

BANNAR, Your Rheum and VERSUS ARTHRITIS

Annual Partnership Report

November 2020 – October 2021

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 the appointment of the Project Officer in November 2020 – to November 2021
- Evidence the impact of the relationship for both BANNAR/Your Rheum and Versus Arthritis.
- Outline shared agreement of direction of travel for the partnership

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 recently re-housed within Versus Arthritis. 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 reaching every child and young person with arthritis.

4. Impact of the BANNAR/Your Rheum and Versus Arthritis relationship: Year 1 Summary

4.1 Strategic Theme/Objective 1: Communication Strategy

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 are 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. Membership now stands at 106 (as of 30th October 2021)– a 36% increase.

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, North-West England, and Scotland. The East Midlands has the lowest membership numbers, currently at three, with Northern Ireland, Wales, and the West Midlands at four members respectively. This has been discussed at members meetings with plans in place to target key individuals in underrepresented areas.

BANNAR members' clinical roles reflect the multidisciplinary nature of our speciality and includes doctors, nurses and six AHPs (including Occupational and Physiotherapists). The

BANNAR Leadership team includes doctors, one of whom is a clinical academic, and one clinical academic physiotherapist, – key to ensuring true representation across the wider clinical multidisciplinary team.

For Versus Arthritis this means a richer network to support the Reaching Every Child and Young Person (RECYP) strategic priority. 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.

4.1.2 Regular communication to members and members meetings

The BANNAR Project Officer distributes 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.

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 164 followers with an average of 96 impressions a day. 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 animations and videos from both Versus Arthritis and Your Rheum; for example, the latest Your Rheum recruitment animation (which earned 875 impressions) and the Versus Arthritis “Young Experts” opportunity (which earned 4974 impressions).

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.

4.1.4 Developing a new BANNAR Webpage

BANNAR now have a website holding page 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 webpage, both aesthetically and technically. It currently serves as a great space for holding the BANNAR Membership survey MS Forms link.

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

BANNAR are in the process of setting up a suite of BANNAR webpages that will be placed on the Versus Arthritis website.

The Project Officer has instigated the purchasing of BANNAR web domains to avoid any future difficulties. She has also taken the old BANNAR website down in order to ensure BANNAR adheres to GDPR and Copyright policies.

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.

A *History of BANNAR* document is also being written using key papers, documents and articles that help explain the foundations, past studies, research and aims of BANNAR.

These documents will be available of the BANNAR webpages, once created.

4.2 Strategic Theme/Objective 2: Data and Technical Workflow

In Year 1 the Project Officer has gathered consent statements which are to be added into the ThankQ database. This is to ensure that BANNAR hold all membership information securely and is GDPR compliant. This in turn will create less risk and 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.

4.3 Strategic Theme/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. There is an ambition to explore existing resources available for this demographic.

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.

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

4.4 Strategic Theme/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.

4.5 Strategic Theme/Objective 5: Education Package

The membership are planning a series of educational webinars focussed on provision of developmentally appropriate healthcare in 2022-2023. The Project Officer is seeking advice regarding how best to use technology to fully utilise these sessions. Members of the Versus Arthritis HealthCare Professionals team have recently run a Core Skills Package which used a similar format and platform, so knowledge sharing will take place.

4.6 Strategic Theme/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 soon.

The Project Officer regularly attends YPFS meetings where she shares the relevant Your Rheum updates, including the latest Your Rheum animation to assist with recruitment. This helps with the Versus Arthritis strategy of RECYP, as it is another offering to our young people.

5. Planned future activity

5.1 Planned Communication Strategy

Growth of the network: The membership does not presently include any adult pharmacists, and only two 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.

Social media planner: This could help to grow the network and also improve collaboration with the various other charities BANNAR work with and align with the work that the YPFS teams work on.

Webpages: The new pages will be able to hold BANNAR documents (such as Letter of Support documents, Terms of Reference, Comms Policies etc) and other key informative pieces (including A History of BANNAR, surveys, and information animations). The Project Officer is liaising with the Versus Arthritis Digital team and the BANNAR Leadership team to begin workshopping these site pages. She has also suggested forming a BANNAR Web Working Group – where BANNAR members can contribute to ideas on the website, giving a further sense of ownership through contribution. Will help to have all the BANNAR information in one, accessible place and also gain greater reach. It will also look very professional and on brand with both BANNAR and Versus Arthritis.

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.

5.3 Planned Psychological resources workstream

Initial discussions are yet to be formalised. Recruitment of Clinical Psychologists is a key aim of the BANNAR recruitment, acknowledging the current limited service provision in this area. Will be taken to the BANNAR membership to get their opinions.

