First and foremost, thank you so very much for all your input, time and effort you have given to Your Rheum – it has been very much appreciated. But now it’s time to look at what life looks like beyond Your Rheum!

This document is designed to help you work out what you might want to do next, following on from your time spent as a member of Your Rheum.

It includes **some questions to encourage you to reflect on what you may want to do next,** some **useful resources** on research involvement organisations and other volunteer organisations, and **templates** you might find helpful in the future.

We would also like to offer all Your Rheum members who are leaving the group the opportunity to become part the **Your Rheum alumni**. In the alumni, we will keep you updated on future opportunities we think previous members would be interested in. You can also get in touch with us if you need anything, such as a job reference, or if you have any questions. Similarly, we would love to hear from you if you have any opportunities you think we should be aware of, and that could help current and future members of Your Rheum.



**What’s N**

**ext?**

We are always looking for ways to improve what we do too – if you have suggestions of what should be included in this document or resources to add, please get in touch. **EMAIL: your.rheum@versusarthritis.org**



**Looking Back**

Here are some questions to help guide your thoughts and think about what you want to do next.

1. What did you **enjoy most** about being a member of Your Rheum?

|  |
| --- |
|  |

1. And, what did you **like least** about being a member?

|  |
| --- |
|  |

1. What, if anything, did you gain from being part of Your Rheum that you would like to continue to use or build upon? (e.g. a skill, an area of interest, personal development)

|  |
| --- |
|  |

1. Below is a list of statements. Circle the ones you feel are important to you. Or add your own.

“I want to be involved in rheumatology research”

“I want to be involved in paediatric

(children’s) research”

“I want to be involved in health research”

“Volunteering is important to me”

“I want to be an advocate for young people” “I want to raise awareness about young

people living with a rheumatic condition”

“I want to share my personal experiences”

“I enjoy listening to others”

“I want to solve problems”

“I want to work/volunteer in my local community / beyond my local community”



**Looking Forward**

Hopefully the first section of this document has helped you think about what it is you are really interested in and what is important to you moving forward.

Here is a list of resources which we think you might find useful – including non-specific groups and some specific to arthritis and other musculoskeletal conditions. Most of these organisations are on social media such as Twitter and Facebook.

# Volunteering

Have you thought about volunteering in your local community? Volunteering is a great way to gain a lot of skills that can be transferred into a workplace. Most importantly, from the process of volunteering, you will gain a sense of personal satisfaction gained by assisting another person/organisation. There are different ways you can do this. Below are a few examples.

1. British Youth Council www.byc.org.uk
2. https://vinspired.com
3. https://volunteeringmatters.org.uk/pillars/young-people/
4. Local hospitals
5. Local care homes
6. Schools, colleges and universities
7. Community youth centres
8. Rainbows, Brownies, Guides, Scouts, Cubs
9. Other charities and non-for-profit organisations eg various charity shops, National Trust

* **Versus Arthritis – Volunteers**

Versus Arthritis volunteers play a vital role in supporting people with arthritis, raising funds and raising awareness about arthritis. The organisation couldn't operate without them. Volunteering is a great way to:

* Develop and share your skills
* Meet new people
* Work with people who are passionate about making a difference

Versus Arthritis have a wide variety of volunteer opportunities available. However you choose to donate your time, your contribution will help us to transform lives and support the 10 million people who are living with arthritis in the UK. To find out more about the volunteering opportunities available and to register your interest visit the website or email directly.

Website: https://www.versusarthritis.org/get-involved/volunteer/

Contact: Volunteering@versusarthritis.org

# Further Education

Perhaps Your Rheum has given you a taste for research yourself or careers in the NHS.

1. https://www.thecompleteuniversityguide.co.uk/courses
2. https://www.healthcareers.nhs.uk/explore-roles
3. https://www.stepintothenhs.nhs.uk/careers
4. http://www.open.ac.uk/

**Involvement in research and advocacy: UK musculoskeletal condition organisations**

There are many more adult condition-specific charities with a web presence so worth checking these out and seeing if there are any opportunities linked with them.

* **Versus Arthritis – Patient Insight Partner**

The patient voice is integrated fully into Versus Arthritis research activities through close collaboration with patient insight partners. This group work alongside researchers and health care professionals to ensure relevance whilst maintaining high standards of research quality.

