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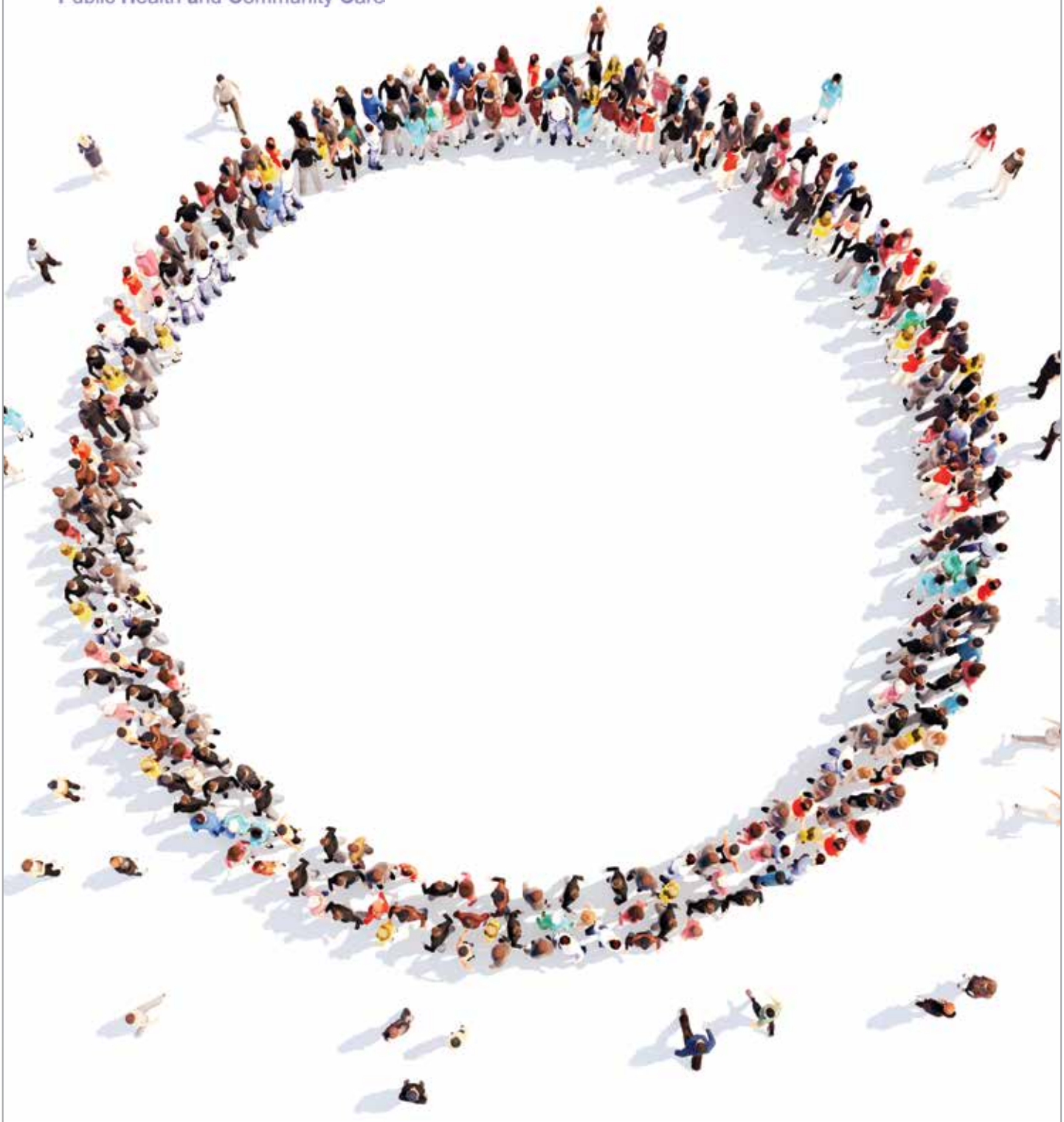


Guidance for Researchers: **Feedback**

PATIENT and PUBLIC INVOLVEMENT (PPI): Feedback from Researchers to PPI Contributors

Members of the public, patients, carers, service users, sometimes known as Patient and Public (PPI) contributors are now expected to be involved in health research due to the many benefits.

