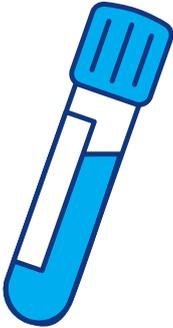


Patient and public involvement

Guidance for researchers



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What is patient and public involvement and why is it important?

Good patient and public involvement (PPI) means involving people affected by a health condition and/or their carers in the various stages of a research proposal. This may include planning, designing, implementing, managing, evaluating and/or disseminating their research. They are **not** just participants in the research - they are actively involved in the decisions made about the research and are considered part of the research team.

We believe that involving people affected by diabetes at all stages of research can produce higher quality and more relevant research, which in turn is more likely to receive funding. This will ultimately make sure that methods used are appropriate and the benefits of the research are relevant to people with diabetes.

We have put together this guidance document to help diabetes researchers effectively involve people affected by diabetes in their research.

Participation, engagement or involvement

There is a difference between patient and public **involvement**, **participation** and **engagement in research**.

- 1. Involvement** refers to people with a health condition inputting into stages of a research proposal. It **doesn't** refer to researchers raising awareness of their research, sharing knowledge or engaging with the public. It also **doesn't** refer to the recruitment of patients as participants in research. However, these different activities – involvement, engagement and participation – can complement each other.

Examples of involvement

- Commenting on and helping with the development of the grant application.
- Involvement in identifying research priorities relevant to the health condition.

- 2. Participation** means recruiting people to take part in your study – this **isn't** patient and public involvement.

Examples of participation

- People being recruited to a clinical trial, or volunteering in observational, intervention or other research as study participants.
- Completing a questionnaire or participating in a focus group as part of a research study.

- 3. Engagement** is sharing information and knowledge about your research which is important for demonstrating the importance of research to both the general public and individuals affected by the health condition. Engagement also builds confidence in your research by the people affected by the condition. Engagement **isn't** patient and public involvement

Examples of engagement

- Attending local diabetes groups and/or presenting your research at an event or conference.
- Raising awareness of research through the media such as social media or television.
- Dissemination of your research findings to research participants, colleagues or members of the public.

Benefits of patient and public involvement for researchers



Patient and public involvement can help you improve your research proposal and make sure it's possible and that your research question is relevant to people affected by diabetes. It will also offer you further opportunities to critically evaluate your research at all stages.

The Grants Advisory Panel (GAP), a group of lay reviewers affected by diabetes, will review your research application, and will be looking for evidence of patient and public involvement throughout the research. It's important to consider how you can involve people affected by diabetes at key stages when putting together your application.

Areas where you can involve people

- 1. Planning**
- 2. Design**
- 3. Implementation**
- 4. Management**
- 5. Evaluation and/or dissemination**

Nick Lemoine

Queen Mary University
Chair of Diabetes UK
Research Committee

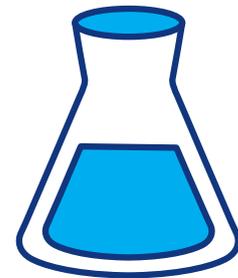


Diabetes UK is a condition-focused charity, funded by the people who have a personal interest in diabetes and its impact on their lives. Ensuring that it is evident that your research is relevant to those people makes it much more likely that it will be funded. Bear in mind that the first person to speak in the discussion about every grant application at Diabetes UK Research Committee is a patient or carer from our Grants Advisory Panel – they give the rest of the committee their views on the relevance and potential impact for those with diabetes.

However excellent your science, you have to convince them that what you propose is going to make a difference. How are you going to do that? The best way is to talk to people affected by diabetes. Engage with patient groups and tell them about your work. Hear what they have to say about it, and particularly listen to what they think about how it could be translated into patient benefit. If your work is going to need patients to participate in a study, then having feedback from someone who has been involved in something similar will help guide you.

They want your help – let them help you.

Benefits of patient and public involvement for researchers



Professor Susan Wong

Cardiff University

Diabetes UK Research Committee Member

Why you think patient and public involvement is important in research?

PPI offers the opportunity to gain different perspectives on the research questions and to improve the quality and relevance of research. It is important that people who have direct experience of diabetes have the opportunity to feed into questions that particularly concern them and that they may understand what questions research may or may not be able to answer.

How have you have used patient and public involvement in the past and at what stage?

I have used PPI in the past in early stages in thinking about how best to frame basic science questions and how to explain the type of research that we do and why it may be important. I have also used PPI to help guide future directions, once we already have generated some results that we have discussed with patient groups.



How did you find people affected by diabetes?

I have accessed people affected by diabetes as inpatients and in outpatient clinics as they express interest in current and future research. I have also had contact with patient groups and lay committee members of grant panels in diabetes charities.

