

Versus Arthritis

- Research Advisory Groups

Call for Patient and Carer representative members

- **Adult inflammatory arthritis Group Members**
- **Autoimmune rheumatic diseases Group Members**
- **Musculoskeletal disorders Group Members**

About Versus Arthritis - demanding more for people with arthritis

Launched on 19 September 2018, Versus Arthritis is a new charity formed from the merger of Arthritis Research UK and Arthritis Care. Versus Arthritis exists to push back the limits of arthritis by funding research, providing support and campaigning for the appropriate recognition for a condition that affects over 10 million people in the UK alone.

For far too long, arthritis has been viewed as something that is inevitable, insignificant and untreatable; shrugged off as 'just a bit of arthritis'. However, arthritis is none of these things and we no longer accept it as something that has to just be lived with.

As Versus Arthritis, we strive to do more and to be more ambitious in everything we do, working with and for people with arthritis. We understand what living with arthritis is like, and realise the strength it can so often require, and so whenever people are in need of help, we are here to support them. There's a lot to be done, but we won't stop until no-one has to tolerate the pain, fatigue and isolation of arthritis. We're 10 million people living with arthritis.

Summary

Versus Arthritis is establishing **three new Research Advisory Groups** to engage and network the respective patient, research, clinical and trainee communities and interact with the charity. The Research Advisory Groups will bring insight from **patients, trainees, clinical and allied health professional practitioners, discovery science, clinical and disease management and health services research**.

The primary function of these groups will be the identification key issues and opportunities to develop and influence research funding for each area.

For each Research Advisory Group we are recruiting a multidisciplinary representation across 16-20 members, including those with lived experience of Arthritis.

Applications are invited from individuals interested in becoming members of our newly forming Research Advisory Groups in the areas of Adult inflammatory arthritis, Autoimmune rheumatic diseases and Musculoskeletal disorders.

Applications should be submitted by email with pdf attachments to patientinsight@versusarthritis.org by midnight **9am Wednesday 17th April 2019**.

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Posts are formally available from spring 2019, appointments are for a three-year term in the first instance. The posts are not associated with a monetary allowance but travel expenses to face to face meetings will be supported.

Group aims and activities

Research Advisory Groups bring insight from patients, trainees, clinical and allied health professional practitioners, discovery science, clinical and applied disease management and health service research.

Each group will undertake activities to support the identification of unmet needs and priority research areas and the approaches to address them. Groups seek knowledge and insight from the relevant communities from their discussion at face-to-face meetings, workshops and working group activity as well as via other communications and interactions. Groups are informed by the literature and from engagement and relationship management with key organisations and initiatives in the landscape.

Further definition of the **Remit** and the associated **Roles and Responsibilities** of Research Advisory Groups is available separately.

Patient and Carer representatives

Patient and Carer representatives who we refer to as 'Patient Insight Partners', will play a crucial role in integrating the perspective of people affected by musculoskeletal disorders into the groups' activities. This may mean, where relevant, sharing your personal experience to help other Research Advisory Group members consider the perspective of patients and carers. It will also mean considering the needs of other people with Arthritis, including those with conditions not represented within the group.

As the work of the Research Advisory Groups develops, an additional part of this role will be to inform our thinking in how we bring wider patient voice into this work. This may be by suggesting mechanisms for gaining the views of a larger number of patients or commenting on draft proposals for what this wider patient involvement or attending relevant meetings with patients.

Length of membership

Posts are available from spring 2019, appointments are for a three-year term in the first instance.

Key responsibilities and time commitment

As a Research Advisory Group member you will be expected to:

- Attend an initial induction and training session in London on 10 May and identifying any further training and development needs in discussion with your key contact
- Where relevant, assist the other Research Advisory Group members in understanding the perspective of patients and carers to inform the strategic priorities of our research
- Attend and contribute thoughtfully and constructively at face to face meetings - we anticipate these to be held twice per year and are likely to take place in London

