

## **Patient Advocate Role Description**

### **Osteoporosis and Bone Research Academy (The Academy)**

#### **Introduction**

The Royal Osteoporosis Society has outlined its strategic direction for the future and in doing so has identified a new strategic aim: finding a cure for osteoporosis, so that people will have fewer fractures and live well because of new interventions. The Osteoporosis and Bone Research Academy (The Academy) is the means by which the *Cure Strategy* will be delivered.

The Academy strengthens our involvement in research and has four overarching aims:

1. Co-ordinate complex work programmes to identify research needed to end osteoporosis
2. Broker new partnerships and collaborations
3. Engage, nurture and back the best and brightest minds to unlock new discoveries
4. Influence future funding for research

For more information on the Royal Osteoporosis Society's current research programme please visit [www.theros.org.uk/research](http://www.theros.org.uk/research).

#### **The Academy Working Groups**

The Academy Working Groups are overseen by the Academy Advisory Committee and Academy Director. Each Working Group consists of a group of scientific experts who have an interest in academia, clinical practice, science and technology aligned to the Working Group focus, and at least two patient advocates (who represent people affected by osteoporosis, including patients and carers).

There are three Academy Working Groups:

- **Causes:** Understanding the causes and mechanisms of osteoporosis
- **Technology:** Exploring and developing new and innovative technologies
- **Effectiveness:** Understanding the effectiveness of current and potential new diagnostic tools, treatments and interventions

Each Working Group will:

- Support the development of the Academy work programme;
- Develop new priority areas and the recommended actions or interventions to be taken to address priorities;
- Recommend when to cease or reduce investment or work in existing areas or identified potential areas of interest and work;
- Actively encourage ambitious and innovative new ways of working;

- Explore opportunities in the UK and internationally to harness new ideas and identify potential new partnerships and collaborations;
- Develop and mentor new researchers;
- Participate in communicating the Academy's work to beneficiaries and funders.
- Contribute to writing and production of reports involving the review and synthesise of scientific, clinical or detailed information as needed;
- Participate in research related workshops to discuss research priorities etc.

The Academy Working Groups aim to reflect a fair balance of experience and scientific disciplines, with views from all members given equal weighting.

## **Patient and Public Involvement in The Academy**

### **Why is it important to involve patient advocates in the Academy?**

As someone who is affected by osteoporosis, your knowledge and experience provide a unique and valuable perspective to facilitate the development of the charity's *Cure* work programme and Academy's research agenda. You have a particularly important role in using your experience with the condition to:

- Support the charity in listening to what patients and carers need from future research (including priorities and concerns).
- Champion the journey of working towards a cure for osteoporosis by influencing the way that new areas of osteoporosis care are designed and delivered.
- Advocate for those living with osteoporosis to ensure that new research also focuses on helping people to live well with the condition.
- Think through how easy/difficult it would be to recruit participants for proposed research studies and for them to participate and fulfil the requirements e.g. will it be too onerous that they are unlikely to agree to take part?

These perspectives are not often addressed by researchers and clinicians. They tend to focus more on the scientific evidence, research methods, and value for money.

### **What will your role as a patient advocate of an Academy Working Group involve?**

As a patient advocate member of an Academy Working Group, the Royal Osteoporosis Society would like you to:

- Work together with the other patient advocate members before and after meetings to constructively represent the views of patients and carers in Working Group discussions and in reviewing reports. This will often be co-ordinated electronically and therefore access to a computer will be essential.
- Attend Academy Working Group meetings, usually three per year, in London or Bath (at the charity's offices). The number of meetings may change as determined by the level and complexity of the work of the Academy. Occasionally meetings will be conducted by teleconference in an effort to reduce travel time and cost.
- Possibly attend other meetings or events to report on the work of the Academy.

For further details on the role of a patient advocate please read the ***Academy Working Group Terms of Reference*** and ***Academy Working Group Member Agreement***.

The position of patient advocate is offered on a voluntary unpaid basis, but any travelling expenses incurred to attend meetings will be reimbursed in line with the charity's Travel and Subsistence Policy.

## How to Apply

The Academy is currently looking to appoint two new patient advocates for each of the three Working Groups.

To apply to become a patient advocate on an Academy Working Group please complete an application form.

Applications must be submitted either electronically to Dr Caroline Sangan, Research Manager via e-mail to [caroline.sangan@boneacademy.org.uk](mailto:caroline.sangan@boneacademy.org.uk) or via post to Royal Osteoporosis Society, Camerton, Bath, BA2 0PJ.

**Application Deadline: Tuesday 30<sup>th</sup> April 2019 at 5pm.**

Applicants will be shortlisted and short telephone discussions planned to be conducted on **28th May 2019** and **30th May 2019**.