

BANNAR, Your Rheum and VERSUS ARTHRITIS

Annual Partnership Report

November 2021 – April 2023

1. Purpose of the report

The purpose of this report is to:

- Describe the foundation of BANNAR and Your Rheum and explain the rationale for the basis of the relationship.
- Reflect on the activities undertaken against the key objectives agreed by BANNAR/Your Rheum and Versus Arthritis from November 2021 – to April 2023
- Evidence the impact of the relationship for both BANNAR/Your Rheum and Versus Arthritis.
- Outline shared agreement of direction of travel for the partnership.
- Give an update before the Memorandum of Understanding and contracts for BANNAR/ Your Rheum are renewed and reviewed in May 2023

2. Background to BANNAR/Your Rheum

The Barbara Ansell National Network for Adolescent and Young Adult Rheumatology (BANNAR) was formed in 2013 by a group of interested and keen rheumatologists with the aim of improving outcomes for adolescent and young adults (AYA) with rheumatic conditions. The network acts as a central point of reference for a UK-wide network of professionals in AYA rheumatology research covering the spectrum of disease, research methods and implementation science and provides signposting to relevant resources for this community.

The BANNAR network works closely with other organisations and charities including: AYA with rheumatic conditions and their families/carers, the British Society for Rheumatology, the Royal College of Paediatrics and Child Health, NIHR/Children/Arthritis Research UK Paediatric Rheumatology Clinical Studies Group, Versus Arthritis and many others (please see BANNAR Terms of Reference for full list).

BANNAR's focus is to enable the AYA rheumatology community to empower AYA's with rheumatic disease, and to contribute to key research priorities for these conditions across the UK and internationally.

3. Rationale behind the relationship between BANNAR/Your Rheum and Versus Arthritis

Following discussions and 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 was re-housed within Versus Arthritis in November 2020. Sarah Yorke (BANNAR Project Officer) is embedded within Versus Arthritis. Her roles include strengthening the network, improving BANNAR visibility, advocating for AYA within VA and discrete project work on behalf of BANNAR. The Centre for Adolescent Rheumatology and others continue to work in close partnership with BANNAR and BANNAR will continue to push links through other organisations eg BSR, CSG, CSAC etc.

The Project Officer role was initially funded by a grant fund to the Adolescent Research Centre earmarked for sustainability. The intended benefit of the relationship to Versus Arthritis is to have a thriving and engaged network of professionals to share knowledge and collaborate with and help to support Versus Arthritis' strategic priority of representing all ages throughout the life course of having arthritis.

4. Impact of the BANNAR/Your Rheum and Versus Arthritis relationship: Year 2 Summary - Evidencing and sharing impact of BANNAR activities.

4.1 Objective 1: Communication Strategy (objective information can be found in the appendix)

4.1.1 Consolidating and growing the network members

At the time the BANNAR Project Officer took up her post, there were 78 BANNAR members, but several contacts were out of date, with limited data available on the profile of the network.

Since then, the Project Officer has worked with the IT and data teams at Versus Arthritis, alongside the BANNAR leadership team, to implement a new sign-up form collecting more data about members. Data is stored in a GDPR compliant way with data processes in place to ensure redundant data expires and is removed. This has refreshed the membership and ensures that all members are now active. As of 30th October 2021, membership stood at 106 a 36% increase from November 2020. Now, as of 1st April 2023 we now have 161 members. A 52% increase from the year before. *See appendix for full list of KPIs at a glance.*

For BANNAR and Your Rheum this means more clinicians, researchers, and charity representatives are involved in contributing to the BANNAR research agenda, through a more diverse and engaged network. The BANNAR membership includes representation from all regions of England and the devolved nations, with the largest numbers based in London (27), North-West England (27), and Yorkshire and the Humber (16).

Last year, the East Midlands had the lowest membership numbers, with three members, with Northern Ireland, Wales, and the West Midlands at four members respectively.

