Versus Arthritis - Research Advisory Groups

Call for Scientific and Clinical representative members

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

Summary

Versus Arthritis is establishing *three new Research Advisory Groups* to engage and network the respective wider 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 applied disease management and health services research.*

Between 2007-2016 Arthritis Research UK supported seven Clinical Studies Groups. We are *adapting* the Clinical Studies Group operations to work with our revised funding structures and adapting approaches to research funding. The Research Advisory Groups *will be of broader scope* building on the successes of the Clinical Studies Group operations.

Research Advisory Groups will *primarily function with the role of identifying key issues and opportunities to develop and influence research funding*.

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 <u>research@versusarthritis.org</u> by midnight **Monday 29th April 2019.**

Posts are formally available from early summer 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.

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.



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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.

Research Advisory Group establishment

We are establishing three new Research Advisory Groups to build on the successes of the Clinical Studies Group framework; the Clinical Studies Groups formally completed their activities in March 2017. *Our existing Paediatric Group remains in operation within the National Institute for Health Research (NIHR) Clinical Research Network.*

We have appointed a senior clinical academic Lead (see table below) for each Research Advisory Groups in these groupings:

- Adult inflammatory arthritis Research Advisory Group encompassing the Adult Inflammatory arthritis and the Spondyloarthropathies Clinical Studies Groups
- Autoimmune rheumatic diseases Research Advisory Group encompassing the Autoimmune disease Clinical Studies Group
- **Musculoskeletal disorders Research Advisory Group** encompassing the Pain, the Osteoarthritis and crystal diseases and the Metabolic bone and Trauma Clinical Studies Groups

Over their ten-year period of operation, the Clinical Studies Groups delivered impressively and continually developed their ways of working, providing a framework to facilitate community networking of rheumatologists, allied health professionals, psychologists, researchers and orthopaedic surgeons; as well as facilitating involvement with patient groups, trainees and commercial partners, and other funders and stakeholders in the clinical research landscape.

Group aims and activities

Research Advisory Groups (Groups) engage and network the respective patient, research and practitioner communities and interact with the charity as per the separately defined Group Remit. Groups bring insight from patients, trainees, clinical and allied health professional practitioners, discovery science, clinical and applied disease management and health service research.

Groups 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.



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Length of membership

Posts are available from early summer 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 and contribute thoughtfully and constructively at face to face Group meetings anticipated to be held quarterly (twice per year face to face) and are likely to take place in London
- Read any paperwork required before each meeting/workshop/telephone conference
- Proactively communicate to seek clarification or further information
- Attend and contribute to workshops, each Research Advisory Group will organise longer meetings with a wider group to discuss areas in more detail. We anticipate that these may be held up to twice per year
- Contribute thoughts and feedback over email where requested
- Contribute to additional activities (optional) We hope that as the work of Research Advisory Groups develops, new opportunities may arise which may match your interests

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. 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.

Application and Appointment

Applicants should submit

- (i) a one page summary or CV of your background and experience, including prior experience in research involvement activities
- (ii) a 300 word maximum statement which covers Which Group Why you want to join the Group
 Skills and experience you would bring to the role How you would manage the time required to adequately perform the role

Individuals interested in applying to be Group members are welcome to contact Dr Sarah Rudkin, Head of Clinical Studies and Experimental Medicine or the Research Advisory Group Leads with any queries via <u>research@versusarthritis.org</u>. Remit and Roles and Responsibilities documents are available in support.

Applications should be submitted by email with pdf attachments to <u>research@versusarthritis.org</u> by 9am **Monday 29th April 2019.**

No interviews will be held. Appointments will be made via a desk assessment of the two submitted documents by the Research Advisory Group Leads and the Versus Arthritis office. Selection will be made to achieve an appropriate spread of geography, experience and gender.

The outcomes of applications are anticipated to be notified to applicants by early June 2019.



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Meeting dates

To allow you to have plenty of notice to attend the relevant Group meeting, should your application be successful, meetings have been tentatively scheduled as per the following table:

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

We encourage interested parties to hold these dates at this stage where possible.

We also encourage those not intending to apply to join the Groups but interested to engage in the wider activities sponsored by the Groups to hold these dates at this stage where possible.

Multidisciplinary representation - areas of expertise sought

For each new Research Advisory Group, we are recruiting a multidisciplinary representation across 16-20 members. Activities undertaken will be on a voluntary basis without payment, but travel expenses for face to face meetings will be supported.

GROUP	LEAD	Scope of Group	Areas of experience sought
Adult inflammatory arthritis	Stefan Siebert	 Rheumatoid arthritis Psoriatic arthritis (PsA) Ankylosing Spondylitis (AS) and axial spondyloarthritis (axSpA) Seronegative arthritis Enteropathic-associated arthritis 	 Clinical and AHP Practice Trainees Discovery / Translational science Disease management research Health service research Clinical research
Autoimmune rheumatic diseases	Chris Denton	 Lupus Scleroderma (systemic sclerosis) Raynaud's disease Vasculitis Antiphospholipid syndrome Myositis Sjogren's Syndrome Behcet's Syndrome 	 Clinical and AHP Practice Trainees Discovery / Translational science Disease management research Health service research Clinical research
Musculoskeletal disorders	Fiona Watt	 Osteoarthritis Crystal disease Regional and widespread pain (including back pain, shoulder pain, other regional pain syndromes, fibromyalgia) metabolic bone disorders (Paget's disease, osteoporosis, rare diseases) rheumatic and musculoskeletal system injuries caused by acute traumatic events 	 Clinical and AHP Practice Trainees Discovery / Translational science Disease management research Health service research Clinical research

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