One common PPI activity is being involved in the design of a research study; PPI contributors make comments on study documents (for example; patient information sheets, consent forms, protocols, ethics submissions, interview questions) as well as research activities such as sitting on Advisory Committees, data collection, analysis and dissemination.

However, many PPI contributors do not hear if their contributions and comments have been received, if they have been used or if they are beneficial.

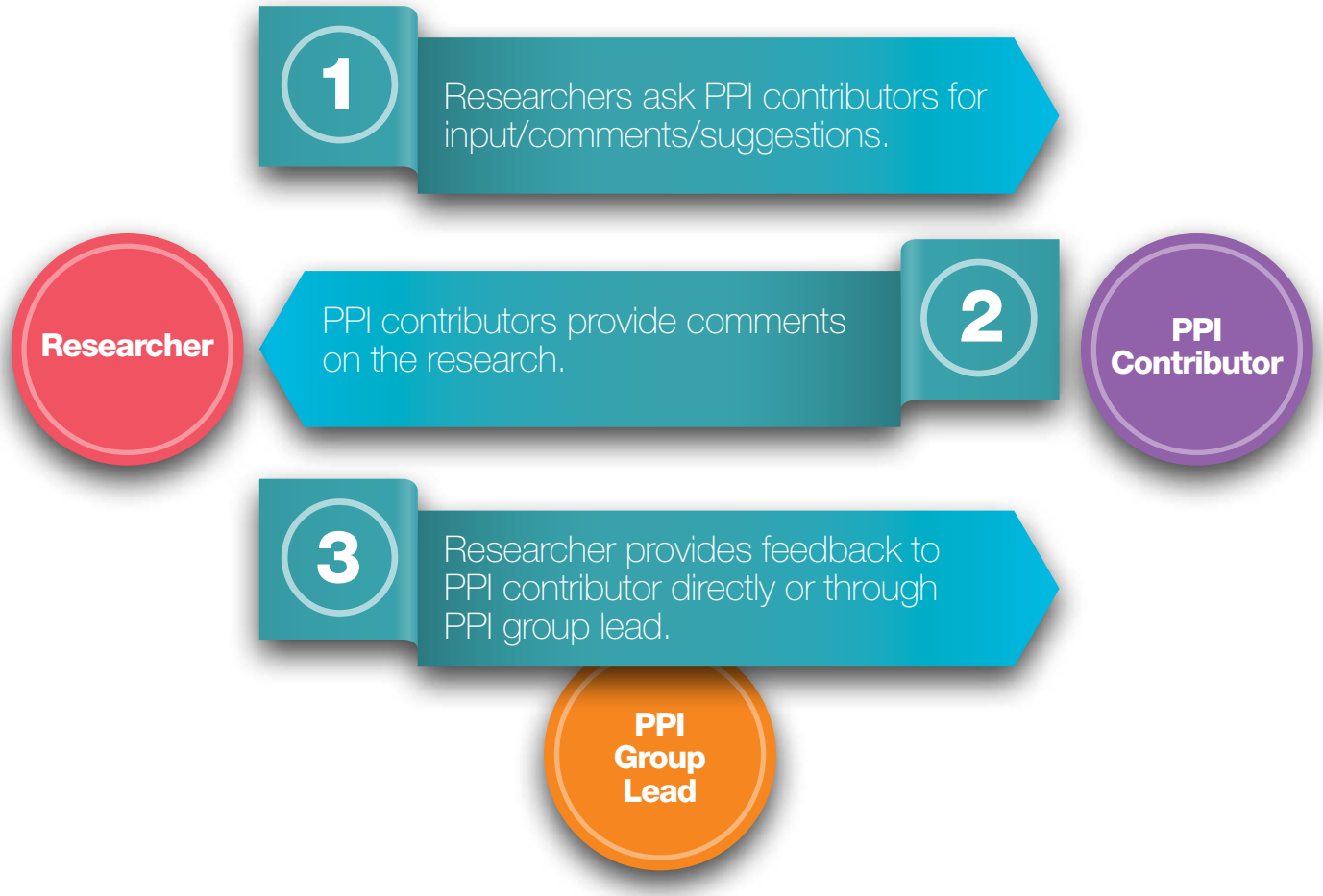
This guidance provides some practical tips on the **Who**, **Why**, **When**, **What** and **How** researchers could improve their ***Feedback*** to PPI contributors.