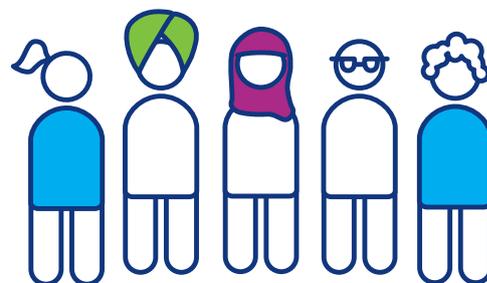
How your research benefited from patient and public involvement?

Our research has benefitted in a number of ways that include an expansion of the scope of the research questions as well as increased desire for involvement from patients who have participated in earlier stages of PPI.

Any advice for researchers that you might have?

Take on board the very good guidance provided by Diabetes UK.

Levels of involvement



You can involve people affected by diabetes at all stages of research.

- Commenting on research applications prior to their submission – helping identify research priorities relevant to people affected by diabetes, developing the grant application, including making sure that the research is relevant to people affected by diabetes and the lay summary is communicated well.
- As co-applicants on a research project.
- As members of a project advisory or steering group throughout the research process.
- Reviewing materials such as leaflets, posters, webpages, and questionnaires prior to their use in research.
- Offering suggestions to you about the suitability of proposed methods.
- Contributing to the design and management of your research study.
- Undertaking your research, including helping to create leaflets or completing questionnaires.
- Disseminating your research findings to lay audiences.
- Guiding the translation of your research findings, for example into altering clinical practice or guiding further research.
- Evaluating its impact for people affected by diabetes.

Consultation or Collaboration

Once you have decided the stage(s) at which you plan to involve people affected by diabetes, you will need to think about how to do this by defining the level of involvement users will have in your research project. Will their involvement be consultation or collaboration?

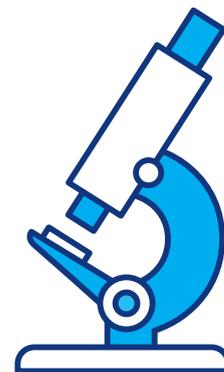
Consultation

You can ask people affected by diabetes their views and advice on aspects of the research to help shape it better. This could include asking them to comment on the research proposal, either through a survey or by holding a focus group.

Collaboration

This means that you and people affected by diabetes work together to make decisions, for example on a study steering group. This could include working together to identify relevant research questions or which research methods to use or ensuring the research stays focused.

Patient and public involvement in clinical research



PPI in clinical research can have a huge impact on the quality and success of a study. Clinical research that involves patient participation should also involve the voice and expertise of the patient or carer in planning, design, implementation, management and/or dissemination.

Here are some different ways you can consult and/or collaborate with people affected by diabetes and carers.

Develop your grant application and plan your research question

This will help you discuss ideas and find out what research area will reflect patient needs. This may also help to identify research priorities.

Involve the patient perspective in the development of your application and the design of your research

It's important to identify areas where people affected by diabetes can be involved in your research. This will help to identify any pitfalls in your plan from a lay perspective.

Involve the patient perspective in the management of your research

Involving patients here can help connect you with networks of people affected by diabetes, develop your recruitment and retention plans and resolve any problems you might face.

Design your study protocol

This might help you spot practical issues and provide an idea of whether people would take part in the research, and if not, why not?

People affected by diabetes will be able to comment on the time commitment or burden of your proposal on the study participants.

Inform the design of materials

Asking people to comment on leaflets, questionnaires, communication material and consent forms will make sure your language is appropriate.

Collect, analyse or interpret data

Provided training is available, you can involve people affected by diabetes in data collection, like helping to develop questionnaires. They can identify gaps in data or provide insight into future research questions from the perspective of someone who is living with the condition.

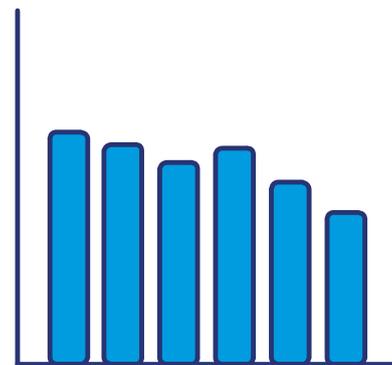
Disseminate or evaluate the results

Lay members can help evaluate your research findings from a patient perspective and the impact they will have. They can also help guide the translation of your research findings, for example into altering clinical practice.

Patient and public involvement in basic research

PPI in basic research is also a requirement in the research application process. At Diabetes UK, the Grants Advisory Panel comment on how well basic science researchers have involved people affected by diabetes in the research plan.

Many basic researchers find it challenging to involve people affected by health conditions in their research. We know that it can be harder to communicate the benefits and potential impact of basic research to a non-scientific audience. Often, basic science researchers undertake more engagement than involvement. However, you can involve people affected by diabetes in the development of your application to make the research more meaningful.



