

## **Autosomal Dominant Polycystic Kidney Disease Priority Setting Partnership**

### **Steering Group – Terms of Reference**

This document sets out the Terms of Reference for the Steering Group of the James Lind Alliance Autosomal Dominant Polycystic Kidney Disease Priority Setting Partnership (ADPKD PSP), which will be run in association with the James Lind Alliance. The Steering Group will coordinate the Priority Setting Partnership (PSP) and organise its activities.

The Steering Group includes patients, carers, clinicians and other health professionals. These may be members of a charity or professional organisation within the area of the ADPKD PSP. Members will bring with them experience and expertise including: knowledge and/or experience of the condition, an understanding of the patient, carer and clinician populations and access to networks of patients, carers and clinicians. Members will need to be fully engaged in the process and have the time to carry out the work involved.

The background and wider aims and responsibilities of the ADPKD PSP are set out in its Draft Protocol.

### **Introduction to the James Lind Alliance and priority setting**

The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004 with the aim of enabling groups of patients, carers and clinicians to work together to agree priorities for health research. The JLA facilitates PSPs in particular health areas.

Each PSP consists of patients, carers and their representatives, and clinicians, and is led by a Steering Group. Collaboration between patients, carers and clinicians to set the research agenda is extremely rare, but vital in drawing issues to the attention of research funders that might not otherwise be suggested or prioritised.

The role of the PSP is to identify questions that have not been answered by research to date, and then to prioritise these. The first stage is to ask patients, carers and clinicians for unanswered questions about ADPKD. These questions are then assessed to check they are in scope for the PSP, and are checked and verified as true uncertainties. An interim prioritisation exercise then takes place, before a priority-setting workshop is convened where participants debate and finally arrive at a Top 10 list of research priorities.

The eventual aim is to turn these priorities into research questions, and for members of the Steering Group to work with researchers and research funders to obtain funding for that research.

All JLA will display all priorities on the JLA website. Further details about the JLA and PSPs are at <http://www.jla.nihr.ac.uk/>. A flowchart of the PSP process can be seen in the Templates and useful documents section of the JLA website at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm>.

## **The ADPKD Priority Setting Partnership**

### **Membership of the Steering Group**

The Steering Group membership is a balance of patients, carers and professionals.

Members include individual patients with ADPKD and carers, plus clinicians from the following specialities: adult and paediatric nephrology, genetics, renal or genetic nursing, surgery and primary care. Members may also include individuals and representatives of organisations which can reach and advocate for patients and clinicians.

### **Role of Steering Group members**

Steering Group members are asked to contribute, as a minimum, their expertise and their time, and to be prepared to approach their established contacts and networks.

All Steering Group members are asked to commit to working according to the JLA principles:

- **Inclusivity:** working with other members respectfully and constructively and ensuring the full range of patient, carer and clinical stakeholder are involved in the PSP process.
- **Equality:** patients, carers and clinicians, and the knowledge and experience they bring, are of equal value to the PSP.
- **Fairness and transparency:** declaring any personal interests, and ensuring decisions and activities are documented openly.
- **Evidence based:** ensuring the work of the PSP recognises the existing knowledge based for ADPKD and contributes to this through the PSP's evidence checking and open publication of information from the PSP.

Members of the Steering Group will:

- Take part in Steering Group meetings/teleconferences, either by teleconference or face to face on an approximately monthly basis.
- If unable to attend, submit comments ahead of the meeting; where a Steering Group member is unable to attend a meeting, decisions made at the meeting will be respected.
- Respond promptly with feedback on project materials.
- Help publicise the initiative to potential partners. This includes advising on membership of the PSP (to ensure a wide and representative group of patients, carers and clinicians) and emailing contacts to invite them to participate.
- Have oversight of the collection of evidence uncertainties from patients, carers, clinicians and existing literature.
- Oversee and lend expertise to the data management process, including agreeing the scope and process for data-checking.
- Have oversight of the interim priority setting stage.
- Agree the final shortlist of questions to be taken to the final priority setting workshop.
- Oversee the planning for the final priority-setting workshop, and help to publicise it. This is the one-day workshop that brings patients, carers and clinicians together to debate, rank and agree a final Top 10. It is only attended by patients, carers and the health professionals or support workers who actively work with them.
- Ensure that the PSP's working spreadsheet of uncertainties and the final prioritised list of questions are supplied to the JLA, for publication on the JLA website.
- Help publicise the final top 10 uncertainties to the research community.

