

KIDNEY PATIENT INVOLVEMENT NETWORK (KPIN)

PATIENT ADVISORY GROUP (PAG)

TERMS OF REFERENCE

1. Introduction

- Patient Involvement and Engagement is a critical element of the Kidney Patient Involvement Network (KPIN) and as such, a Patient Advisory Group (PAG) has been established to support Network activities.
- These Terms of Reference (TOR's) provide clarity in the outline role of PAG members.
- The PAG Lead is Andy Henwood (a KPIN Patient Involvement Facilitator) who will be supported by Holly Loughton (also a KPIN Patient Involvement Facilitator).
- Both Andy and Holly are members of the KPIN Working Group both contributing to ensuring an entirely equal footing between Patients/Carers and healthcare professionals.
- Application to the PAG will be open to any Peritoneal (PD), Haemodialysis (HD) or kidney Transplanted patients or carers. The term of membership will be open, with patients or carers contributing as their time permits (personal circumstances withstanding).

2. The basic role of the PAG

- To provide Information, Advice and Guidance (IAG) to the **KPIN** Working Group
- *Where possible and experience permitting, to provide peer to peer patient/carer support to those who have asked for become engaged in the PAG.*

3. Scope of the group

- Helping to ensure that the patient/carer 'voice' is at the centre of the Network and that the patient involvement and engagement perspectives are strongly represented across Quality Improvement, Service Design and Research. This will help to refine how KPIN to matches the needs of patient, carers and professionals wishing to get involved/engaged and evaluating KPIN interventions
- Through experience, provide feedback on patients' needs, concerns and interest and challenge the **KPIN** network constructively whenever necessary
- Contribute views and give advice and guidance to the 'working group' on how to communicate and engage with the patients including the development and delivery of all patient-facing materials within the scope of the network, including the website
- Alert the working group to potential risks
- Where appropriate, assist the **KPIN** networks(s) and its patients by providing 'guidance' (peer to peer support) around areas of involvement
- Promote good health and higher levels of health literacy by encouraging and supporting activities within the **KPIN** Programme and promoting patient/carer involvement/engagement
- Disseminate and share the benefits and outputs of the network to patients, carers and Healthcare Groups

4. Key Principles

- The PAG will promote positive change in the delivery of **KPIN** by adopting the following key principles:

C confidentiality
H honesty
O openness
R respect
T timeliness
L listen and learn
E enjoyment

additionally, this includes transparency; listening to one another and doing what we say we will; agreed and consistent ways of giving and receiving feedback; joint commitment to the ongoing commitment to developing Shared Care.

5. Responsibilities:

- The PAG members will be asked to;
 - Play an active part within the PAG
 - Not use the PAG as a forum for complaints or to raise personal issues which are not of relevance to the **KPIN** Programme
 - Attend meetings of the PAG notifying the PAG Lead should they not be able to attend
 - Respect the PAG Key Principles
 - Provide limited feedback (summary) on activities they are undertaking within the programme
 - Be an 'advocate' and 'influencer' for KPIN and KPIN Membership
- The PAG will meet face to face e.g. Zoom as required, but through email/phone on a regular basis for interim updates, discussions, and PAG member contributions to other project aspects e.g. reports/feedback etc.

6. Expected outcomes

- Mutually enhanced health provision
- Better informed and engaged renal patients regarding **KPIN**
- An improved 'Quality of Life' for both the patient and carer
- Improved communication between units involved in the **KPIN** Programme and its patients.
- Increased patient/carer representation on decision-making bodies for renal care services.

7. Finance

- Members of the group will be reimbursed in accordance with NIHR Guidelines (2010).

8. Programme PAG Support:

- The PAG will be supported by the governance infrastructure of Kidney Care UK, the KPIN working Group as well as wider KPIN partners and professionals.