PPI Guidance 6: Setting up a PPI group – Why, What, When, Who

This guidance has been developed by PPI leads from the Oxford PPI Staff Group. It is piloted with researchers.

Any changes to the original document are those of the users and not necessarily those of the Oxford PPI leads group. Original versions of Researcher PPI guidance and templates are available on the Oxford BRC website or from one of the PPI staff leads.

Why:
Be clear about why this group is required. Key considerations:
- What is the group’s function?
- Write a short description – check out with a researcher and lay person – does it make sense?
- Reasons for a group might be: A requirement of a grant application on a particular project or to support researchers doing research in a particular area e.g. lung disease.
- What will be measures of success? Evaluating impact for researchers, research and PPI contributors.

What: Find out what success looks like for this project. Key considerations:
- Group size.
- Number of meetings.
- Online/in person.
- What is the budget.
- Support available – staff to manage, marketing, comms.

When: When will the group start and duration. Key considerations:
- Need 2-3 months for recruitment – advertising, interviewing.
- Induction and welcome documents.
- Find meaningful projects for group to work on from the outset.

Who: Who will be part of the group and how will you find them? Key considerations:
- Patients/former patients with the condition.
- Carers of people with the condition.
- Interested members of the public.
- People from under-served communities (particularly those worst affected by the condition being investigated).

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1 The group meets quarterly and includes leads from the local NIHR organisations and departments of the Oxford University Medical Sciences Division.

2 This document is being piloted (December 2023-April 2024) with researchers. Any suggestions for improvements should be sent to Rachel.taylor@ouh.nhs.uk.
• Some recruitment options are: OBRC mailing list, Trust membership newsletter, charities, community groups, existing PPI contributors.

Templates we can provide you with (these can be adapted for your use)
1. Posters for advertising
2. Estimated Cost of PPI Activities (attached)
3. Recruitment guidance
4. Role description
5. PPI Group Welcome Pack
6. Induction slides
7. Terms of reference PPI Group
8. Privacy statement
9. Payment policy
10. Ways of working
11. Evaluation form

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Please add relevant logo and keep/take off the NIHR OBRC logo as appropriate