Since then, the East Midlands membership has more than doubled, now having seven members. Northern Ireland has six members, Wales has seven and the West Midlands has also doubled its numbers, now having eight.

We have also recruited 1 paediatric pharmacist and 5 clinical/health psychologists. They are very difficult groups to target which last year had zero representation. BANNAR recruitment will continue to focus on these underrepresented areas.

Recruitment can be attributed to several aspects including events, the webinar series, and greater collaboration between Versus Arthritis teams. In addition, it shows that having discussions at members meetings with plans in place to target key individuals in underrepresented areas has been successful.

BANNAR members' clinical roles reflect the multidisciplinary nature of our speciality and includes doctors, nurses and AHPs (including Occupational and Physiotherapists). In November 2022 a new BANNAR Leadership team was elected.

The BANNAR Leadership team includes doctors who span the whole life course of rheumatology, from a Consultant Paediatric Rheumatologist, Adolescent Rheumatologist to Adult Rheumatologist. We also have a rheumatology nurse and a clinical academic physiotherapist– key to ensuring true representation across the wider clinical multidisciplinary team.

BANNAR continues to support Versus Arthritis' equality, diversity, and inclusion values, and this is reflected in our leadership team now having a woman of colour as one of our Vice Chairs. We continue to strive for a diverse and representative BANNAR membership giving consideration to factors including ethnicity, gender, age, geographical spread and a broad range of roles.

For Versus Arthritis this means a richer network from the Leadership team flowing down to its members, to support the strategic priority of a whole life course approach, from bringing our expertise, not only in AYA rheumatology, but having the knowledge of the whole life course of arthritis.

Examples highlighting the symbiotic relationship between BANNAR and Versus Arthritis include promotion of events and workshops through the BANNAR Bulletin and the @BANNARGroup Twitter feed; promotion of the new Young People and Families Service (YPFS) digital app and the YPFS podcasts (also through the BANNAR Bulletin); advertising of Your Rheum throughout the Versus Arthritis membership and collaboration with the YPFS manager, Lynne Woolley. The BANNAR Project Officer regularly attends the YPFS team meetings.

The BANNAR Project Officer is now regularly meeting with the Research Liaison and YPFS team at Versus Arthritis to ensure BANNAR and Your Rheum are aligned with Versus Arthritis research and the projects that our researchers are conducting.

4.1.2 Regular communication to members and members meetings

On the 22nd March 2023 we held a very successful Members meeting in Manchester. This was a whole day event and very well attended with 30 members in attendance. It was the first face to face meeting post pandemic, as one scheduled for November 2022 had to be postponed due to train strikes.

An outcome of the members meeting was that the Research Portfolio can now begin to be developed, as time was dedicated through the day for members to complete the Research Submission form (which is also available on the BANNAR webpages). The day also consisted of a BANNAR Business Update, Information on BANNAR research support including our Letters of Support and research dissemination, a Your Rheum update and two research presentations.

Feedback forms were completed for impact and evaluation purposes, and over 90% of attendees rated the event 5 out of 5. Below are a few quotes from the members regarding the meeting:

“So good to meet, discuss common issues and network”.

“A realisation (again) of the huge networking potential of BANNAR.”

“Incorporation of research ideas was very helpful.”

“I will visit BANNAR with research queries.”

“A lovely day, thank you for organising!”

The BANNAR Project Officer continues to distribute a monthly members bulletin (BANNAR Bulletin) and organises quarterly meetings to allow networking and discussion of key research projects and BANNAR protocols.

Regular communication with the BANNAR membership is crucial to keeping the network engaged and associated networking opportunities allows greater collaboration and support. High attendance at the members meetings illustrates the importance of the network to clinicians, academics and to the third sector.

There is also a strong benefit for Versus Arthritis, with an established mechanism for information sharing with the BANNAR membership.

