a multicentre study funded by BANNAR. Working with YP and health care professionals (HCP) standards of best practice for rheumatology healthcare service provision for YP with JIA were identified and ranked to create a ‘benchmarking’ toolkit.

The team, led by Dr Eleftheriou subsequently obtained further funding for ARUK (£152,186.93) to continue this work and scope services in participating centres across the UK as well as explore the relationship between these assessments and health outcomes, particularly quality of life. This, culminated in an App being developed for use by young people in supported self-management.

### Quantitative Imaging of sacroiliitis; Inter-centre (Bath/UCLH) validation and generalizability in adolescence and young adults (Hall-Craggs and Sengupta, Bath and London).

This project took quantitative MRI (qMRI) techniques developed at UCLH to measure inflammation in adolescents with arthritis and testing whether they can be implemented more widely and be available across the UK. qMRI can measure joint inflammation objectively and could help diagnose and manage disease. This study tested whether qMRI can be applied across sites and across different MRI scanners and confirmed such techniques could be shared. This project has leveraged further funding from the Roetrees Foundation (**£56,000**).

### The relationship between psychosocial factors and transition readiness (Hawley et al, Sheffield).

The transition from paediatric to adult health services is not always well-managed and is often associated with the deterioration of health in patients with chronic illnesses. This study aimed to examine the relationships between psychosocial outcomes (e.g., anxiety) and readiness to transition from paediatric to adult rheumatology services in adolescents and young adults aged 10-25 years with Juvenile Idiopathic Arthritis (JIA).

Forty adolescents aged 10-16 years, together with a parent/guardian, at Sheffield Children’s Hospital and forty young adults aged 16-25 years at Sheffield Teaching Hospitals participated in this study. The results from this study have leveraged a further grant of £38,422 to complete a similar study in the uveitis transition service.

[290 Describing relationships between psychosocial outcomes and readiness for transition in adolescent and young adult patients with juvenile idiopathic arthritis: a pilot study | Rheumatology | Oxford Academic (oup.com)](https://academic.oup.com/rheumatology/article/57/suppl_3/key075.514/4971416)

### United Kingdom Survey of Access to Psychology Services for Adolescents and Young Adults with Rheumatic and Musculoskeletal Disease (Hawley et al., Sheffield).

In addition to scoping out transition research and care, mental health and psychological resources for young people with rheumatic conditions is a main research agenda for BANNAR.

In 2018 BANNAR members developed an e-survey that aimed to collect data to describe current access to psychology support services for young people (YP) with rheumatic musculoskeletal disease (RMD) managed in NHS rheumatology services.

Most YP with RMD require transfer of care from paediatric to adult rheumatology services. Significant lapses in care have been widely reported following transfer to adult rheumatology services. Developmentally appropriate healthcare should address YP’s psychological and social needs in addition to their medical needs.

Despite this, anecdotal evidence suggests psychological support services are scarce, vary between centres, and are more challenging to access following transfer from paediatric to adult services. Understanding YP’s access to psychology services is a necessary precursor to improved targeting of psychology services.

Results from the e-survey concluded that access to psychology services for young people with rheumatic and musculoskeletal disease varies significantly between paediatric and adult rheumatology centres, between paediatric centres and between adult centres. As of 2018, psychology service provision for 10–25-year-olds was reported as inadequate.

[P24 United Kingdom survey of access to psychology services for adolescents and young adults with rheumatic and musculoskeletal disease | Rheumatology | Oxford Academic (oup.com)](https://academic.oup.com/rheumatology/article/57/suppl_8/key273.026/5123462?login=false)

Mental health is currently a top research priority for BANNAR.

### Adolescent and Young Adults Rheumatology in Clinical Practice textbook

In 2019 BANNAR and Your Rheum members edited and contributed to the Adolescent and Young Adults Rheumatology in Clinical Practice textbook. It is a landmark text for clinicians, researchers, and allied healthcare professionals alike, in both paediatric and adult rheumatology care settings.

The textbook aims to highlight the importance of using a developmental lens to look at adolescent and young adult rheumatology and to describe what developmentally appropriate, young person-centred rheumatology care looks like in practice.

[Adolescent and Young Adult Rheumatology In Clinical Practice | SpringerLink](https://link.springer.com/book/10.1007/978-3-319-95519-3)

### BANNAR involvement in EULAR and PReS guidance on transition

With the greater understanding of rheumatological transitional care, gaps were reported of existing unmet needs. There was a need for both paediatric and adult rheumatologists to look beyond their own disciplines and explore what aspects of care made transition a success. Below are a couple of papers where BANNAR contributed to research into transition.

[EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases | Annals of the Rheumatic Diseases (bmj.com)](https://ard.bmj.com/content/76/4/639.short)

[Developmentally appropriate transitional care during the Covid-19 pandemic for young people with juvenile-onset rheumatic and musculoskeletal diseases: the rationale for a position statement | SpringerLink](https://link.springer.com/article/10.1186/s12969-021-00609-y)

### BANNAR and Versus Arthritis

In 2020, following discussions, subsequent agreement of the Terms of Reference (April 2021), and in the context of a memorandum of understanding enabling BANNAR to retain its identity and autonomy, BANNAR became nested within Versus Arthritis.

