

Chapter 5: Project Advisory Groups (PAG)

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Introduction

The Project Advisory Group (PAG) is an important element of Pocklington projects. Each group helps to ensure that the relevant expertise, insight and knowledge inform the project. The group provides opportunities for comment and reflection on the project as it develops.

This chapter explores the purpose of the PAG and provides some suggestions on how they can be run in a way that allows all members to contribute fully. While the recommendations in this chapter are specific to members of the PAG who have sight loss, most are conducive to a productive and inclusive meeting more generally.

Pocklington has created a template of guidelines for the research team to complete and distribute to potential and agreed members of the PAG. They describe the purpose of the PAG and tell members about their contribution to the project. This chapter explores some of the issues to consider prior to the guidelines being completed. The template can be found as the Appendix to this chapter.

Previous members of Pocklington PAGs, including researchers, individuals within Pocklington and external colleagues, have contributed to the guidance given in this chapter. There are several useful online resources that discuss public involvement in research generally and PAGs more specifically. Those that have informed this chapter are listed in the section 'Helpful resources'.

In Pocklington funded projects, it is usually the responsibility of the commissioned research team to set up, administer, run meetings and fund the PAG. The PAG meeting expenses are included in the project budget (venues, refreshments, members' travel and subsistence costs and, where agreed, fees).

The purpose of a PAG

The PAG is made up of people with expertise in several areas. Generally speaking, a research team uses the PAG to talk through the progress of the project, discuss challenges and acquire feedback from a cross-section of experts. Topics of discussion at PAG meetings might include:

- **Background information and context.** PAG members might be able to signpost research teams to relevant resources including published and unpublished research, and share information about other work in progress or about other policy and practice developments. They may also advise on stakeholders and consultants for the project.
- **Recruiting research participants.** Members might advise researchers on how to find potential participants. They may have direct access to relevant networks.
- **Data collection.** Researchers we spoke to found that talking to members of the PAG – especially those who had direct experience of the issues concerned – shaped the questions that were asked of participants during data collection.
- **Accessible materials.** PAG members might advise on how research teams can produce accessible materials and provide comments on the accessibility of questionnaires, forms and presentations.
- **Interpreting findings.** PAG members might be asked to contribute their views on what the findings say and mean in practice or policy contexts.
- **Reports.** PAG members may be asked to comment on drafts of reports.
- **Dissemination.** Discuss how the findings can be shared most effectively and reach the relevant policy-makers, practitioners and service users. PAG members might be able to use their own networks to publicise the project's findings.

- **Feedback.** Find the most effective and appropriate way to feed results back to research participants.
- **The longer term effect of the research.** Comment on potential follow-on work such as further research or implementation.

Inviting members to join the PAG

PAGs include a member of the Pocklington Research and Development Team and the research project team.

Depending on the nature of the project, other members might be:

- People with direct experience of the issues under consideration in the project e.g. people with sight loss, users of relevant services or their family members, partners, friends or carers.
- Practitioners with an interest in the project or policy area.
- Policy makers or influencers.
- People engaged in relevant research.
- People with relevant methodological expertise.
- People engaged in relevant development work.
- Key stakeholders or partners in the development of the project and the implementation of findings.

Researchers that have previously carried out Pocklington funded projects were asked what factors they took into consideration when inviting members to join their PAG. Their remarks are summarised below.

- **Skills / expertise.** The PAG will be particularly useful if its external members possess skills and expertise that add to those of the research team.
- **Location.** If relevant, research teams may wish to include a member from the area(s) to which the project relates. The research team may benefit from representatives from more than one area on the group, especially if the project relates to more than one geographical area, as places are likely to differ in terms of local services and the most appropriate sources through which to recruit research participants.
- **Demographics.** If relevant, research teams might wish to focus representation from the population being studied, for example older people.

- **Members with sight loss as individuals/service users.** The appropriateness of including individuals with sight loss as members of the PAG will vary from project to project. Research teams should evaluate if formal PAG meetings are the best route through which to involve people with sight loss and not underestimate the additional work that may be required in order to ensure that their participation is on an equal footing to that of all other members.
- **The number of people with sight loss.** Research teams may think it appropriate to have more than one person with sight loss on the PAG. Researchers that did told us that encountering a divergence of views within the microcosm of the PAG alerted them to the fact that there would be a multitude of experiences existing outside it. Involving more than one person with sight loss in any group can also help address any issues of balance of perceived power or authority.
- **Members with sight loss from organisations.** It is good practice to be clear from the outset about the basis on which a member has been invited. For example, if they have been invited on the basis of their professional or personal experience, or both. This can be achieved by providing a description of the role and outlining the tasks that you expect each member to perform.