This guidance was co-produced by PPI contributors, PPI leads & researchers in the East of England, 2018

Summary of the PPI Feedback Study (2016-2018)

National Institute for Health Research (NIHR) funded research strongly encourages researchers to include PPI contributors in the design, dissemination and implementation of their research. Researchers seek the involvement of PPI contributors by asking for their written comments at different stages of the research process. PPI good practice guidelines encourage researchers to then provide feedback to PPI contributors on the comments they have provided.

The PPI feedback cycle:



However, evidence indicates that this feedback is not routine and is very variable. Many PPI contributors say they do not know if their comments have arrived, were used, beneficial or if they had any impact on the research.

This study aimed to find out the views and experience of PPI leads, PPI contributors and researchers to PPI feedback. Six PPI groups in the East of England participated in the research. The results can be found in the paper *Mathie, E., Wythe, H., Munday, D., et al. (2018) Reciprocal Relationships and the Importance of Feedback in Patient and Public Involvement: A Mixed Methods Study, Health Expectations, Article DOI: 10.1111/hex.12684*

In 2016 and 2017 PPI leads, PPI contributors and researchers came together and co-designed PPI feedback tools and guidance and this document is the result. PPI contributors have been involved from the initial idea of the study, through to data collection, analysis and co-presenting at the INVOLVE conference in November 2017. Their involvement has shaped the research, produced user-friendly documents, interpreted the findings and been a continual critical friend.

Who gives feedback?

Definition of Feedback:

Researchers ask PPI contributors for comments on their research, PPI contributors provide comments and then researchers should FEEDBACK.

- An allocated member of the research team provides feedback directly to the PPI contributor

OR

- An allocated member of the research team provides feedback via the PPI group lead or administrator and they pass on the feedback to the PPI contributor

Recommendations

- Someone in the research team or PPI lead must take responsibility for feedback. Who in the team feeds back?
- A plan is needed for when researchers leave, at the end of project or for handover mid-way.
- Extra administration costs may be needed to support feedback.

Why is PPI feedback important?

Have a discussion about why PPI contributors are doing PPI and why feedback might be important to them.

> **respectful** for the commitment of the time (PPI)

> Constructive & honest feedback increases my **confidence** (PPI)

> keeps your **motivation** going and your commitment going (PPI)

> **Acknowledgement** at least is a matter of good **courtesy** as not everyone has confidence in the robustness of email routes (PPI)

> I need to know for my own **self-development and learning** so that I can do better (PPI)

> **Acknowledge** the contribution PPI has made (i.e better research proposal) – validates ownership or origin of ideas

There are also good reasons why researchers provide feedback

> Investing time in **developing relationships** with PPI members (Researcher)

> They help so we should **reciprocate** (Researcher)

> So they know how their input **makes a difference** (Researcher)

> It shows them that you **value** their input (Researcher)

Discuss how and when feedback can best be given.

Recommendations

- A **thank you** is **minimal feedback (courtesy, respect)**
- PPI contributors are **entitled to ask for (and receive) feedback**
- Feedback can be a **key motivator** to stay involved in research
- Reasons for feedback may change – at first feedback maybe important for **confidence** (“am I doing it right?) and later it might be important for **learning and developing** (“how can I do it better?”)
- Feedback helps to record the **impact** of PPI contributions
- Feedback provides **accountability for decisions** and origin of ideas
- Feedback helps **transparency and continuity in research process**
- As an opportunity for researchers to learn through reflection
- Feedback creates a **well-motivated, informed and continuously** learning PPI community

When do I give feedback?

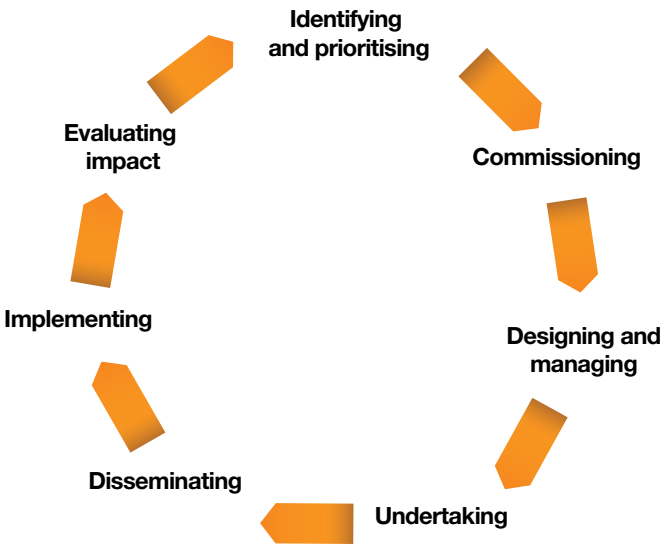
As soon as PPI contributors are involved have a conversation about when they will be involved and when you can provide feedback.

