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# Setting up a research advisory/ involvement group

January 2025

This guide has been prepared and reviewed by engagement practitioners/researchers who have vast experience of initiating and implementing a wide range of Community Advisory Boards (CAB), Patient and Public Involvement and Engagement (PPIE) groups and Young Persons Advisory Groups (YPAGs)

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By

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## 1. Purpose of this guide

This guide aims at providing researchers with a guide, with access to resources, for establishing an ‘advisory/involvement group.’ These groups vary tremendously depending on the purpose. In this roadmap ‘advisory/involvement group’ is an umbrella term describing a group comprising patients, community members, leaders or young people—who work with health researchers to make research studies more meaningful and useful. They share their experiences and ideas to help ensure the research focuses on real needs, is done ethically, and leads to results that benefit everyone involved. These groups help build trust and improve how research makes a difference in people’s lives. The groups comprise **Community Advisory Boards (CABs), Patient and Public Involvement (PPI) Groups, Young Persons Advisory Groups (YPAGs)**, and other variations. They can vary in terms of membership composition depending on the type of research they contribute to and/or their function.

### Types of advisory/involvement groups

- **A Research Programme CAB** – may comprise diverse members representing the local community and may be involved in various research studies.
- **A vaccine trial CAB** – may be funded for a single clinical trial with its composition reflecting the general population of the trial location.
- **A PPI group for a cancer treatment clinical trial** – may comprise patients who have lived experience of the type of cancer being studied.
- **A YPAG for a school-based health intervention study** may comprise students and/or teachers.
- **An advisory group for a hospital-based study** on hospital intensive care unit staff management may comprise nurses, doctors, and managers.

## 2. Guiding principles

Regardless of the type of advisory group, some general **guiding principles** comprise:

- Being clear about the purpose of the group and what it’s being asked to do is essential for an effective advisory/involvement group.
- The type and composition of an advisory/involvement group will depend on its function, and the type of research it supports.
- Diversity, for example, in terms of ethnicity, gender, the inclusion of marginalised groups, and other characteristics, is key to achieving broad representation of experiences and views.
- Fostering trust throughout the process by being open, transparent and respectful is essential.
- Listening and responding appropriately to expressed views is a way of demonstrating respect for the lived experience and expertise of advisory group members.
- It is somewhat inevitable that diverse groups have power imbalances among members. Careful and skilled preparation and facilitation is needed to address these imbalances prospectively, to enable all voices to be heard equally.
- Being clear and achieving an agreement on the terms of reference for group members at the outset is essential for minimising misplaced expectations.

### 3. Functions of an advisory/involvement group

The roles and functions of advisory/involvement groups vary tremendously. Here are some common functions:

- Providing a forum for discussing research priorities with researchers.
- Providing a forum to share community perspectives, concerns, rumours and fears about research throughout the project, and contributing to the development of appropriate strategies to address them.
- Providing a forum where members can share their views on specific research plans, proposals and protocols with researchers. This might mean discussing whether the proposed research is:
  - Relevant and useful to the populations where the research is being carried out,
  - Acceptable to participants and whether the benefits of conducting the research out-weigh the risks, and
  - Feasible within the context and timeframe in which the proposed research is taking place.
- Providing a forum where members can share their views and ideas on research designs, recruitment, implementation, procedures, and dissemination.
- To advise on appropriate ways of engaging communities and/or the public and to identify additional parties of interest.
- Reviewing and modifying informed consent forms and communications materials to improve appropriateness for participants and the public.

### 4. How can researchers be responsive to advisory/involvement groups?

**‘Responding’** to advisory/involvement group views, concerns and suggestions can involve a range of actions including:

- Alleviating concerns or fears about research through providing clear information about research procedures, their risks and their potential benefits.
- Incorporating advisory group ideas into research design, implementation, dissemination or engagement methods.
- Discussing, giving clear explanations, why some suggestions were not taken up by the research team.



Overall, clear communication, subsequent responses/actions and regular feedback loops between research leads and the advisory group (often through engagement facilitators) are essential for maximising the contribution of the advisory/involvement group to improving research, and for expressing respect.

### 5. How can an advisory/involvement group be established?

Once funding has been secured for the advisory/involvement group, the following steps might be useful for establishing and maintaining an advisory/involvement group.

## 1. Foundations & Preparations

### Essential foundations

- Institutional support
- Funding for the duration of the research, including:
  - Venue, member honoraria, travel reimbursement, printing, and refreshments for regular meetings
  - Staff with time and relevant skills

### Policies, documents and resources

- A framework for reimbursement and honoraria
- Information sheet and terms of reference for members
- A schedule and venue for meetings and training
- Training resources including:
  - Planned activities (presentations, role plays, debates, lab tour etc)
  - Teaching resources, materials and slides

## 2. Scoping

Decide with your team on the most suitable type of advisory/ involvement group and most appropriate contributors to inform your research

### Community-based research?

- Members representative of the community
- Community or religious leaders
- Charity and NGO staff from a relevant field

### Hospital-based research?

- Relevant interested parties: Managers, healthcare workers, pharmacists, receptionists, researchers
- Patients with lived experience of a health condition, their carers or family members

### Research involving children or young people?

- Education staff, or
- College, school, out-of-school children or youth (might need education authority, principal & parental permission) or their parents

## 3. Recruiting

Decide with your team on suitable methods for recruiting a diverse membership

### Recruiting, depending on your group, might involve:

- Purposive selection aimed at achieving a diversity through individual invitation.
- Advertisements (e.g. social media, leaflets, newsletters) to invite people to apply with selection after an interview
- Community-based democratic process, for example, village nomination and voting
- Other important strategic considerations may be to include people with specific skills, for example, individuals working in marketing, arts or communication

## 4. Initiating

Needs careful planning and implementation to ensure mutual-understanding

### Initial meetings might comprise:

- Outlining the group's purpose, priorities and roles
- Agreement on member terms of reference
- Agreement on meeting frequency, schedule, venue
- Initial training (understanding health research, clinical trials, ethical review, etc.)

## 5. Meetings

Aimed to gather member insights towards improving

### Meetings might involve:

- Discussing/setting research agendas
- Researchers sharing research plans/protocols for group input on design, acceptability, feasibility, recruitment, engagement
- Co-production of research materials, e.g. consent forms, study leaflets, posters, letters, videos, engagement plans

## 6. Review

Aimed to gather member insights towards improvement

### From time to time, it is important to evaluate & review:

- Terms of reference
- Honoraria
- Group membership (replacing some members periodically)
- Ways of working and whether they can be modified to improve the groups contribution to improving research

## 6. *Links to useful resources:*

- [WHO Guide: Working with Community Advisory Boards for COVID-19 related studies](#)
- [Ziauddin University Critical Care Research Group PPIE resources and article](#)
- [The Tak Province Border \(Thai Myanmar\) Community Ethics Advisory Board – Project report](#)
- [A hill tribe community advisory board in Northern Thailand: Lessons learned one year on](#)
- [Engagement of a community advisory group to shape and build up participation in TB research \(Vietnam\) - Article](#)
- [Engaging communities to strengthen research ethics in low-income settings: selection and perceptions of members of a network of representatives in coastal Kenya – \(Article\)](#)
- [NIHR PPI PPI \(Patient and Public Involvement\) resources for applicants to NIHR research programmes](#)
- [Unitaid’s Community Advisory Board Model: putting people at the centre and engaging communities](#)