INVOLVE offers some useful practical advice on how to find the 'right' people, manage expectations and advertise effectively:

INVOLVE (2012), Tips sheets: Recruiting members of the public to get involved in research funding and commissioning processes. INVOLVE, Eastleigh. To download a PDF of the tips sheet, visit www.invo.org.uk/posttypepublication/tips-sheet-recruiting-members-of-the-public-to-get-involved-in-research-funding-and-commissioning-processes/ [last accessed July 2014].

Encouraging full participation of all members

While members of the PAG will have varying expectations, requirements and confidence, there are several steps research teams can take to ensure that all members feel included and their contributions are valued. The following suggestions are based on the views of facilitators and members of previous PAGs as well as research that has been conducted by other organisations.

Provide job descriptions

Identify the skills, experience and personal attributes you wish members to have. Inform all members of the PAG from the outset what you want their involvement to look like throughout the process.

INVOLVE gives examples and templates of job descriptions to be issued to members of PAGs:

INVOLVE, Resource for researchers templates
<http://www.invo.org.uk/resource-for-researchers-templates/> [last accessed July 2014].

Manage expectations

Research teams may wish to have an initial discussion about the level of involvement each member wishes to have. By confirming the basic terms and conditions of involvement, members know what tasks they – and others – are expected to perform. Be clear to distinguish between the knowledge, skills and experience that an individual is expected to bring with them and the knowledge, skills and experience that they will have the opportunity to develop when they have been appointed to the group.[1] Research teams should make it clear that the PAG has advisory, not decision making, powers.

Think about access in its widest sense

Research teams that take into account people's wide range of access needs are more likely to enable them to contribute on equal terms. The Joseph Rowntree Foundation carried out a study about user involvement, which found that the lack of proper access and tokenism were closely interrelated: 'The failure to ensure good access for service users so that what they had to say could be listened to and learned from, reflected the lack of real interest which many service users felt there was in it.'[2] If the research project is UK-wide, choose a place that suits the members and has major transport links. Select a meeting space compatible with

1 INVOLVE (2012), Tips sheets: Recruiting members of the public to get involved in research funding and commissioning processes. INVOLVE, Eastleigh.

2 Branfield, F. and Beresford, P. (2006), 'Making user involvement work: supporting service user networking and knowledge'. Joseph Rowntree Foundation, London.

members' needs. This might include wheelchair access, nearby toilets, green space and meeting room space for a guide dog.

Support members

At an initial stage, ask members what support would enable them to participate fully. This might include holding meetings in an accessible building, providing lay summaries, issuing materials in their preferred format two weeks prior to the meeting or booking a support worker such as a BSL interpreter. It may also include training, networking or encouraging members to share mutual support. With this knowledge, research teams and members can discuss what may or may not be possible.

Provide a timetable

Members should be told at the outset how long the project will run, how many times the group will meet, where the meetings will take place and if any time is needed for additional involvement, such as reading time. Be clear if you need someone to attend the meetings or if their involvement can take place from home.

Have a continual dialogue

As there will be a limited number of formal meetings, it is good practice to offer continual communication and encourage members to contact an individual within the research team if there is something they wish to discuss or suggest for the next meeting's agenda. Research teams may also wish to give and invite feedback between the meetings. The research team could appoint one researcher to coordinate contact and answer queries between meetings. This individual could provide their telephone number and / or suggest discussion via email, depending on the most appropriate means of contact.

Practicalities

In advance of the meetings

- **Choice of venue.** The venue must be close to major transport links and fully accessible. Check that it welcomes guide dogs and that there is somewhere the dog can be walked and toileted.
- **Transport.** Provide clear information about transport options to the venue. Consider offering to order a taxi in advance.