Here are some ways you can consult or collaborate with people affected by diabe-

Inform the development of your lay summary

People affected by diabetes can help you make sure your lay summary is written in plain English so that it is understandable to people without a scientific background. The Grants Advisory Panel will review your lay summary and use it to assess your application, so it is important that your research is clearly written for this audience.

Guidelines on writing a good lay summary and examples of good lay summaries are available on the Diabetes UK Research webpage.

Inform research ideas

You can consult people affected by diabetes to help identify research areas that are relevant and of priority. They can also help to identify future research questions.

Help set outcome measures

This can make sure your research is important and relevant to people affected by diabetes

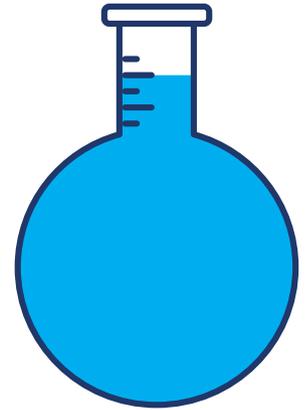
Help you communicate your research

Lay members can help you talk more effectively about your research to the public, making sure you emphasise the relevance, impact and future of your research to people living with diabetes. They can also help prepare or be involved in presentations for meetings.

Review the progress of your research

Lay members can advise how to report the progress of your research more effectively.

Doing patient and public involvement the right way



Often, researchers approach PPI as an afterthought, making patients and carers feel the process is tokenistic and that their input won't have an impact on the overall research. We understand that research proposals take a long time to put together and that researchers are working on applications right through to the submission deadline. However, it is important to involve people affected by diabetes in your research at an early stage in order for PPI to be meaningful and valuable.

Key principles of involvement

Plan involvement

Make sure your involvement of lay people starts as early as possible when planning your research. Here's some things to consider when planning your PPI.

- What do you want from the people involved and how will it influence your research?
- How many people affected by diabetes would you like to be involved?
- How will you find people to be involved? Consider the different avenues to approach, such as clinics, Research Design Service, individuals you know through your own network, the University User Involvement Team, support groups, forums etc.
- How will you budget for PPI in your research, including any training (if needed)? It's important to include a budget for PPI in your grant application and to make sure there is support to involve people. This may include payment for their time, travel expenses, or meeting room accommodation.
- What method of involvement will be most suitable for your research – consultation and/or collaboration?
- Will you involve a patient steering group? Where possible, this should be specific to your research.
- Who from the research group will be responsible for managing PPI?

Preparing involvement

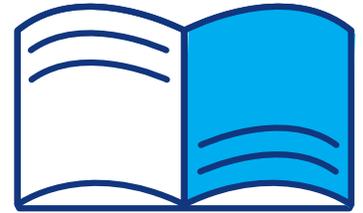
Once you know who you're going to involve you need to make sure their involvement is as valuable as possible.

Here's some things you should to prepare for your PPI.



- Be clear what questions you'd like them to answer, how they will contribute and also what they **won't** be required to do.
 - If you aim to have a patient steering group, it is important to identify 'role terms', including how often the group will meet, what the group will and will not be doing etc.
 - Include a clear statement of the activities to which they have committed and of how they should carry them out.
 - Consider what training (if any) is required.
 - Make sure deadlines are clear.
 - Be clear about the proposed time commitment.
 - Make sure people involved can communicate with the researchers easily.
 - Prepare FAQs – be consistent in the information you provide.
- Consider practical issues, such as timing of meetings, being sensitive to the needs of people you are working with, any ethical requirements and safeguarding the individuals involved.
 - Record outcomes of involvement and circulate to all members.
 - Consider potential challenges, like making sure voices are heard, people are kept engaged, discussions are focused, how to deal with difficult situations.
 - Plan for miscellaneous items - room hire, refreshments, stationary, telephone calls and documents etc.
 - Provide regular progress reports - feedback to members the progress so far and the impact of their involvement.
 - Acknowledge and formally thank those who have been involved to provide closure. Ask for feedback on their experience.

Useful resources



Patient and public involvement in health and social care research

Help to plan, manage and carry out PPI activities.

NIHR Research Design Service – Involving users in research

These guidelines assist researchers to fulfil the NIHR requirement for public and patient involvement in research.

Budgeting for PPI

Practical advice on how to budget for involving patients, carers and the public in research.

Involvement cost calculator

Practical advice on how to work out the actual costs of involving people in your study.

INVOLVE ‘Make it Clear’ campaign

Guidance on how to ensure each research study has a clear and concise plain English summary.

Academic Health Science Network

Body that connects NHS and academic organisations, local authorities, the third sector and industry, to create change across whole health and social care economies, with a clear focus on improving outcomes for patients.

Diabetes UK Local Support Groups

The Regional Officers of Diabetes UK support groups may be able to put you in touch with your local group.

TwoCan Associates

Training for researchers about involvement in health research.

Involving People Network (Wales)