Empowering Patient Involvement in Cancer Clinical Trials

Workshop 1C: Improving Clinical Trials with PPI
CSO Patient and Public Involvement Event

Dundee

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Empowering Patient Involvement in Cancer Clinical Trials

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Elspeth Banks, PPI OG Chair, PPI Panel and PPI Representative

- Glasgow Oncology Clinical Trials Unit (GO CTU)
- Glasgow Adult ECMC







GO CTU PPI - Pre-2020

- In-House Trial Advisory Board (IHTAB) 3 PPI members
- UTSC 1 independent PPI member
- Inclusion of PPI on most trials within the CTU portfolio
- PPI Panel led by Glasgow Cancer PPI Coordinator







GO CTU PPI Short Life Working Group (SLWG)

- SLWG formed and first meeting 7th September 2020
- Considered and inclusive membership:
 - CTU Senior Management Led by CTU Director and Operations Director
 - CTU Project Manager
 - CTU Local Chief Investigator
 - Glasgow Cancer PPI Coordinator
 - All members of the PPI Panel
- 6 meetings between September 2020 and June 2021
- 12-month Delivery Plan April 2021 to March 2022







PPI SLWG Outputs

- New CTU Vision for PPI
- Update to CTU Statement of Intent
- Study PPI Plan
- Formation of a PPI Oversight Group (PPI OG)







CTU Vision for PPI

Vision for PPI:

"People affected by cancer will be at the heart of everything we do"







CTU Vision for PPI

Goals:

- 1. Our portfolio of trials will be shaped by and reflects a research agenda that has been informed by patients and, where appropriate, the general public
- 2. Our trials will be designed to deliver impacts commensurate with the ambitions of patients and, where appropriate, the general public
- 3. We will conduct our trials in a patient-friendly manner which always takes the best interests of trial participants as our primary responsibility
- 4. We will conduct our business in a manner which considers the best interests of our trial participants, patients, carers and the general public
- 5. We will involve, engage with, and seek feedback from, patients and the general public to inform them of the work we do
- 6. We will develop capacity and capability for PPI representation and involvement within the CTU
- 7. We will consider the diversity of the patient population in the activities and trials of the CTU, to ensure we achieve the goals above







Revised CTU Statement of Intent

"Science and Patients driving better outcomes"

Priority 4: People affected by cancer will be at the heart of everything we do

- Patient representatives will be involved at every stage of every trial
- Patient representatives will have a role in independent oversight of every trial
- The portfolio will be shaped and reviewed by people affected by cancer
- Every patient matters. Where possible, we endeavour to develop trials which are inclusive of, and have results which are impactful for, all those affected by the disease







Study PPI Plan

The purpose of the PPI Plan is to document the PPI associated with the trial:

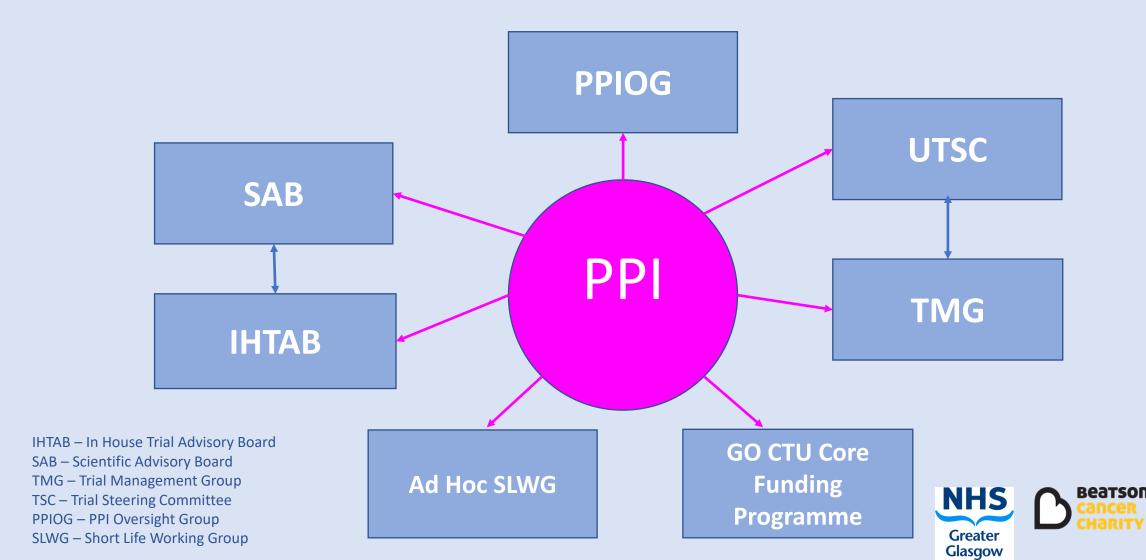
- To ensure compliance with the CTU Vision for PPI
- To include detail of the decision-making process regarding the required level of PPI and rationale around these decisions
- To record the key activities of the PPI representative(s) throughout the duration of the trial
- To provide a complete overview of the PPI associated with the trial from concept to conclusion







CTU PPI Organogram



PPI Oversight Group

- My involvement
- Types of Study PPI Plan review
- Study PPI Plan template
- Review process benefits







PPI Oversight Group

Sharing good practice

- The majority of documents were completed well and it was again reassuring to see the amount and quality of PPI being incorporated across studies. There was evidence of growth in PPI involvement in some studies and in the quality of information provided since the last review. This was encouraging.
- There were excellent exemplars of strong evidence of PPI in response to individual questions, to the Summary of the Agreed PPI Plan and to outcomes and impacts of PPI involvement.







Thank you for your time