These initial discussions can help to avoid unrealistic expectations. Consider drafting an agreement to document (see tips p.12).

Plot feedback on research GANTT chart, charting the key milestones or use the INVOLVE research cycle (see below) as time points to contact your PPI contributors.

Give PPI contributors feedback within an agreed timeframe.

Research Cycle



INVOLVE
http://www.invo.org.uk/posttyperesource/where-and-how-to-involve-in-the-research-cycle/

INVOLVE was established in 1996 and is part of, and funded by, the **National Institute for Health Research**, to support active public involvement in NHS, public health and social care research. It is one of the few government funded programmes of its kind in the world.

Recommendations

- **When** to give feedback may be different for different groups, and for different activities so the processes involved may differ
- Different PPI activities (i.e. being on a steering committee, communication by email and being a co-researcher meeting face to face) may require **different sorts of feedback**

What sort of feedback do I give? What sort of feedback do PPI contributors want?

Refer to and abide by the pre-study discussions and agreement you have made with your PPI contributors.

Give general or individual feedback depending on the PPI activity and according to the agreement made.

There are four types of feedback PPI contributors might want:

1. **Acknowledgement** ("thank you") of comments.
   - Let PPI contributors know comments have been received & comments are appreciated as soon as you receive them.

2. **Outcome of study bids and ethics submissions.**
   - Let PPI contributors know if the study is successful or not
   - Let them know **why** if not successful (provide funder's statement).

3. **Study Progress**
   - Let PPI contributors know how the study is progressing – this is especially important if there is a quiet period and you are not in contact with the PPI contributor.
   - Consider sending out regular newsletters (emails, twitter) for PPI contributors (those who are involved in shaping the research) and participants (those who take part in the study).
   - Let PPI contributors know if academic papers have been published even if this is after the end of the study.
   - PPI contributors are not always interested or have capacity to stay involved (get out clause, opt out (not opt in)).

4. **Impact of PPI contribution on study**
   PPI contributors are interested in what impact they have had. Were their comments useful, or helpful? Did you make any changes?

> "Just a thank you"

> "Wonder if the study was funded and if not, why not"

> "Wonder how the study is going"

> "Were my comments useful, were they used?"

What sort of feedback do I give?

4 Impact of PPI contribution on study

Did the comments lead to changes or not?

Changes

Let PPI contributors know whether you made changes and if so what they were.

- Changes to documents.
- Changes to the design of the study (i.e. recruitment strategy).
- Changed direction of the study due to a conversation.
- Change the process of research.
- Changed ethics section.
- Changed way of thinking.

No Changes

Let PPI contributors know why you did not use their comments.

- Researchers have a duty of care to give negative feedback in a sensitive way. Sensitive to vulnerabilities and circumstances of PPI contributors. Have a conversation about whether PPI contributors want to hear if comments were not used.
- PPI lead can help to act as conduit/mediator for feedback.
- Provide reasons (word limit, outside scope of study design, governance issues, ethical implications, doesn't quite fit with current research evidence in this area).
- Sometimes PPI contributors provide comments which do not agree with other PPI contributors and might contradict each other, the researcher has to decide which ones to use and explain why.
- Comments validated your initial ideas.

- Make general comments if replying to a group but if possible detail individual/specific changes to give feedback.

How to give feedback

Agree the route through which feedback will be given – email, paper, text, phone call, face to face and record in an agreement.

Ideally feedback should be given face to face as dialogue is the best feedback.

Where to meet for feedback?- ask PPI contributors.

Or virtual feedback via project website portal?

Keep a written copy of feedback so that it can be referred to later on as evidence of impact.

