

Patient Information Committee

Purpose of committee/how it supports our mission

The Patient Information Committee makes a major contribution to the Renal Association's mission by ensuring it supports its members in delivering high quality care to improve lives.

It is fundamental to the following supporting statements:

- **Patient enablement.** Working in partnership with patients, careers and organisations to promote patient engagement and involvement in their own healthcare.
- **Communications.** Developing the RA and our membership to influence and increase impact.

Accountability

The committee is a subcommittee of the Clinical Affairs Board and reports directly to it. It is a joint enterprise between the Renal Association and Kidney Care UK.

Responsibilities

- The Patient Information Committee will undertake programmes of work as directed by the Chair, in partnership with representatives from Kidney Care UK.
- This work will include the development and maintenance of a series of high quality patient information leaflets for use by kidney doctors, patients, families and carers in the UK.
- This work will include the preparation of collaborative information leaflets with other specialist societies such as the Renal Nutrition Group.
- Between 10-12 new leaflets will be produced each year
- A rolling programme will ensure revision of all leaflets at intervals no greater than 3 years.
- All leaflets should follow the systems and processes to facilitate the continuation of Information Standard accreditation.
- This work will ensure that patients are represented on each leaflet development review group.
- The Committee Secretariat and Project Administration will be provided by Renal Registry and funded for an initial three year period (2016 – 2019) by Kidney Care UK.
- The Chair will prepare written reports of the business of the Committee for the Clinical Affairs Board, or delegate this task to a member of the Committee.
- The Chair will be responsible for keeping the Committee's website area up to date with information about the current Committee membership and other relevant documents.

- The Chair will be responsible for keeping the membership of the Association informed of the Committee's activities through the website, Association monthly eNews, and other appropriate communications strategies.

Membership

- The Patient Information Committee will consist of no less than eight members who will be appointed on the recommendation of the Committee Chair.
- Membership of the Committee will include the following :
 - Adult and paediatric Nephrologists
 - Representatives from Kidney Care UK
 - Representatives of the renal multidisciplinary team
 - Representation from within the SpR community
- All members are expected to serve through the initial three year timespan for the project (2016-2019)
- Membership will then be reviewed following a decision in regards to the continuation of the Committee.
- A separate Patient Editorial Board falls under the remit of the Patient Information Committee and serves to provide a lay perspective on leaflet topic selection, language use and presentation style. The Patient Editorial Board is coordinated by Kidney Care UK.

Committee Rules

- The Chair shall be appointed by an Appointments Panel.
- The Appointments Panel or the appointed Chair may if thought appropriate, appoint a Vice Chair to assist in the running of the Committee.
- The Chair is a member of the Clinical Affairs Board.
- The committee will meet four times a year - two face to face meetings and two teleconferences. In addition, Committee business will be maintained using e-mail and telephone communications between meetings.
- Quorum for a meeting will be one third of membership and includes at least one of the either the Chair or Vice Chair, and at least one of the Kidney Care UK representatives. Those attending via videoconference or teleconference are considered part of quorum.
- Members are expected to attend 75% of scheduled meetings and to send apologies to the project administrator if they are unable to attend a meeting.
- Decisions will be taken in the same way as dictated in the articles for the board
- The committee will be supported by the Renal Association staff and agendas will be agreed by the chair and circulated at least two weeks before the meeting
- Other papers will be circulated a week before the meeting
- Minutes will be taken and kept in the archive

Task & Finish Groups

The committee may establish task and finish groups or sub committees with the appropriate membership to execute its responsibilities while maintaining responsibility and monitoring progress and quality/cost

Key objectives

2019

- Produce a minimum of 10 new patient information leaflets
- Promote the current resources to hospitals and patients, both online and at events
- Research alternative accreditation schemes due to the closing of the Information Standard
- Reach a decision as to the continuation of the Committee after its current end date of December 2019

Risk Management

Risks to achieving the key objectives will be escalated to the secretariat who will inform appropriate trustees and record in the risk register.

Date Agreed

Date Reviewed

Corporate Sponsorship -