



***UK Renal Registry
Members Terms of Reference: Patient Council***

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Background

The UK Renal Registry (UKRR) is a non-profit organisation and is part of the Renal Association. It started in the nineties with support from the Department of Health to collect information that can help develop and improve care for patients who have kidney disease.

The main function of the UKRR is to collect and analyse data from all the UK Renal Centres for patients who are already receiving dialysis or have received a transplant.

The UKRR collects data from all the Renal Centres in England, Wales and Northern Ireland, with Scottish data being provided by the Scottish Renal Registry. This goes into a yearly report that is made available to the renal units, NHS Trusts and commissioners who provide their funding. In the early days the UKRR was guided by what was seen as important to the renal clinicians providing patient care but this has changed and we now work alongside other renal groups or those who have a general interest in improving treatment or health care available to kidney patients.

There has been a significant shift over the past few years to provide patient choice and involve them in the care provided by health professionals. Some patients and carers have confidence to question that care and are in an environment which encourages this, for others this is harder due to the pressures of the clinical teams providing the care. With easy access to the internet, patients and carers are able to source information but it does not always answer their questions.

Up to now patients and carers have not had a direct active voice in the work of the UKRR and it has been agreed that a patient council will be formed to advise the UKRR on audit and research ideas which will help drive forward changes to their care. The purpose of which is to give a voice to patients with kidney disease and to promote partnerships between the Renal Centres, Patients and carers to the mutual benefit of both.

The Role of the Patient Council

- Act as representatives for kidney patients and their carers
- To guide and influence methods of delivery of care.
- Advice on opportunities for new work ideas and initiatives for the UKRR.
- Contribute to the development of new audit, research and survey proposals.
- Provide an arena that will encourage discussions between patients and clinical teams to promote patient involvement at renal centre, regional and national levels.
- Monitor and review patient facing initiatives recommended by the Department of Health
- Review applications and contribute towards the production of patient leaflets, posters, reports and other patient information products developed by the Renal Association.
- Support the UKRR in issues relating to information governance and patient consent.
- Use personal networks to spread awareness of the UKRR and its work with the council.
- Occasionally represent the Patient Council at other external meetings

The Patient Council will not

- Discuss or encourage any debates which are related directly to an individual's care or treatment
- Discuss or encourage any debates about specific renal centres where it is not relevant to the work in hand

Principal responsibilities

1. To attend Patient Council meetings
2. To contribute during Patient Council meetings
3. To take part in group communications via email and telephone
4. To deal with any paperwork or tasks they have agreed to do within the time required
5. Maintain Confidentiality
6. Treat everyone with courtesy, politeness and respect.

Authority & Accountability

The council is an independent work group which is supported by the UKRR through the Chief Executive and Medical Director of the UKRR.

All recommendations made by the Patient Council will be considered in relation to other work being carried out by the UKRR, cost implications and availability of staff to undertake the work. Final authorisation for any new work requests which require funding and/or other UKRR or Renal Association resources will be made by either the Chief Executive or Medical Director of the UKRR.

The Patient Council is representative of the wider renal community and is accountable to the UKRR.

Patient Qualification for Membership

The UKRR will have an open recruitment process and will invite applications from patients who have been identified as having chronic kidney disease stage 3 or above or are either a close relative or carer of a kidney patient and who is registered with, or known by, their local kidney centre.

Ideally the Patient Council will have a good mix of patients from different stages of kidney disease and treatment types.

As part of the initial selection process a reference/letter of recommendation is required. This can be provided by any kidney professional in your local renal centre. Where a patient is defined as stage 3 or 4 CKD and are not actively being managed by the local renal centre references can be provided by your GP. A form will be sent to the referee when we have received the application for membership.

Group Membership and Structure

The council will consist of 12 members in total from across the UK and consist of the following:

- Patient Experts – preferably at least 1 patient from each treatment modality groups, (HD, Home HD, PD, Transplant, CKD3 and AKI)
- Chief Executive/Medical Director or nominee of the UKRR
- UKRR Registrar
- BKPA representative
- NKF representative

Technical expertise from web-development, statisticians and clinical informatics can be invited to meetings at the discretion of the Patient Council Chairperson.

The term of office for members will be three years renewable at the discretion of the UKRR Senior Management team, and in consultation with the Patient Council Chairperson. Over the first three years of the council the term of office may vary to ensure that not all members leave and new ones start at the same time.

If members do not attend meetings/calls on 3 occasions in a row without good reason their membership may be terminated and a replacement member found.

The first chairperson will be Fiona Loud and will hold the post for 3 years. All subsequent chairs will be selected by open recruitment but must be someone who is known to a local Renal Centre as a Renal Patient.

Existing members can re-apply for membership once, meaning a maximum term of office of 6 years from first appointment.

Due to the nature of Renal Disease we are aware that prolonged periods of illness can prevent participation and members of the board can request 1 sabbatical for a maximum of 12 months.

Benefits to Members

- Personal development: members will be offered opportunities to develop knowledge and skills in areas relating to the councils role and function
- Personal satisfaction in making a much valued contribution to the work of the UKRR

Expenses

Patient and carers, who are members of the Patient Council, can claim the following for attendance at meetings:

1. re-imburement of travel expenses is available in line with the UKRR expenses policy. Expense claim forms will be available at meetings. A copy of the expense policy will be issued when you join the council but can also be requested from Steph Lock (tel: 0117 414 8150, email: Stephanie.lock@renalregistry.nhs.uk). Re-imburement of additional 'special need' expenses will also be considered outside of the expense policy but this must be discussed and agreed in advance of the meeting date.
2. an honorarium (allowance) is available to patients and carers who are council members to cover your time (travel and meeting attendance) and in recognition of your input of
 - a. £40 for up to 5 hours
 - b. £75 for 5 or more hours.

The honorarium is optional and can be claimed as outlined or donated to a registered renal charity. If not taken or donated it will remain within the project budget and used to further the aims of council.

This honorarium is not available to carers who are needed to accompany council members to meetings.

Members are responsible for any tax or benefit implications resulting from these payments. The UKRR will not be liable for any tax due or any reduction in benefit payment.

Quorum

To be quorate the meeting must have either the Chief Executive or Medical Director or nominee of the UKRR present along with 4 other group members, one of which must be the Chairperson or a nominated deputy to the chair role.

Frequency of Meetings

The Patient Council will meet at least 4 times per year according to demands on work.

Between meetings, tasks and other ad-hoc work can be managed via emails or via the phone to enable work to be completed on time.

Meetings venues may vary but where possible will be held centrally in England.

Minutes

These will be action based and therefore captured as action minutes after each meeting. They will be available to:

- Members and the groups they represent
- Renal Information Governance Board
- Other UKRR Committees as appropriate
- To the general public via the UKRR website

Any conflicts of interest must be declared and recorded in the minutes.