BANNAR Meetings 2022:

- The leadership team met virtually each month.
- In 2022 we held 3 virtual meetings of the membership (February, June and November with median number of 31 members attending each meeting (ranging from 25 (June) to 37 (November)).
- In 2023 we held our first BANNAR Face to Face members meeting with 30 in attendance

Number of letters of support given: 3

Number of research projects supported: 10 surveys/ 13 recruitment adverts etc. circulated

Number of presentations by researchers at meetings: 7

4.1.3 Establishing a social media presence

Before the Project Officer took her post there was no BANNAR social media presence. Sarah liaised with the BANNAR Chair and Vice Chair to discuss the most appropriate platform for the organisation, and it was agreed to start a BANNAR Twitter profile; @BANNARGroup.

@BANNARGroup now has 318 followers, up from 164 followers in November 2021. This is an increase of 94%. BANNAR members regularly retweet from the profile and engage with the content.

Having a social media presence has been of huge benefit, enabling sharing of information and surveys, and improving visibility outside of the network. We have been able to share and disseminate research and recruitment posters from both Versus Arthritis and our other members organisations and networks.

The BANNAR Twitter account is a new link between charities and research institutions, and this is illustrated by the retweeting of posts that are important for the BANNAR audience. This has been helpful for relationship building.

BANNAR also follow accounts from diverse backgrounds, with the aim of recruiting a wider membership to BANNAR.

Internally, at Versus Arthritis, the Project Officer has written several posts on YAMMER, highlighting project successes including webinars, reports and meetings. Since writing these greater awareness has been generated through Versus Arthritis about BANNAR and the work we do. This resulted BANNAR featuring in the Trustee newsletter.

4.1.4 Developing new BANNAR Webpages – held on the Versus Arthritis site

BANNAR now have a suite of webpages held on the Versus Arthritis site. This is of benefit to both organisations, as it brings traffic to the site from BANNAR members – who later explore other pages of the Versus Arthritis website, and BANNAR who now have a very professional website, both aesthetically and technically. It currently serves as a great space for holding the BANNAR Membership link, Useful documentation for HCPs and researchers, The History of BANNAR, and information on the BANNAR Leadership team and upcoming events.

The Project Officer designed and co-created these pages with the assistance of the Versus Arthritis digital team.

The collaboration between organisations has been of benefit through sharing technical knowledge and expertise from Versus Arthritis, and clinical and research knowledge content from BANNAR.

4.1.5 Developing and writing documents that underpin the communication strategy

Since the appointment of the Project Officer, documents have been created to align the work and support that BANNAR provides.

The BANNAR Request for Support, Terms of Reference, and Communication Policy provide a firm foundation for BANNAR members and Versus Arthritis to have a clear understanding of the BANNAR remit and protocols. As of April 2023 a new Memorandum of Understanding and Terms of Reference between Versus Arthritis and BANNAR/ Your Rheum is currently being written up by BANNAR Chair, Flora McErlane and the Versus Arthritis Senior Leadership and Governance team. This will be available from May 2023 when the funding for both BANNAR and Your Rheum will be reassessed.

A social media policy has also been written up to ensure there is a clear line of reporting should any issue arise that needs escalating.

A *History of BANNAR* document has been created using key papers, documents and articles that help explain the foundations, past studies, research and aims of BANNAR.

4.2 Objective 2: Data and Technical Workflow

In Year 1 the Project Officer gathered consent statements which were added into the ThankQ database. This is to ensure that BANNAR hold all membership information securely and is GDPR compliant. This in turn creates less risk which is essential to maintain the reputations of both organisations. Using the ThankQ database will enable BANNAR to use mailer platforms and use booking software for future events (should this arise).

The Project Officer has met with the Head of Data Protection and has had data protection training from Versus Arthritis.