- Attend and contribute thoughtfully and constructively in telephone conferences- we anticipate these to be every six months but could be held more frequently according to the needs of the work
- Read any paperwork required before each meeting/workshop/telephone conference - which may take up to 3 hours per meeting/telephone conference
- Proactively communicate with your key contact prior to meetings to seek clarification of anything you are unsure of, or where you need further information
- Attend and contribute to workshops where relevant. Each Research Advisory Group lead will organise longer meetings with a wider group to discuss areas identified as priorities in more detail. We anticipate that these may be held up to twice per year
- Contribute thoughts and feedback over email where requested
- Complete a short de-brief survey after each meeting/telephone conference and return this to the research involvement team so we can continuously improve our work
- Any additional activities (optional) - We hope that as the work of Research Advisory Groups develops, new opportunities may arise, and this will depend upon organisational needs as well as your interests – however any additional opportunities offered would be optional and would include training and support

Skills and Attributes

The types of skills and attributes that we are looking for are:

- Personal experience of Arthritis or other relevant condition (further details of the scope of conditions we fund research into can be found [here](#)) this may include through the experience of caring for a loved one
- Ability to confidently provide views from the perspective of someone with lived experience of Arthritis where relevant to the discussion
- A keen interest in research
- Objectivity, with the ability to consider the needs of all people with experience of Arthritis and share thoughts and concerns appropriately
- Knowledge and interest in keeping up to date with current issues important to those affected by Arthritis
- Excellent communication skills with an ability to listen to and respect differing opinions and constructively express your own views
- Ability to maintain confidentiality where required
- Ability to identify conflicts of interest and declare these to Versus Arthritis
- Experience of taking part in large formal meetings (for example committees or boards)

Training and Support

- A training and induction session to provide you with background information on the role, the group and general information about the Research Advisory Groups
- You will be assigned a key contact who will be in regular contact with you through email for information, advice and support
- We will provide you with all meeting materials at least one week before the meeting

Expenses

We are able to book your travel and accommodation in advance or reimburse reasonable expenses for this where necessary and agreed in advance.

Declaration of Interests

All Research Advisory Group members are expected to declare if they have any conflicts of interest with any of the paperwork or items for discussion at meetings. We recognise that many of our patient and carer representatives generously give their insights to a range of research projects both linked to and outside of Versus Arthritis. This will not prohibit anyone being a member of the Research Advisory Group. However it may mean you are asked to leave the room for certain parts of meetings where discussions are taking place about areas you may have a conflict of interest. If in any doubt please discuss this with your key contact.

Application and Appointment

If you are interested in applying please complete the accompanying application form and return by **9am 17th April 2019** to patientinsight@versusarthritis.org.uk.

Individuals interested in applying to be Research Advisory Group members are welcome to contact Naomi Gray, Research Involvement Manager or Sarah Rudkin, Head of Clinical Studies and Experimental Medicine with any queries via patientinsight@versusarthritis.org.uk.

Remit and Roles and Responsibilities documents are available in support.

We will invite people with the most relevant skills and experience to a short **telephone interview on 29th April**.

Successful candidates will be invited to an induction and training session in London, planned to take place on **Friday 10th May**. Following this induction day you will have a greater understanding of the role, the work of the Research Advisory Groups and if you can commit to the role for three years. Based on your interest and after getting to know you better, we will **then offer the role to the people whose skills we think are most suitable**. Selection will be made to achieve an appropriate spread of geography, experience and gender.

Meeting dates

Please note that to allow you to have plenty of notice to attend the relevant Group meeting, should your application be successful, meetings have been tentatively scheduled:

GROUP	LEAD	Inaugural Group meeting (face to face in London or possibly telephone conference)	Wider Group-sponsored meeting / workshop (face to face)
Adult inflammatory arthritis	Stefan Siebert	Thursday 20 th June 2019 OR Friday 19 th July 2019	Wednesday 11 th September 2019 OR Wednesday 18 th September 2019
Autoimmune rheumatic diseases	Chris Denton	Tuesday 2 nd July 2019	Friday 30 th August 2019 OR Tuesday 3 rd September 2019

Musculoskeletal disorders	Fiona Watt	Friday 5 th July 2019 OR Thursday 11 th July 2019	A date in September 2019
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We encourage people interested in this group to hold these dates at this stage where possible.

If you have any queries related to this role please contact patientinsight@versusarthritis.org . Further information about the research that Versus Arthritis funds can be found [here](#).