

# Versus Arthritis

## - Research Advisory Groups

Remit (v1.0 February 2019)

### Research Advisory Groups

Three Research Advisory Groups operate in the domains of:

- **Adult inflammatory arthritis**

Including adult inflammatory arthritis, peripheral and axial spondyloarthritis (SpA), psoriatic arthritis (PsA), enteropathic-associated arthritis, seronegative arthritis and related conditions

- **Autoimmune rheumatic diseases**

Including lupus, antiphospholipid syndrome, scleroderma (systemic sclerosis), Sjogren's syndrome, myositis, vasculitis, Behcet's syndrome and overlap/undifferentiated connective tissue disease.

- **Musculoskeletal disorders**

Including 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.

### Group Purpose

Research Advisory Groups function to gather and connect the patient, research and practitioner communities in activities around research prioritisation and investment.

Research Advisory Groups engage in two-way interaction with the charity, the charity requesting activity of the advisory groups and approaches and suggestions from the advisory groups being welcomed by the charity.

### Group Remit

Each Research Advisory Group has a UK-wide remit to:

- Provide input to the charity to identify unmet needs and questions across the research spectrum from discovery and translational science, treatment development and evaluation to disease management and health service research:
  - to include research training and career progression
  - to foster translational research that enhances the potential for personalised medicine
  - to encompass an international view as appropriate
  - to encompass industry engagement as appropriate
  - to encompass a partnership and leverage approach

- Undertake activity to generate outputs and insight in the development of areas of focus for the charity, such activities are supported by the charity in terms of administrative and logistical delivery:
  - Organise Group and wider community telephone conferences, workshops or other consensus building events, to engage the patient, research and practitioner communities in contributing to the research agenda and derive priorities for research questions
  - Contribute to gathering horizon scans and evidence reviews
- Inform and scope approaches to take in addressing identified priorities
- Integrate the patient perspective, views and advice in the groups' activities
- Integrate trainees' perspective within the Group
- Engage with Versus Arthritis in managing activities of the Group and its subgroups
- Engage with Versus Arthritis in managing the membership of the Group
- Provide summary reports of group and subgroup activity as requested

Secondarily, each Group may (as requested and able to respond):

- Contribute insight and expert commentary to policy, public affairs, professional engagement, national initiatives, strategic partnerships and national consultations

Thirdly, each Group may self-determine the extent of its remit to:

- Engage in the identification and development of chief/principal investigators
- Advise/facilitate the development of research studies and funding applications to Versus Arthritis and other funders (Support application workup, Provide letters of support)
- Oversee delivery and progress of some studies, notably clinical and applied research projects in conjunction with the Progress Review Committee and Versus Arthritis

Research Advisory Groups do not:

- Generate public facing strategic priorities
- Call for, receive, assess or manage expressions of interest for potential research studies from potential applicants
- Endorse the submission of applications to Versus Arthritis

# Versus Arthritis

## - Research Advisory Groups

### Roles and Responsibilities, Leads and Members (v1.0 March 2019)

#### 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 required 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 published literature, by patient, clinical and scientific experience and expertise and from engagement and relationship management with key organisations and initiatives in the landscape.

#### Group Roles

Each group is led by a senior clinical academic.

Groups are constituted of (i) Patient members (ii) Researcher members (iii) Practitioner members (iv) Trainee members.

All Group members de facto become members of the Versus Arthritis College of Experts.

#### Subgroups

Establishment of subgroups, with separate leads, is permitted and encouraged as need arises. Subgroup members are recruited directly by the Subgroup lead, membership is limited to 8 people.

#### Group Lead

##### Role

The Group Lead is the key liaison contact point for charity staff and for Group members. The Group Lead works with the charity in identifying and developing approaches to areas of research strategy and collaboration. The Group Lead communicates inclusively with the Group members in managing Group activities, guiding and directing Group members and the wider communities in the definition, development and collation of group insights and advice. The Group Lead monitors and facilitates participation of members.

Key attributes - The most important attributes required are enthusiasm for the philosophy behind the establishment of Research Advisory Groups and a dedication to ensuring success via collaborative working and leadership. The Group Lead requires excellent communication skills with an ability to listen to, respect and constructively facilitate the presentation of differing opinions, contributions and

insights. The Group Lead must work to maintain confidentiality where required and to identify conflicts of interest and declare these to Versus Arthritis.

## **Level of commitment and term**

Group Leads are remunerated for their time on defined daily rate and volume basis.

Appointments are for a three-year term in the first instance, with an option to reapply or be invited to extend for a further 3 years. Review and recruitment takes place mid-year three.

Group Leads are expected to attend an orientation meeting, regular (anticipated quarterly) Group meetings (face to face and telephone conference), wider Group-sponsored activities (anticipated twice per year) (workshops and meetings), read any paperwork required before each meeting/workshop/telephone conference, optionally participate in new opportunities which may arise as the Group progresses.