The agreement led to the appointment of a full-time Project Officer. The Project Officer has led important work towards modernisation of the network, implementing a BANNAR Comms Strategy including BANNAR social media, a monthly BANNAR Bulletin, and recruitment strategy though a BANNAR Membership survey.

The collaboration between Versus Arthritis and BANNAR will help to further support the network and the guidance it gives to professionals and young people with MSK and rheumatic conditions alike.

#### Historical milestones and a brief history of paediatric and adolescent rheumatology:

**1928: British Paediatric Association founded**

**1959: Platt Report –** highlighted that adolescents were different to children

**Early 1980’S: British Paediatric Rheumatology Group (BPRG) formed**

**1997: House of Commons Select Committee on Health -** Fifth report: Hospital Services for Children and Young People. “*Services for adolescents should be given greater focus and priority.”*

**1999***:* Arthritis Research Campaign Education Week entitled “Arthritis and Adolescence – it’s not just old people…”

**2000: BPRG audit - British Paediatric Rheumatology Group –** Before most paediatric rheumatology centres were established, a national audit exploring quality of rheumatology services for adolescents and young adults demonstrated [key areas of unmet needs](https://doi.org/10.1093/rheumatology/39.6.596):

* Only 9/61 centres surveyed had a dedicated adolescent clinic
* Generic health issues addressed in only 2/9 clinics ***McDonagh JE et al 2000***

This led to the first BPRG multicentre research study into transitional care 2001-2004 funded by the Arthritis Research Campaign, conducted in collaboration with CCAA and the Lady Hoare Trust and involved 10 rheumatology centres representing in England, Scotland, and Wales. Awareness then gradually developed.

The monthly Young People’s Health Newsletter which formed part of the centre support in the research still exists with a wide national and international readership. Individualised transition plans developed as parts of this research were adopted by the Ready Steady Go programme in 2015 and are now in widespread use across the UK.

**2003: Bridging the Gap: Health Care for Adolescents (RCPCH)**

Report from the Intercollegiate working party on Adolescent Health including paediatric and adult colleges as well as General practice, Public Health, Psychiatry, O&G, Public Health and Nursing raising awareness of the need for dedicated services for young people:

[Performance assessment (adlibhosting.com)](http://rcpch.adlibhosting.com/files/Bridging%20the%20Gaps%20-%20Health%20Care%20for%20Adolescents%202003-06.pdf)

**2005: BSPAR and RCPCH subspecialty recognition:**

<http://www.bspar.org.uk/>

[RCPCH | The Royal College of Paediatrics and Child Health](https://www.rcpch.ac.uk/)

### Barbara Ansell Fellowships

The Barbara Ansell Fellowships in Paediatric Rheumatology were established in 2005. The Fellowship programme aimed to support early phase paediatric rheumatology clinical or basic science researchers, allowing junior doctors, nurses or allied health professionals to take one year out of their everyday job to focus on research, accruing key research knowledge and skills and completing a project of their choice. It is not always easy for busy clinicians to find the funding to support their first steps into the world of research.

**Name Fellowship host institution Year awarded**

Dr Orla Killeen University of Glasgow 2005

Dr Kiran Nistala University College London 2006

Dr Zoe McLaren University of Liverpool 2007

Dr Harsha Gunawardena University of Bath 2007

Dr Despina Eleftheriou University College London 2007

Dr Flora McErlane University of Liverpool/ Alder Hey 2010

Mrs Maureen Todd (nurse) University of Glasgow 2010

Dr Corinne Fisher University College London 2012

Dr Ethan Sen University of Bristol 2012

Email BANNAR Project Officer s.yorke@versusarthritis.org if you would like further information on the Barbara Ansell Fellows and their work.

**2007: The RCPCH Young Persons Health Special Interest Group YPHSIG is established**

The monthly Young People’s Health newsletter arose out of the original transitional care research. <https://www.yphsig.org.uk/>

**2012: Centre for Adolescent Rheumatology at University College London**

Arthritis Research UK (now Versus Arthritis) co-funded the Centre for Adolescent Rheumatology in London – the world’s first centre dedicated to advancing the treatment of arthritis and other rheumatological conditions in adolescence. [Centre for Adolescent Rheumatology – research and support for young people Centre for Adolescent Rheumatology Versus Arthritis (adolescent-rheumatology.uk)](https://adolescent-rheumatology.uk/)

**2012: BANNAR part of the Centre for Adolescent Rheumatology.**

In 2012 BANNAR was developed as an integral part of the Centre for Adolescent Rheumatology to provide a network of motivated and enthusiastic individuals working across the UK to promote research into adolescent rheumatology and drive forward the development of excellent clinical care for AYA with rheumatic and musculoskeletal disease across the UK.The name was chosen to recognise the innovative Barbara Ansell. [**https://adc.bmj.com/content/88/3/185**](https://adc.bmj.com/content/88/3/185)

The network has steadily grown to a national professional network (of over 110 members). It has funded key adolescent and young adult research including a programme of work leading to the development of a successful national youth advisory panel (Your Rheum) which is now an integral component of BANNAR work as well as the development of a quality improvement toolkit for adolescent and young adult services (the BeTAR Toolkit).

[Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR) | Pediatric Rheumatology | Full Text (biomedcentral.com)](https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-019-0323-8)