NDORMS OPEN ARMS Patient & Public Role Description Template

***Purpose of document***

This document is to be completed by researchers to indicate what is the nature and commitment of the assistance they are requiring of Patient and Public Involvement Members. Members will be given this information in order for them to make an informed view on whether they wish to participate in the activities. To be used for activities such as participation in focus groups and membership of steering committees.

**Background:** Patient involvement is the creation of a partnership between patients, members of the public and researchers to try to make the research process more effective. The Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS) is a medical department within the University of Oxford. It aims to discover the causes of bone, muscle and joint diseases and develop the best treatments to improve people’s quality of life.

OPEN ARMS is the Oxford Patient Engagement Network for Arthritis and Musculoskeletal Conditions.  By forming a partnership between patients, public members (including carers and patients’ families), health researchers, and clinicians, we aim to make our research relevant and accessible to all and improve future patient care.

**Role**:

Userrepresentative on: **[specify study title]**

**Purpose of the Patient and Public Involvement role**:

**[For example: To give the patients’ perspective to the development of a study focussing on …]**

**Details of the study**:

**[Please provide a jargon free summary of your research]**

A panel of researchers, including **[list of named researchers]** will develop this study protocol and grant application. We need to make sure that the study takes into account the needs and understanding of the views of patients.

**Role Responsibilities:**

**[add / modify as appropriate for the role]**

* To be a representative of the views and concerns of other patients and carers.
* To offer advice, where you think it appropriate, on the study design and commitment that is being ask of patients in this study.
* Contribute to discussion and the preparation of the final document (checking language is accessible for the lay summary, etc.)
* To share your experiences and views about patient and public involvement.
* To identify ways in which the study could be improved.

**Commitment:**

**[add / modify as appropriate for the role]**

* There is a requirement to attend **[specify meeting(s) frequency and duration]**
* We would like you to read and review the study documents, offering advice on the aspects that you think are important. We would expect this to take no longer than **[specify expected duration]**
* The term of involvement we require is **[Specify duration]** days/weeks for this particular grant role; however if you are willing to be an advisor on future grant applications, the term of the role could be until **[specify duration]**

**Qualities:**

Patient representatives should have experience, knowledge or interest as any of the following:

* As a patient.
* As a family member or carer of a patient.
* As a member of an organisation that represents patients and public interests in issues relating to **[add as appropriate].**

**Essential criteria:**

* Be able to maintain confidentiality.
* The ability to represent and express the views of other patients and carers is essential to the role.
* An enthusiasm to share your experiences and life skills.
* The ability to engage in discussion with other participants.
* Understanding of the issues relating to **[add specific detail].**
* Have the time to attend meetings and read final documentation if required.

**Desirable criteria:**

* Knowledge or experience of **[add specific detail]** would be advantageous but not essential.
* Have an understanding of research processes and procedures.
* Have access to a computer and e-mail.

**Support:**

* We wish to recruit **[add number]** members of the group for each meeting to provide support and advice.
* Researcher contact details **[add details].**
* Louise Hailey is the main contact for the OPEN ARMS group and can be contacted through the department openarms@ndorms.ox.ac.uk
* Training and access to resources such as terminology glossaries will be arranged as appropriate.
* Regular updates or feedback will be provided on a regular basis as we value your commitment and participation.
* User representation is unpaid. However, travel reimbursement is available up to £50 per session. Refreshments will be provided where appropriate.
* Child and carers care cover is not available.

**Considerations before applying for the role:**

* You will also be asked not to disclose any confidential information and to sign a Code of Conduct before participating. If unsure over confidentiality issues, this should be discussed with Louise Hailey openarms@ndorms.ox.ac.uk
* Do you have the time to be involved?
* What do you wish to achieve by being involved?
* What support would you require?

**Thank you for your support.**