

Patient and Carer members of Sheffield Hospital 'Scaling Up' Shared Haemodialysis Care Project: SHAREHD

The Group:

- Advises on the development of strategies, activities and approaches to Scaling Up Shared Haemodialysis Care across designated hospital sites
- Oversees the strategic planning and implementation of Shared Haemodialysis Care
- Monitors the setting up and conduct of the Scaling Up of the Shared Haemodialysis Care Programme - ensuring good quality improvement techniques are employed

The core role of patient/carer representatives

The core role of a patient/carer member is to contribute to the development of the 'Scaling Up' process from the point of view of someone with direct or indirect experience of Haemodialysis treatment.

Patient/Carer members on the Group will be able to contribute to the development of the project as follows:

- Attend relevant meetings
- Work constructively as part of the PAG/Project Team to foster the aims of the groups
- Read through the papers and other items beforehand
- Read and consider consultation documents, to provide comments on the consultation documents where appropriate from a patient/public perspective
- Discuss and comment on items during meetings, and raise issues for consideration
- Take into account the responsibilities, viewpoints and expertise of other members
- Provide a patient/carer perspective on research deliberations
- Consider methods for wider patient and carer involvement in the strategic development of Shared Haemodialysis Care
- Contribute to the training of new project members (patients, carers, staff etc.)
- Respond to virtual sub-group meetings if appropriate, or external events/conferences and report back to the group
- Advise on Shared Care newsletters and general publicity
- Respect any requests for confidentiality and declare any conflicts of interest if they arise.
- Contribute to reviews and evaluations of the Scaling Up Shared Haemodialysis Care's work

The person

People interested in becoming patient/carer members will come from different backgrounds. Below is a wide-ranging list of skills and qualities for the role. It is recognised

that individuals will have different combinations of skills to contribute. Selection will aim at balancing different characteristics, although obviously not all will be included.

Essential skills and qualities of patient/Carer members

The most important personal skill for the role is a willingness to bring to the project team a balanced understanding of the wide range of different perspectives which Renal patients, carers and Health Care Professionals will have.

Patient members should have direct or indirect experience of Renal Haemodialysis diagnosis and treatments in one of the following ways:

- as a Haemodialysis patient or carer
- as a kidney transplanted patient who has experienced Haemodialysis
- as an ex-carer of a Haemodialysis patient
- as a Renal patient

Other essential qualities

- Able to give a balanced viewpoint, including an understanding of a range of different perspectives on Renal treatments
- Able to travel to attend meetings, and to carry out other activities, such as reviewing documents.

Desirable personal qualities of patient/public members

- Experience of patient and public involvement
- Keen interest in Renal healthcare in the UK
- An understanding of the Shared Haemodialysis processes
- Good communication and team-work skills, and a potential willingness to speak in public
- Experience of committee/project work
- Experience of running things, and management experience
- Prospective patient/carers will find it highly advantageous to have access to email, the internet, and a printer, and be reasonably proficient in their use.
- Self confidence in a mixed group of individuals

Duration

It would normally be hoped that patient/carers would commit to up to two years, or at least one year. However, to ensure a full range of patient's health considerations can be taken into account, planned duration of membership may be shorter or open-ended.

Remuneration

Membership of the Shared Haemodialysis Care – Scaling Up project is unpaid. Reasonable travel expenses, that are agreed, will be reimbursed in accordance with Sheffield Hospital Expenses Procedures, Policy or local policies where indicated and lunch will be provided at meetings.

Raising concerns

If there is something about the Group or meetings that makes the person feel uncomfortable, approach the Patient Advisory Group Lead or someone else appropriate.

Conflicts of interest

Members shall be required to disclose any involvement with individuals, government bodies, commercial interests or third parties which could lead to a conflict of interest with the work of the Shared Haemodialysis Care – Scaling Up. A conflict of interest doesn't stop someone from being a patient/public member.

Confidentiality

Some papers circulated for Shared Haemodialysis Care – Scaling Up project meetings are considered to be confidential, even if not marked as such. Many patient/carer members will be in contact with other patients and people affected by a particular condition, and will feel there are general issues, arising from the meeting, that they would like to discuss. Indeed, this will be an important avenue to provide a broader patient/carer perspective on many issues.

Members should not communicate any potentially confidential information that they learn as a result of being a member of the group.

Mentoring

The formal responsibility for arranging a person to offer support lies with the Patient Advisory Group Lead, in agreement with the relevant parties. The Patient Advisory Group Lead can support the group members identifying training needs, providing relevant information, assisting to resolve outstanding issues, ensuring that there are opportunities to link with other patient/carer or Health Care members.