- **Welcome others.** Make it clear that participants can bring someone with them such as a personal assistant, friend or family member. Guests' transport costs should be covered by the project budget.
- **Support.** Ask members if they require additional support mechanisms to ensure their full contribution. This could include training or peer support. Research teams may wish to give people the opportunity to identify their own support needs during an induction meeting or telephone conversation. This process could be repeated at regular intervals, as people's needs are likely to change over time.
- **Expenses.** The members' reasonable travel and refreshment costs are usually included in the project budget. Research teams should give clear information about the reimbursement of expenses and should pay them promptly.
- **Payment.** It is possible that PAG members can be paid if this is required to enable them to participate. Research teams should be clear about whether it is possible to offer payment and how this will be done.
- **Provide background information.** Provide all new recruits with some core, introductory information, in their preferred formats, which they can refer back to.
- **Send materials in advance.** Ensure that all materials that will be used in the meeting are sent out in preferred formats preferably two weeks in advance. This might require research teams to provide copies in braille, audio, electronic or large print. Chapter 6 provides further information on producing accessible materials.
- **Plan the agenda carefully.** Carefully consider what you wish to discuss at the meeting, send out the agenda in advance and try not to digress from it during the meeting. It may be helpful to discuss any queries or agenda items on the phone before a meeting, once the meeting papers have been circulated.
- **Give advance warning of complex subject matter.** If you wish to use a PAG meeting as an opportunity to discuss a complex or detailed issue, it is crucial that you give all members advance notice and provide background information in preferred formats.

INVOLVE states that how you plan these meetings can make a huge difference to how people feel about the research and how much they are able and want to get involved in your work. It provides tips at the following resource:

INVOLVE, Getting started, <http://www.invo.org.uk/getting-started/> [last accessed July 2014].

On the day of the meeting

- **Offer to meet.** Meet members at an agreed point such as a bus or train station or the venue itself. Let them know what the timetable is for the day.
- **Toilets.** Toilets should be easy to access. Tell people where they are early on in the meeting. Give clear instructions or offer to take people to them.
- **Introductions.** At the beginning of the meeting, introduce all members and – if relevant – their assistant, friend or family member. If someone arrives late, it is best to interrupt the meeting and repeat introductions so that everyone knows who is there and what their roles are.
- **Give background information.** At the beginning of each meeting, give some background to the project and its progress, including timeline and broad objectives.
- **Use language that all members can access at all times.** The strength of a PAG is the range of skills and expertise it possesses. For this reason, it is beneficial to conduct the meeting in lay terms so that everyone can follow the discussion and contribute, whether it relates to their area of expertise or not. If using technical terms, provide a lay description, and don't assume everyone will know vocabulary relating to sight loss or research methodology.
- **Presenting information.** Information should have been circulated in advance. Giving handouts out on the day will rarely be helpful for people with sight loss unless they have told you they are happy to receive them in large print or read them in standard print with a magnifier. If planning to give a PowerPoint presentation, think carefully about whether it is the best way to present information to everyone. Make sure that the font is at least size 32 and provide verbal description of all content. Chapter 5 provides further information on producing accessible materials.
- **Refreshments.** If providing refreshments, assign someone to the role of assisting people with sight loss or mobility issues.
- **Encourage and moderate.** Encourage the input of everyone in the group. The meeting should be effectively chaired so that it is not dominated by a few and so that less confident members feel comfortable to contribute. Allow sufficient time for discussions.

TwoCan Associates provides a resource that gives tips on drawing out quieter members and preventing louder participants from dominating the meeting:

TwoCan Associates (2010), Patient and public involvement in research groups – guidance for chairs. TwoCan Associates, London. A Word document version can be downloaded from www.twocanassociates.co.uk/pubs.php [last accessed July 2014].

- **Transport home.** Ensure that members with sight loss can leave the building independently or accompany them to the exit. Make sure that they can access transport home.

After the meetings

- **Maintain contact.** Invite dialogue between meetings. Following the final formal meeting, research teams may wish to inform PAG members of any future related work that grows out of the project, or pass on any news and updates.
- **Express gratitude.** Thank members for their time. Acknowledge their contribution in the publications.

Helpful resources

INVOLVE, Training and support for project advisory group member <http://www.invo.org.uk/posttyperesource/training-and-support-for-project-advisory-group-member/> [last accessed July 2014] is a web resource that gives guidance on setting up the PAG and supporting members.