Recommendations

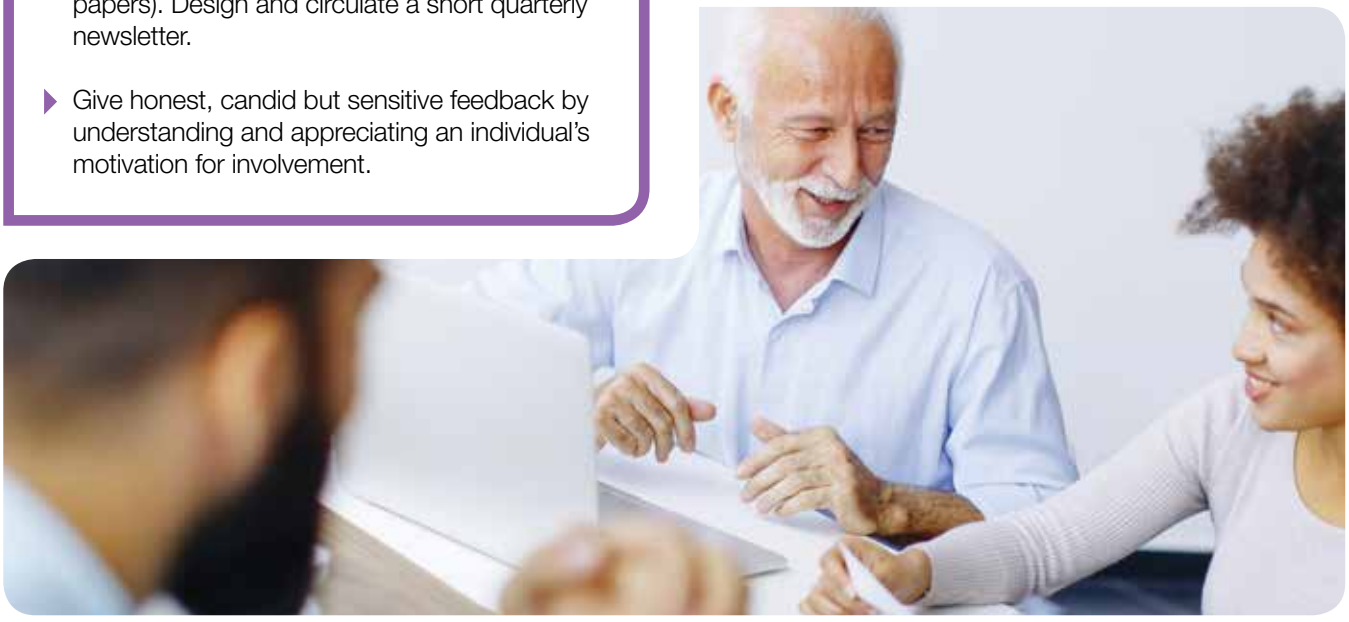
- **Always put PPI** on any meeting **agenda** (update/feedback to PPI contributors, opportunity for PPI).
- Feedback in Steering Committees – detail PPI contributor's **comments in minutes** and speak face to face or on the phone afterwards.
- Make time to have **de-briefing chats** after meetings.
- Make time to have time to **reflect** after each research event.
- **Tone of feedback:** Face to face is best, dialogue, honest, frank and timely.
- Have **time, funding and dedicated team members** to carry out PPI/feedback.

In summary for researchers:

- Discuss expectations at the start of the project.
- Prioritise PPI feedback by building it into your GANTT chart and your budget.
- Identify someone on the research team who is responsible for PPI during the study and who can provide feedback.
- Allocate resources (time and money) within the study budget to make sure general feedback routinely happens for everyone and for individual feedback if requested.
- Make PPI a rolling agenda item for meetings.
- For general feedback, consider circulating existing routine documents available to you (Ethics approval letter, final documents with track changes, minutes of meetings, final papers). Design and circulate a short quarterly newsletter.
- Give honest, candid but sensitive feedback by understanding and appreciating an individual's motivation for involvement.

In summary for PPI contributors: for discussion together

- At the beginning of a project: try to meet with us (researchers) to discuss who will feedback to you, when, what and how. Be honest with us about your motivations for doing PPI so that feedback can be tailored to you as much as possible.
- If you have not heard from us (researchers) within an allotted timescale, don't be shy in politely reminding us.
- Remember that research is a complex process with many opinions being sought and given, and decisions taken on a near continual basis. Do not be disheartened if we (researchers) cannot take on your comments but aim to find out why and if there is an opportunity to learn for the future.