It is very important that BANNAR is representative. The data that has been collected through the new membership survey captures gender, age, and ethnicity for diversity monitoring. 84% of the membership is female. 6 members identify as Black/Black British African, 12 members identify as South Asian/Asian British, 2 as Asian Chinese/Chinese British with the majority of the membership identifying as White British (112). In regard to age, interestingly it was almost a 50/50 split (of those who answered) with 80 members being born in 1980 or earlier, and 71 members being born after 1980. Our youngest member is also on our BANNAR Leadership team, ensuring we keep a fresh and innovative approach to our work.

4.3 Objective 3: Psychological Resources

Initial conversations regarding the mental health and psychological resources available to adolescents and young people (AYAs) who are diagnosed with MSK conditions have taken place with BANNAR and several of the charity representatives that are in the BANNAR Membership.

This also ties in with the work of the Versus Arthritis YPFS who are also interested in this area, and could be an avenue for possible collaboration, along with the other interested charities.

Following the success of the Mental Health questionnaire, that was a collaboration between Versus Arthritis and several BANNAR members and charity representatives, the Project Officer has scoped out interest for a Mental Health Subgroup. The aim of the Mental Health Subgroup is to push forward research in this area, and then use this research in policy and eventually service provision for the young people we work with.

There was opportunity for BANNAR members to register interest in this group at the members meeting, as well as emails that had previously been sent around the group. The Research Portfolio will be able to link up researchers working on similar mental health projects, in order to collaborate and advise each other should they wish.

Currently, psychological resources are featured in the BANNAR Bulletin, which includes relevant mental health first aid training for the BANNAR membership.

BANNAR are also collaborating with the Strategic Digital Comms team to develop a Mental Health blog piece that will be shared during Mental Health Awareness Month in May 2023. This will have a focus on adolescents and young adults, and questions will be answered by one of our BANNAR Clinical Psychologists. We will point to the potential mental health webinar that they YPFS team are running, as well as their pages on Emotions, local area resources/community and the Helpline.

4.4 Objective 4: Quality of Care

The membership would like to support a service scoping project with the aim of establishing the proportion of AYA with access to dedicated AYA services.

BANNAR are often approached by members of Versus Arthritis to provide various numbers of patients/clinics/demographics.

This piece of work would be a very useful information for the HCP and YPFS teams at Versus Arthritis.

Flora McErlane has been investigating what we can learn from the 6 JIALearn improvement collaborative teams about how to implement it in practice.

The Mental Health subgroup has an aim of providing better mental health resources and services for the young people that we work with.

4.5 Objective 5: Education Package

So far, the BANNAR Webinars and Education package demonstrated the value of the BANNAR network, and was good PR to develop growth of network. It was inclusive to those BANNAR members who cannot access funding for webinars that charge for such educational resources. BANNAR members were asked what topics they are interested in and if/what they would like to contribute to. The BANNAR Leadership team chaired and organised the webinars and it was a great recruitment tool for BANNAR Membership.

Webinars took place on MS Teams in both the evening and lunchtime, in order to assess which sessions were most accessible to our membership. Although there was initial interest in attending, the actual attendance numbers were significantly lower, regardless of time. It was decided by the BANNAR Leadership team not to record the sessions due to copyright and storage.

This prompted discussion at the BANNAR Members meeting that it might be more effective to run an educational day, perhaps as part of our face-to-face next Members Meeting later on in the year.

It was also discussed that a podcast could be helpful to those who can't join a meeting but could listen at a later date. Members also considered having a live chat at the same time as the webinars, again, in order to widen participation. All these options will be considered for the next year, whilst keeping within budget and capacity.

The list of the webinars is available in the appendix.

4.6 Objective 6: Your Rheum

BANNAR members are key to ensure the success of Your Rheum by individually actively promoting it with young people in their respective centres, involving them at the various stages of their own research initiatives as well as supporting Your Rheum-led initiatives. BANNAR also promotes Your Rheum through the BANNAR Bulletin where they regularly post recruitment messages, meetings and updates from the Your Rheum team. One of the Your Rheum chairs attended the October 2021 BANNAR members meeting.