5.4 Planned Quality of Care project

Initial discussions are yet to be started. This is to be taken to the BANNAR membership to get their initial thoughts.

5.5 Planned Education package

Webinar Education Package: Will demonstrate value of BANNAR network and good PR to develop growth of network. It will also appeal to those BANNAR members who cannot access funding for webinars that charge for such educational resources. BANNAR members will be asked what topics they are interested in and if/what they would like to contribute to.

5.6 Planned Your Rheum activity

Your Rheum chairs are aiming to come to future BANNAR meetings. Recruitment continues from BANNAR members and also from the Versus Arthritis YPFS national teams. Your Rheum members are also keen to involve BANNAR Members in 2 youth-led projects around (i) vocation and (ii) pain which have arisen out of recent Your Rheum meetings.

Appendix

Appendix 1

BANNAR and Your Rheum publications/presentations past 12 months

* Your Rheum members

Papers

McDonagh, J. E., Tattersall, R., Clinch, J., Swan, J., Foster, H. E., & McCann, L. (2021). 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. *Paediatric Rheumatology*, 19(1), 1-9.

Shoop-Worrall, S. J., Cresswell, K., *Bolger, I., *Dillon, B., Hyrich, K. L., & Geifman, N. (2021). Nothing about us without us: involving patient collaborators for machine learning applications in rheumatology.

Published abstracts

Lunt LE, Leslie L, *Gnanenthiran S, *Purvis M, *Kierkegaard Holt T, McDonagh JE, on behalf of Your Rheum, a national advisory group of the Barbara Ansell National network for Adolescent rheumatology. Experiences of virtual research involvement activities: from the perspectives of young people and researchers. *Paediatric Rheumatology* 2021; 19(supplement 1):P345

Presentations

BSR Annual Conference 2021: Janet McDonagh. Barbara Ansell Address

BSR Symposium 2021: Janet McDonagh, Rachel Tattersall. Developmentally Appropriate Care

5th Adolescent Rheumatology Symposium 2021: Janet McDonagh and Rachel Tattersall as Chairs. The Patient Perspective, mental health and coping with disease

5th Adolescent Rheumatology Symposium 2021: CAPTURE-JIA: Capturing the young person's perspective of routine data collection in clinics (Presenter Laura Lunt).

5th Adolescent Rheumatology Symposium 2021: Young people discussing research addressing their readiness for work (Presenters *Hamza Choudhary & Janet McDonagh).

5th Adolescent Rheumatology Symposium 2021: Getting into Adolescent Heads - importance of routinely addressing mental health in rheumatology clinics with *Eleanor Edgar a young person with JIA (Presenters Eleanor Edgar & Janet McDonagh)
<https://mediacentral.ucl.ac.uk/Play/56345>

Advanced Medicine Course at the Royal College of Physicians April 2021 Importance of routinely addressing mental health in adolescent clinics (Presenters *Hamza Choudhary & Janet McDonagh) <http://www.kaltura.com/tiny/zqur6>

Your Rheum Posters/e-posters

PReS conference 2021, Experiences of virtual research involvement activities: from the perspectives of young people and researchers (Presenters *Suruthi Gnanenthiran, *Tilda Kierkegaard Holt & Laura Lunt).

Miscellaneous

2020 Hidden Illness, One Patient's Journey, *Sophie Ainsworth, Arthritis Digest, May 2020

2021 The World of Work, Dr Janet E McDonagh, Arthritis Digest Issue 4 2021

2021 Young Minds Matter, *E Edgar, Dr Janet E McDonagh, NRAS spring 2021 newsletter

Appendix 2

BANNAR Letters of support past 12 months

Date of Application Submission	Name of Applicant (person requesting)	Host institution	Name/Summary of Project	BANNAR Member signed off	BANNAR Sign off date	How is BANNAR Supporting	Is requester a BANNAR member? (Yes/No)
25/06/2021	Lianne Kearsley-Fleet	Manchester	Planning for a future without fear: Epidemiological investigation of long-term health-related outcomes in adults with JIA	Flora McErlane	2nd July 2021	Letter of Support to Versus Arthritis	Yes
25/06/2021	Janet McDonagh and Janine Hackett	Manchester	Work Ready Champions for Young People: the role of Occupational therapy in addressing the pre-vocational and early-employment needs of young people with long term health conditions.	Flora McErlane	Surveys distributed in July 2021	Survey dissemination through email and social media (Twitter)	Yes
17/08/2021	Danielle Mountain	Manchester	Explore and compare lived pain experiences in children and young people with musculoskeletal conditions.	Flora McErlane	13th September 2021	Survey dissemination through email and social media (Twitter)	Yes