

SHAREHD PATIENT ADVISORY GROUP MEMBER

“Patient volunteers needed to become part of a team helping haemodialysis patients (and carers) take greater control of their care”

PROGRAMME TITLE: ‘Scaling Up’ Shared Haemodialysis Care (SHAREHD)

BACKGROUND

The first [Shared Haemodialysis Care Programme](#), supported by [Health Foundation ‘Closing the Gap’](#) funding began in the Yorkshire and Humberside area in 2010, with the aim of improving patients’ (and as a consequence their carers) quality of life and outlook, by supporting them to become more independent in managing their own dialysis. Nurses helped patients and carers to learn how to perform a series of 14 key treatment related tasks associated with haemodialysis, such as preparing equipment, measuring weight and blood pressure and self-cannulation. The programme focused on shared care rather than self-care and patients were encouraged to learn at their own pace, doing as little or as much as they wanted to.

Patients were involved in all aspects of the programme – including its overall design. They discussed potential barriers to increased shared care and considered ways to overcome challenges. They also worked closely with renal staff and the programme team to develop a wide variety of resources and tools. These included a three-day training programme for healthcare staff, a patient handbook, a nurse training journal and a dedicated website – all of which helped to spread the idea of shared haemodialysis care to 26 renal units in the region.

THE ‘SCALING UP’ PROGRAMME OUTLINE

The ‘**Scaling Up Programme**’ has been selected to be part of The Health Foundation’s recent £3.5 million [Scaling Up Improvement programme](#) – a national initiative which takes successful health care improvement interventions (treatments and actions) and helps to deliver them on a larger scale.

From April 2016 to January 2019 the Shared Haemodialysis Care Scaling Up team will set up the Programme, known as **SHAREHD**, working with patients and health care professionals across 12 (18) renal units throughout England (Northern Ireland and Scotland). The programme is being led by Professor Martin Wilkie and his team at Sheffield Teaching Hospitals NHS Foundation in collaboration with partners including Kidney Research UK, patient charities and 12 (18) NHS trusts.

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ROLE DESCRIPTION:

Location: Flexible – You are able to work from home but will need to attend meetings across the country, mostly in Sheffield/York

Reporting to: Lead of **SHAREHD** Patient Group

Liaison with: **SHAREHD** members, Programme Manager, Programme Team, external patients, carers and NHS Professionals

Main purpose and role of **SHAREHD** Patient Group:

- The group will consist of at least 6-8 patients/carers who have had experience of kidney disease as patients/carers e.g. haemodialysis, HD transplantee or home haemodialysis patient
- Work at the heart of the Programme (within the Programme Board and/or workstreams) to support development, delivery, evaluation, quality improvement and promotion of the Programme and its findings
- Advise the Programme Board and workstreams on all aspects of the Programme from a patient perspective
- Assist in capturing learnings by recording personal and team findings covering challenges and best practice.
- Raise the profile of the Programme at both a local and national level by acting as a patient ambassador.
- Support the communication and dissemination of the results of the Programme.
- Provide feedback on the impact of the Programme at local sites

*Reasonable 'out of pocket expenses' in attending meetings will be reimbursed. When appropriate, the **SHAREHD** Patient Group members will also receive reimbursement for their time in accordance with NIHR Guidelines. (To be agreed at the next **SHAREHD** board meeting 01/09/16).*

The NIHR Guidelines has identified three levels of payment. All **SHAREHD** activities will be predefined and identified as any one of the following levels from the outset, based upon national guidance from INVOLVE (2010).

Level 1: No greater than 2 hours a week, no payment for time, skill and expertise

Level 2: Expenses* (including lunch, travel). All receipts must be kept for the purposes of reimbursement and no payment is offered for time, skill and expertise.

Level 3** : Half day set rate of £75 or day rate of £150 plus expenses*. This includes payment for preparation, time skill and expertise. All receipts must be kept for the purposes of reimbursement.

* The Programme will pay expenses directly or in advance, where possible. Examples of this include; booking travel tickets in advance.

** This may incur Personal Income Tax implications or if you are in receipt of benefits, these may be affected.

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Training and Support

Patient Group members will be invited to attend an induction day (venue TBC), where they will gain a greater understanding and gain insight into the **SHAREHD** Programme. After discussing what the programme is and how it will assist the 12 (18) sites across England develop their own sustainable programmes, we will be looking at the important role members will play in ensuring that this Programme is run with the benefits of patients, carers and health care professionals in mind. If members can't attend, alternative arrangements could be made.

The goal of the induction process is to ensure that the **SHAREHD** Patient Group members are fully integrated into all aspects of the Programme, enjoying being a member and playing a vital role in ensuring its overall success.

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Role Specification:

Main considerations

Due to the nature of the role, a reasonable understanding and use of computers and electronic media are essential.

SHAREHD Patient Group members will be asked to utilize their skills and experiences in several of the following areas;

- Attend relevant meetings (face to face or virtual e.g. teleconference)
- Provide a patient/carer perspective on Shared Haemodialysis Care matters
- Work constructively as part of a **SHAREHD** workstream and the **SHAREHD** Patient Group to foster the aims of the groups
- Where appropriate, read through agenda papers and other items beforehand
- Read and consider planning documents, to provide comments on them from a patient/carer perspective
- Discuss and comment on items during meetings and raise issues for consideration
- Take into account the responsibilities, viewpoints and expertise of other members
- Consider methods for wider patient and carer involvement in the strategic, sustainable development of Shared Haemodialysis Care
- Where appropriate, contribute to the induction of new healthcare professionals and patient/carers
- Respond to virtual sub-group meetings if appropriate, or external events/conferences and where appropriate feed back to the group
- Advise on **SHAREHD** 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 **SHAREHD** Programme's work

The above are obvious expectations and whilst this list looks daunting, it should not be seen as onerous.

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Factor	Essential Attributes	Desirable Attributes
Experience	<ul style="list-style-type: none"> • Special understanding of kidney health from experience as a patient or carer • Representing the interests of patients/carers • A recognition of the value of patient engagement in order to improve healthcare outcomes. 	Have good links through patient /carer networks and groups within the local hospital/area.
Special skills (for specific workstreams)	<ul style="list-style-type: none"> • Willingness and ability to familiarise themselves with medical and quality improvement language • Comment on and engage with; <ul style="list-style-type: none"> ○ The evaluation workstream (WS) ○ The communications (WS) ○ Quality Improvement aspects ○ Related workshops ○ The Programme Board – by deputising for Patient Group Lead • Commenting on output from the Board 	Keep up to date with current patient/carers issues
Personal qualities	<ul style="list-style-type: none"> • Team oriented – desire to be part of successful team that wants to make a difference • Attention to detail • Willing and able to give the time and to learn • Confidence to put forward own views while understanding the need to give a broad view on behalf of patients and carers • Willingness to use your knowledge and experience of kidney-related health issues • Able to be explicit about likely patient/carers concerns 	Tenacity Patience Resilience Optimism Ability to cope with uncertainty

Further Information

For an outline of the Shared Haemodialysis Care Programme and the **SHAREHD** Programme, please go to the website <https://www.shareddialysis-care.org.uk/>.

For further information or an informal chat please contact the **SHAREHD** Patient Group lead, Andy Henwood via patientandy.york@gmail.com.

Version AHv5: 16/09/2016

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