Your Rheum has 54 members from across the UK. Since November 2022 Your Rheum has held three face-to-face meetings, two virtual meetings and one online activity.

BANNAR assisted Your Rheum with the development and dissemination of the finalised Your Rheum Pain Word Cloud (to aid communication in consultations about pain) and will use in clinic with young people. They also worked together and supported an NIHR HTA funding application rounds one and two with Ethan Sen and BANNAR Chair, Flora McErlane.

Your Rheum Chairs attended a BANNAR meeting, and there has been discussion surrounding a new Expert in Residence position within BANNAR. The group have worked on a GenerationR project relating to learning about health research in school. Your Rheum's discussions will aid conversations going forward.

BANNAR worked with Your Rheum to develop the MSK toolkit for Employers & Further Education:

https://www.som.org.uk/sites/som.org.uk/files/MSK_Health_Toolkit_for_employers_and_further_education_institutions.pdf

The Project Officer regularly attends YPFS meetings where she shares the relevant Your Rheum updates. This helps with the Versus Arthritis strategy of reaching younger people in the arthritis life course, as it is another offering to our young people.

The Project Officer has attended YPFS Away Days in both London and Glasgow, which is an opportunity to share BANNAR and Your Rheum projects, research and initiatives, and ensure that we collaborate effectively. Going forward the YPFS team have been asked to share any opportunities for young people they may have in the BANNAR Bulletin.

Vic Harbottle has moved from being a BANNAR Vice Chair to the Your Rheum Project Lead.

5. Planned future activity

5.1 Planned Communication Strategy

BANNAR will continue to plan and deliver a programme of engaging and informative BANNAR communications throughout 23/24 in order to reach our existing, and potential new members.

Growth of the network: The BANNAR membership target was exceeded for this year, with an initial target of 145, reaching 161. The target for the next financial year is 190 members. This will be done through social media channels, webinar sessions and in person recruitment at conferences and events.

The membership does not presently include any adult pharmacists, and five health/clinical psychologists, key roles within the multidisciplinary team. We would like to develop representation in both areas, although acknowledge that there are limited numbers of dedicated rheumatology pharmacists and clinical psychologists. Inclusion of these key roles will help with the design of relevant projects aimed at enhancing knowledge in these key areas.

Hopefully the instigation of the mental health subgroup will attract further participation from clinical, academic and health psychologists. The BANNAR Project Officer has approached the Versus Arthritis Health Development team to recruit pharmacists at relevant events.

A series of testimonials about the impact Barbara Ansell had on her patients is being written up. This will assist the Versus Arthritis Legacy teams when people leave Gifts in Wills and In Memory donations. The document "Who was Barbara Ansell" will also assist with this aim, in addition to spreading awareness to our HCP and Researcher community. These documents will be available on the BANNAR webpages, once created.

The BANNAR Project Officer will document and share outputs and impact of BANNAR work and the relationship with Versus Arthritis in 23/24 by continuing to send out regular BANNAR Bulletins, update on social media and the Versus Arthritis internal YAMMER pages.

Regular attendance at Health Development, YPFS and Research team meetings will continue to promote BANNARs work, as well as monthly BANNAR Leadership meetings and quarterly Members meetings.

5.2 Planned Data and technical workflow

PowerBI: Reporting of the membership data will enable a more targeted approach to growth and a better understanding of profiles and membership. This will hopefully result in better comms.

ThankQ: Continuing to work with the ThankQ team to ensure data is integrated and managed properly for the benefit of BANNAR members and both organisations' reputational risk.

Impact and evaluation work is being discussed with the Versus Arthritis Research Impact team in how best to capture outputs and outcomes in order to assess the impact of BANNAR.

5.3 Planned Psychological resources workstream

Recruitment of psychologists is a key aim of the BANNAR recruitment, acknowledging the current limited-service provision in this area. This will be taken to the BANNAR membership to get their opinions.