- Be involved in the development of research questions from the agreed priorities, and work with research funders where necessary to provide any extra information they need.

## Specific Roles

**Chair:** The PSP will be chaired by Maryrose Tarpey, a JLA Adviser. The JLA Adviser also Chairs and runs the final priority-setting workshop. The JLA Adviser's role is to support and guide the PSP, as a neutral facilitator, ensuring that the process is followed in a fair, transparent way, with equal input from patients, carers and clinicians and their representatives.

**Lead:** Tess Harris is the lead for the PSP. The Lead works closely with the JLA Adviser and the PSP coordinator to champion the PSP and ensure it is successfully promoted, completed and disseminated to funders.

**Coordinator:** Jane Pugh is responsible for the coordination and administration of the PSP. This includes arranging all meetings and workshops, and ensuring that:

- requests for agenda items are discussed with the group
- papers are available at least a week before meetings
- meeting notes are reviewed by the Chair, circulated within two weeks, and reviewed and agreed at the next meeting.

**Information Specialist:** Ann Daly is the Information Specialist for the PSP. Her role is to advise the Steering Group on data management and analysis strategies and agree these with the group. She also reviews and analyses the data collected, reviews existing evidence, and helps develop the list of indicative questions, under the guidance and assurance of the Steering Group. The outputs delivered by the Information Specialist will be approved by the Steering Group.

## Declaring interests

Steering Group members are asked to declare any interests relevant to the ADPKD PSP. The JLA provides an example form, and the interests of each member will be shared among the group. This is to encourage a culture of openness and transparency. Relevant interests may be professional, personal or related to an interest in or involvement in clinical research. The same form asks Steering Group members to consider their agreement to being named in publicity about the PSP.

Researchers may sit on the Steering Group if the group feels this is appropriate and useful – the JLA Adviser will ensure that they do not have an undue influence on the outcome. Researchers who are currently clinically active may participate in the priority setting if they declare their interests.

## Timescales

The ADPKD PSP first Steering Group meeting will be on 11 September 2019. We propose that the final priority-setting workshop takes place in January 2020.

## Steering Group members

Patients and carers or representative/s:

Mr Patrick Barton	Carer
Mrs Natasha O'Brien	Patient
Mrs Gillian Mundy	Patient
Mr Peter Storey	Kidney Research UK representative

**Health professionals:**

Nurse Specialist Wendy Brown	Imperial College Healthcare Trust	Steering Group member
Dr Ragada El-Damanawi	Addenbrooke's Hospital (adult nephrologist and clinical research fellow)	Steering Group member
Dr Bert Jindal	GP	Steering Group member
Dr Maryam Khosravi	Royal Free Hospital (adult nephrologist)	Steering Group member
Professor Albert Ong	University of Sheffield (adult nephrology)	Steering Group member
Dr Albert Power	Southmead Hospital Bristol (adult nephrology)	Steering Group member
Dr Richard Sandford	Addenbrooke's Hospital (genetics)	Steering Group member
Professor John Sayer	Institute of Genetic Medicine Newcastle (adult nephrology/genetics)	Steering Group member
Dr Roz Simms	Sheffield Teaching Hospitals (adult nephrologist)	Steering Group member
Professor Pat Wilson	PKD Charity Research Advisory Board & UCL Centre for Nephrology	Steering Group member
Professor Paul Winyard	UCL Great Ormond Street Institute of Child Health (paediatric nephrology)	Steering Group member
Dr Grahame Wood	Salford Royal Hospital (adult nephrology)	Steering Group member

**PSP Coordinators:**

Ms Tess Harris	PKD Charity	PSP Lead, Steering Group member (and patient)
Mrs Jane Pugh	PKD Charity	PSP Project Manager, Steering Group member (and patient)
Maryrose Tarpey	James Lind Alliance Adviser	Chair of the Steering Group
Ann Daly	Independent Information Specialist	Steering Group member