Administrative support for group activity is available, provided via a mix of central Versus Arthritis support for managing membership activities and locally supported administration for Group activities.

Travel expenses will be reimbursed where required for face-to-face meetings in accordance with the charities' standard policy.

## **Appointment**

Recruitment is via open advert and application submission, followed by a face to face interview including assessment of skills and experience to be brought to the role in terms of ability to establish consensus and chair activities with similar goals and how time would be managed to adequately perform the role.

Selection is made to achieve an appropriate spread of geography, experience and gender.

## **Responsibilities**

Versus Arthritis Research Advisory Groups Leads responsibilities are to:

- Constitute the Group as a steering group in the defined area and manage the membership in conjunction with the charity office, including the development/support of subgroups
- Contribute to the management of community contacts in line with GDPR requirements
- Organise Group meetings at an appropriate frequency, quarterly being the indicative timing
- Organise meetings, workshops and forums to engage and network relevant communities to gather and formulate insights to inform charity research activities and facilitate delivery of activity against the Groups' Remit
- Report Group activity to the charity
- As a matter of diary priority participate in
  - collective Leads meetings, with and without the charity
  - Group telephone conferences or meetings
  - wider community meetings and workshops
  - charity committee meetings

## Group Member

### Role

Group Members work with the Group Lead and the charity in identifying and developing approaches to areas of research strategy and communicating these areas within and outside Versus Arthritis. The Group members contribute to managing Group sponsored-activities with the wider communities in the definition and development of strategic group activities. Members contribute to two-way interaction with the charity with requests being made to the Groups from the charity and proactive approaches and suggestions being welcomed by the charity from the Groups.

Patient and Carer representative members play a crucial role in integrating the perspective of people affected by musculoskeletal disorders into the Groups' activities. This means, where relevant, exemplifying the perspective of patients and carers by sharing personal experience and sharing perspectives of other people with arthritis, including those with conditions not represented within the group. The role of the patient and career representatives will contribute to informing the approaches to bringing wider patient voice into Group work.

Key attributes - The most important attributes required are enthusiasm for the philosophy behind the establishment of Research Advisory Group and a dedication to ensuring success via collaborative working and leadership. Members require excellent communication skills with an ability to listen to and respect differing opinions and constructively express contributions and insights. Members must work to maintain confidentiality where required and to identify conflicts of interest and declare these to Versus Arthritis.

### Scope of membership

Multidisciplinary, with representation across approximately 16-20 members.

Across (but not limited to) a range of basic science disciplines, orthopaedic surgery, secondary care including rheumatology and other related specialities, primary care, allied health professionals, radiology, nurses, epidemiology, psychology, statistics and translational science.

A minimum of three patient members from the Versus Arthritis Research Patient Insight Group (in the first instance, extending to representation via other patient groups).

Industry representation is excluded; Groups seek to work with industry through other routes.

Membership includes trainees, a minimum of one, providing opportunity for junior researchers to gain experience of such activity.

Membership allows for ex officio representation (by virtue of holding another office) from certain points of expertise or insight.

In the original constitution, membership seeks to include previous clinical study group members.

### Level of commitment and term

Group Members and subgroup leads are not remunerated for their time.

Appointments are for a three-year term in the first instance, with an option to reapply or be invited to extend for a further 3 years. Review and recruitment takes place mid-year three.

Trainees may be appointed for durations shorter than 3 years and managed to allow for overlap with incoming and outgoing trainee members.

Appointed members are expected to attend an orientation meeting, regular (anticipated quarterly) Group meetings (face to face and telephone conference), wider Group-sponsored activities (anticipated twice per year) (workshops and meetings), read any paperwork required before each meeting/workshop/telephone conference, optionally participate in new opportunities which may arise as the Group progresses.

Travel expenses will be reimbursed where required for face-to-face meetings in accordance with the charities' standard policy.

## **Appointment**

Recruitment via open advert and application submission, followed by desk review including assessment of skills and experience to be brought to the role and how time would be managed to adequately perform the role. No interviews held for scientific and clinical members; option for interviews with patient and carer members.

Selection is made to achieve an appropriate spread of geography, experience and gender.

## **Responsibilities**

Versus Arthritis Research Advisory Group Member responsibilities are to:

- Attend and contribute thoughtfully and constructively to Group meetings at an appropriate frequency, quarterly being the indicative timing
- Contribute as requested to Group-sponsored meetings, workshops and forums to engage and network relevant communities to gather and formulate insights to inform activities in line with the Groups' Remit
- Contribute if requested to reporting of Group activity to the charity
- As a matter of diary priority participate in
  - Group telephone conferences or meetings
  - wider community meetings and workshops
- Proactively communicate prior to meetings to seek clarifications or further information
- Complete feedback requests to enable evaluation, if sought
- Respond to emails