The Project Officer discussed starting a Mental Health subgroup for BANNAR Members with training and interest in this area. At the BANNAR Members meeting in March 2023 11 members showed an interest in being part of this group.

The aim is to take forward the work from the Mental Health survey conducted by the charities, and start to further research mental health in AYA, with the aim of pinning this research to service provision.

A collaborative mental health blog piece is also being produced, with BANNAR Members and the Digital Strategic Comms team. This will also link to YPFS resources and the Helpline.

5.4 Planned Quality of Care project

We have been working on various projects that look at how we can use data and measurement for quality improvement. Specifically, Flora McErlane has been investigating what we can learn from the 6 JIALearn improvement collaborative teams about how to implement it in practice.

The development of the Research Portfolio should help to align researchers with each other, in order to facilitate collaboration and in time, better service provisions and funding calls.

As the mental health subgroup continues to grow, our aim is that this will help provide a better quality services for our young people in clinic.

5.5 Planned Education package

BANNAR plan to continue delivering a programme of Education activities in line with BANNAR member needs and Versus Arthritis' resource constraints in 23/24.

Potentially a BANNAR Educational day could be part of the next BANNAR Members meeting. This will follow the business update and research project critiques.

In the BANNAR Members meeting we discussed having the webinars recorded so that those who can't attend are still able to access the talks at a later date. This will be at the discretion of the BANNAR Leadership team.

Two more BANNAR Webinars are to run in spring time (April and May 2023); an Adolescent Research Update and Work Readiness for Clinicians. Details in the appendix.

5.6 BANNAR Research Portfolio

A target for the year April 2023 to March 2024 is to develop and continue to create and maintain a research portfolio that will capture the work that BANNAR members are conducting in AYA Rheumatology. The aim of this is to enable research collaborations and knowledge share within the membership, as well as potentially Versus Arthritis colleagues. It will also provide a clearer mechanism for measuring the impact of the network. Guidelines will be developed with the assistance of the Versus Arthritis Research team to enable all parties to understand the purpose, and to fully utilise the portfolio.

5.7 Planned Your Rheum activity

Your Rheum really needs the continued support of professionals in the recruitment of young people to take part in Your Rheum, particularly younger adolescents and males. E-flyers are available for anyone wanting to advertise the group to young people in their network.

Your Rheum would also be grateful to be made aware as soon as possible of forthcoming research involvement opportunities with BANNAR members which may require Your Rheum so they can plan effectively.

A new MoU between BANNAR/ YourRheum and Versus Arthritis is currently being drawn up and shared with all respective parties.

Appendix

Appendix 1

Objectives are set out as per the original job description for the BANNAR Project Officer from November 2020.

Appendix 2

KPIs at a glance

Year to date	Number
Members	161
Webinars	4
Meetings	3 Virtual, 1 F2F
Research Presentations at Meetings	7
Number of research projects supported:	10 surveys/ 13 recruitment adverts etc. circulated
Letters of Support	3

Appendix 3

Webinar Programme:

Speaker	Title of Webinar	Date/Time	Attendance
Autumn Sessions			
Anne-Lise Goddings	The Adolescent Brain	21/09/22	15
Nicola Webb	Team Working; The Role of Reflective Practice in Paediatric and Adolescent Rheumatology	19/10/22	13
Angela Jackson	Risk factors associated with injury in the active adolescent	16/11/22	16
Spring Sessions			
Polly Livermore	Nursing Research	08/02/2023	17
Coziana Ciurtin	Adolescent Research Update	19/04/2023	Next reporting year
Janine Hackett and Claire Pidgeon	Work Readiness for Clinicians	24/05/2023	Next reporting year

