

Precision-Panc Advisory Group

November 2020, Version 4

What is the Precision-Panc Patient Advisory Group and what does it do?

The Precision-Panc Patient Advisory group (PPAG) was developed to ensure that research within the Precision-Panc (PP) platform is **relevant, acceptable and feasible** to people who are diagnosed with pancreatic cancer. The members of the group are considered to be **collaborators** in Precision-Panc and provide **critical appraisal of research studies, marketing resources (such as the website and brochure)** and **patient-facing information** for researchers wishing to bring potential studies to the programme.

The group was recruited via the Cancer Research UK (CRUK) and Pancreatic Cancer UK (PCUK) research involvement networks, currently comprises 7 members, and has been established since November 2018.

All members have an experience of Pancreatic Cancer, either directly or via a family member and are extremely engaged in the field of pancreatic cancer. They are also knowledgeable about the disease, its prevalence and prognosis.

However, members of the group are **not clinically qualified** therefore, their main role is to ensure that any information about research in the Precision-Panc programme is **accessible** to people unfamiliar with oncology and **easily understandable** for the general public. Researchers are provided with a consultation template to summarise what the proposed research is about, its relevance to Precision-Panc and to detail specific feedback questions. The panel are given a minimum of 2 weeks to provide feedback for each consultation.

To optimise feedback from PPAG, we recommend that you present your project in a format that is understandable to the lay public and not to a clinical or academic audience. Support to optimise the quality of the consultation is provided by the Precision-Panc PPI management group (*)

Upon recruitment, PPAG members received training about Precision-Panc and personalised medicine through written resources developed by the Precision-Panc team. Any additional queries from the group arising from consultations are triaged by the Precision-Panc Public and Patient Involvement (PPI) Lead, in liaison with CRUK and PCUK. The PPAG can claim a small honorarium for each consultation they complete. This funding is part of the Precision-Panc grant award and is managed by the CRUK PPI team.

Precision-Panc PPI Management Group members*

Contact: PPI@precisionpanc.org

Juan Valle (Precision-Panc Lead, Manchester, Chair PPI)

Kate Vaughan (Precision-Panc Lead, Manchester)

Judith Dixon-Hughes (Precision-Panc project manager, Glasgow)

Helen Wilkinson (CRUK, PPI)

Anna Lakey (Pancreatic Cancer UK, PPI)

Maria Cerone (CRUK – Precision Medicine portfolio manager)

Patient Involvement Toolkit

Patient Involvement can improve the quality and relevance of your work, helping you better understand and articulate the benefits your research can have for cancer patients.

This toolkit provides guidance, tips and templates to help you plan, deliver and evaluate your patient involvement.

cruk.org/ppitoolkit

Precision-Panc Advisory Group

What IS expected of PPAG

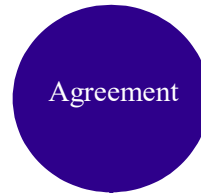
- ✓ Evaluate accessibility, acceptability and design of studies for patients with pancreatic cancer (e.g. number of interventions and tests)
- ✓ Assess how easy the information is to understand based on an average literacy level.
Remember, the information has to be understood by people who may have no knowledge of cancer or trials and whose literacy may be limited
- ✓ Review the format of information (e.g. document length and order of content)
- ✓ **Improve** wording to enhance comprehension for a lay audience

What is NOT expected of PPAG

- ✗ Writing a first draft of patient-facing documents (e.g. Patient Information Sheet)
- ✗ Make the consultation easier to understand. Researchers are expected to present consultations in a way that is easy for anyone to understand
- ✗ Evaluate the scientific or clinical relevance of a study
- ✗ Interpret or understand acronyms, drug terminology or specialised trial nomenclature.



- Researcher makes contact with Precision-Panc PPI management group lead (PPI@precisionpanc.org.)
- Researcher completes consultation template **with support from PPI colleagues**
- TIMELINE: 4-6 weeks **ahead** of requested deadline



- The Patient Involvement plan is agreed, including:
 - key questions asked about the consultation – **what do you want to get out of the consultation?**
 - involvement objectives
 - any methods of feedback other than written consultation (i.e telephone call/ survey)
 - feedback quantity and confirmation of honoraria



- Members of PPAG are approached with the consultation. This is managed by Precision-Panc PPI group lead
- Precision-Panc PPI group lead support PPAG members as they provide feedback and input in line with the request template.
- TIMELINE: PPAG members are given **at least 2 weeks** to provide feedback and input on each request



- Precision-Panc PPI lead will collate anonymous feedback and input from PPAG members in a feedback template and return to researcher



- Precision-Panc PPI lead will request details from the researcher about how PPAG feedback has been incorporated into their project.
- PPAG informed of outcome and impact of their feedback on Precision-Panc activity by CRUK/PCUK. Outcomes recorded by CRUK, PCUK and Precision-Panc PPI leads for reporting purposes.

Precision-Panc project manager will circulate an impact survey to each researcher shortly after receipt of PPAG feedback.