Branfield, F. and Beresford, P. (2006), 'Making user involvement work: supporting service user networking and knowledge'. Joseph Rowntree Foundation, London. A PDF of the report can be found at <http://www.jrf.org.uk/sites/files/jrf/1410-user-networking-knowledge.pdf> [last accessed July 2014].

Asthma UK, Lay involvement <http://www.asthma.org.uk/research-lay-involvement> [last accessed July 2014] provides advice on how to write a lay abstract.

Scottish Health Council, The participation tools http://www.scottishhealthcouncil.org/patient_public_participation/

participation_toolkit/the_participation_tools.aspx [last accessed July 2014] identifies some well known methods for involving public participation in research.

Appendix

The following is a template of guidelines for members of Pocklington PAGs.

Project Advisory Group (PAG): Guidelines for Members – Template

Guiding notes to the template

- The project team and the R&D lead will have a clear view of the purpose of the PAG and any specific task(s) it is expected to undertake. This may be stated in the project brief or proposal or agreed at an early stage in the project. The tasks can then be stated in section 1 of the guidelines for members.
- Some (if not all) members are likely to have been agreed before the terms of reference are issued and their names / organisations can be inserted into section 3.
- Whether fees are / are not being offered / have been agreed should be stated in section 4.
- The project timescale should be stated in section 5.
- The final guidelines should be on the letterhead of the project team (which will include all legal details required and contact details), and sent to all members of the group and others involved with the project.

Project title: [insert]

1. Purpose, roles and function

The Project Advisory Group (PAG) provides an important element of the project. It helps to ensure that relevant expertise, insight and knowledge inform the project and provides opportunities for comment and reflection on the project as it develops.

In detail, the PAG will: [The following list should be amended and completed to correspond to expectations and requirements of the project.]

- Provide the project team with comments and advice on all aspects of the project.
- Recommend resources relevant and useful to the project, including published and unpublished research, current and past projects and / or services, public policy framework and practices.
- Provide the project team with comments on [insert tasks as relevant].

2. Powers

The PAG will enrich the project by informing the project plan and the project team's work. It as an advisory group. As needed, decisions about the development of the project and / or elements of its work (including changes to the project brief or plan) will be made by Pocklington working with the research team. Decisions will be informed by the views of the PAG.

3. Membership

The project team has invited members to join the PAG because each offers relevant expertise, insight and / or experience.

Members include the following [list names and organisations if known / relevant]

4. Administration and Funding

- Meetings of the PAG will be chaired by [insert – this may be the project lead or team member, someone from Pocklington or another funder, or an independent person]
- Meetings will be administered by the project team, including booking venues and refreshments, arrangement of meetings, production and distribution of agenda and paperwork, making and distributing records of meetings, undertaking or monitoring follow up action [it may be that some elements of this will be undertaken by others – such as room bookings – and this list should be amended for such circumstances].

- Materials for the group will be produced and distributed in the form preferred by each member of the group and may include large print, braille, audio, paper or electronic versions.
- Meetings will be conducted in ways that support members' preferred communication. This may include Support Workers such as a BSL interpreter.
- The PAG meeting expenses are included in the project budget (venues, refreshments, members' travel and subsistence costs and, where agreed, fees).
- Members' travel and subsistence costs will be reimbursed by the project team on receipt of signed invoices / claim forms.
- Travel costs should be either second class public transport or mileage at agreed Inland Revenue rates or other appropriate forms such as taxis or shared cars and subsistence costs should be reasonable.
- Where a member will be paid a fee to take part in the group, the agreed fee will be paid by the project team on receipt of signed invoices.

5. Meeting timetable

The PAG will meet [insert frequency] during the course of the project. If further meetings are considered necessary they will be arranged by the project team in consultation with the group.

Meetings will be scheduled to coincide with significant milestones in the project, as defined in the project brief/plan. [If possible, insert a table of dates / time periods]. Members are invited to comment and provide advice on work in progress in between formal meetings.

6. Acknowledgement

The contribution of the PAG will usually be acknowledged in project reports. Here, members and their organisation or profession are usually listed. The wording of acknowledgements will be agreed with the group.

7. Confidentiality

- PAG members are expected to act in a personal capacity and not as representatives of their organisations.

- Materials, draft reports and the content of PAG minutes are confidential to the research team, Pocklington and the PAG.

End of document.