Appendix 4

BANNAR Letters of Support

Date of Application Submission	Name of Applicant	Host Institution	Name/Summary of Project	BANNAR Member signed off	BANNAR Sign off date
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02/12/2021	Flora McErlane	National Confidential Enquiry into Patient Outcome and Death	Topic Proposal CH01. Juvenile Idiopathic Arthritis (JIA	Janet McDonagh	02/12/2021
12/05/2022	Polly Livermore	Great Ormond Street Children's Hospital	IMPACT : Interventions to improve Mental health Provision in children And young people with Chronic rheumaTological conditions	Flora McErlane	19/05/2022
21/06/2022	Heather Rostron	Leeds Children's Hospital Clinical Research Team	How to keep the 'hands on' with 'hands off' paediatric rheumatology: development of a framework for a Technology Enabled Care model to support virtual clinics	Flora McErlane	21/06/2022

BANNAR and Your Rheum publications/presentations

* Your Rheum members

Yorke S, Harbottle V, McErlane F, Tattersall RS, McDonagh JE. The Barbara Ansell National Network for Adolescent Rheumatology – 10 years on. *Rheumatology Advances in Practice*, Volume 6, Issue Supplement_1, October 2022, rkac067.049, <https://doi.org/10.1093/rap/rkac067.049>

BSR & BANNAR . Developmentally appropriate care: top tips (July 2022)

[Developmentally appropriate care: top tips \(rheumatology.org.uk\)](https://www.rheumatology.org.uk/developmentally-appropriate-care-top-tips)

Your Rheum Publications 2022

Esen, E., Gnanenthiran, S., Lunt, L. et al. **The Your Rheum story: involvement of young people in rheumatology research.** *BMC Rheumatol* 6, 43 (2022). <https://doi.org/10.1186/s41927-022-00273-z>

Laura E Lunt, Morgan Purvis, Suruthi Gnanenthiran, Pelin Zing, Janet E McDonagh, Your Rheum, a national advisory group of BANNAR, **OA31 Youth-led development of an animated film to aid recruitment to a national youth advisory group for adolescent and young adult rheumatology**, *Rheumatology*, Volume 61, Issue Supplement_1, May 2022, keac132.031, <https://doi.org/10.1093/rheumatology/keac132.031>

Laura E Lunt, Jasmine Leslie, Suruthi Gnanenthiran, Morgan Purvis, *Tilda Kierkegaard Holt, Janet E McDonagh, Your Rheum, a national advisory group of BANNAR, **P161 Experiences of virtual research involvement activities: from the perspectives of young people and researchers**, *Rheumatology*, Volume 61, Issue Supplement_1, May 2022, keac133.160, <https://doi.org/10.1093/rheumatology/keac133.160>

Tilda Kierkegaard Holt, Zahra Baz, Suruthi Gnanenthiran, Lee R Rebecca, Lunt E Laura, McDonagh E Janet, P04 **The pain word cloud project: development of a clinic prompt to support young people in conversations about pain**, *Rheumatology Advances in Practice*, Volume 6, Issue Supplement_1, October 2022, rkac067.004, <https://doi.org/10.1093/rap/rkac067.004>

Beth Dillon, Suruthi Gnanenthiran, Megan Stubbs, Sarah Yorke, Lunt E Laura, McDonagh E Janet, P56 **Involvement of young people in adolescent and young adult rheumatology services and research**, *Rheumatology Advances in Practice*, Volume 6, Issue Supplement_1, October 2022, rkac067.056, <https://doi.org/10.1093/rap/rkac067.056>

Diarmuid McLaughlin, Samundeeswari Deepak, Laura Lunt, Beth Dillon, Ecem Esen, Janet McDonagh, P58 **young persons' perspectives on the results of a UK multi-centre survey on variations in clinical practice in paediatric rheumatology units during the covid-19 pandemic**, *Rheumatology Advances in Practice*, Volume 6, Issue Supplement_1, October 2022, rkac067.058, <https://doi.org/10.1093/rap/rkac067.058>