Website: https://www.versusarthritis.org/research/involving-people-with-arthritis/ourpatient-insight-partners/

Contact: patientinsight@versusarthritis.org

* **Arthur’s Place**

Arthur's Place embraces all opportunities that allows young people to have their own voice and be heard. Sharing their stories, their talents, their insights and expertise.

Website:

To get an insight about Arthur's Place, our community, and social media groups please go to http://arthursplace.co.uk/ and follow the links.

Facebook:

To join new friends in Arthur's Social group, and to hear about new project opportunities to get involved, please join us at Arthur's Place social.

Contact:

All general enquires to Andrea: andrea@arthursplace.co.uk

Blogging and vlogging enquiries to Tony: Tony@arthursplace.co.uk

* **JIA @ NRAS**

As well as being a source of information and support JIA-at-NRAS are always looking for people to get involved in their work through volunteering to campaigning. You can sign up to their newsletter or follow them on Facebook and Twitter.

Website: https://www.jia.org.uk/get-involved

Contact (general email): jia@nras.org.uk

* **NIHR Biomedical Research Centres: Research User Groups**

Speak to your local rheumatology team (maybe speak to your consultant, or rheumatology nurse) and ask them if there is a local rheumatology research user group. NHIR Biomedical Research Centres (BRC) are based across the UK and will run groups you can get involved in. As an example here are links to the opportunities in Manchester:

Website (Manchester): [Musculoskeletal Research User Network | Vocal (wearevocal.org)](https://wearevocal.org/opportunities/musculoskeletal-research-user-network/)

Contact (Manchester): [vocal@mft.nhs.uk](mailto:vocal@mft.nhs.uk)

* **RheumMates – Facebook group**

This is a peer support group for children and young people with rheumatic conditions

(arthritis, lupus, things like that).

Please join up to be part of sharing your experience and asking questions.

https://www.facebook.com/groups/rheumates/

# Involvement in research and advocacy: International musculoskeletal condition organisations

• **EULAR Young PARE**

Young PARE aims to improve the quality of life of young people (18 to 35 years old) with rheumatic and musculoskeletal diseases (RMDs) by raising the profile of these conditions, and by creating a network of individuals who work in European countries on behalf of young people with RMDs.

Website: http://www.youngpare.org/

Contact online form: http://www.youngpare.org/contact-us/

# Involvement in research: UK non- musculoskeletal organisations

* **National Institute for Health Research (NIHR)**

There are many ways to get involved in NIHR research such as becoming a patient research ambassador, joining an advisory committee or becoming a research application reviewer. Visit their website for more details and various contacts.

Website: https://www.nihr.ac.uk/

* **INVOLVE - funded by NIHR to specifically support public involvement in NHS research** As a national advisory group their role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

Website:

Involvement page: https://www.invo.org.uk/find-out-more/getting-involved/

Organisation searching tool: https://www.invo.org.uk/communities/invodirect/ Contact: involve@nihr.ac.uk



**Templates**

Here are some example templates for you to use, which include a summary of Your Rheum. Please edit and delete to suit your needs.

* **Email / letter**

Dear (NAME),

I am contacting you to (ENQUIRE / EXPRESS AN INTEREST IN XXX).

I have detailed below my previous experience which I feel lends itself to (XXX / ROLE).

I was a member of a national young person’s advisory group called YOUR RHEUM.

Your Rheum is a UK wide group for young people aged 11-24 years, who want to actively be involved in rheumatology research. I worked with researchers, clinicians and experts in the field of rheumatology to help improve their research ideas and clinical studies. I did this via activities such as: reviewing research funding applications and patient information sheets / consent forms; inputting into the design of study data collection and launch events; speaking to others about my experiences.

Please don’t hesitate to get in touch if you have any further questions.

I look forward to hearing from you.

Kind regards

(YOUR NAME)

• **Add to CV**

**Member of Your Rheum**   **(MON/YEAR from – to)**

Your Rheum is a UK wide group for young people aged 11-24 years, who want to actively be involved in rheumatology research. I worked with researchers, clinicians and experts in the field of rheumatology to help improve their research ideas and clinical studies. I did this via activities such as: reviewing research funding applications and patient information sheets / consent forms; inputting into the design of study data collection and launch events; speaking to others about my experiences.