Resources and tips for Researchers

After meeting with your PPI contributors to discuss their feedback needs, consider drafting an agreement to document what was agreed.

An example joint researcher/PPI contributor agreement can be found in Cancer Research's PPI toolkit support pages: http://www.cancerresearchuk.org/funding-for-researchers/patient-and-public-involvement-ppi-toolkit-for-researchers

The 'Starting Out' Guidance for PPI contributors on INVOLVE website has a section on feedback; http://www.invo.org.uk/wp-content/uploads/2018/01/Induction-public-v3.pdf

Possible Points of Contact for Feedback:

Make use of existing documents

- Forward ethics committee comments
- Forward funders reasons why the study was not funded
- Share GANTT chart, timeframe of project, key milestones when they will receive feedback
- Send copies of draft and final published papers
- If possible send before and after copies of documents, (ie. track changes in WORD)

Set up new documents and alerts

- Consider sending out short regular newsletters for PPI contributors and participants. Set up a template and repopulate each time
- Put diary reminders in your email calendar to remind you to contact PPI contributors on a regular basis

Examples of Actual Feedback

Comments can be quite varied, some detailed and others not, depending on what has been changed and how many comments were given. Remember to pay attention to individual needs, it is important to establish relationships to have an understanding of what sort of feedback is required.

> **An example acknowledgment**
> Thank you for taking the time to look at, and submit, your comments to me on XX. I am extremely grateful. I'm still awaiting comments from other people and will then be a position to decide which I can take on board. Once I have all the information I will be in touch (approx. timeline) to show (explain) my decisions

> **Useful but not detailed**
> The PPI group have commented on Patient Information Sheets, Consent forms and Patient Interview Schedules. Their comments have been useful and have instigated changes in the documents *(Feedback - Study documents January 2017)*

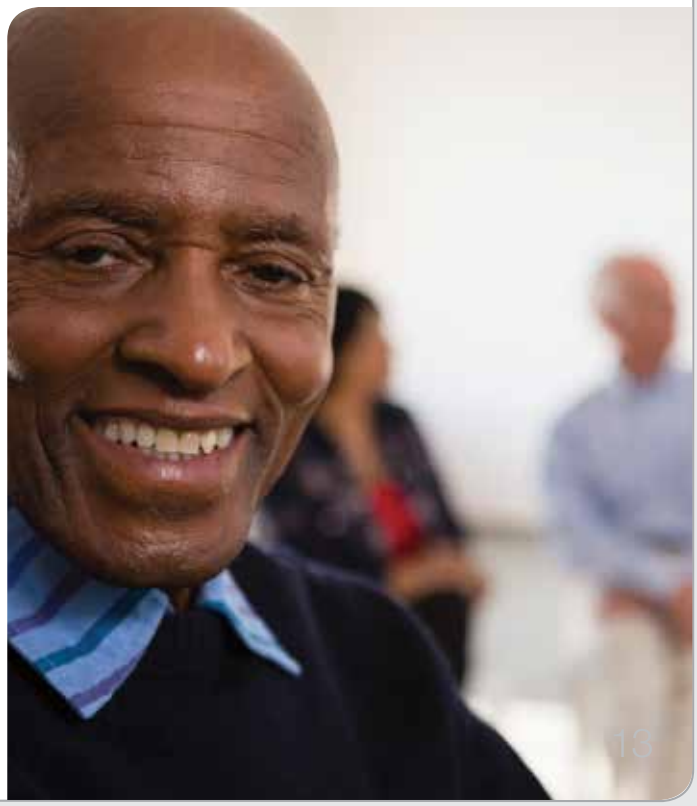
> **Appreciation**
> I'm overwhelmed by the response and really grateful for the detail in which you have read and considered the information. I'm very thankful for your help and for the time you have given to this. I can be a lot more confident with the information I can provide – thank you! *(Feedback - Patient Information February 2017)*

Useful Comments
I will take heed of all the comments when moving forward in my proposal development, ensuring that I clearly explain specialist terminology and process. *(Feedback - Study Summary February/March 2017)*

Detailed - changes
The feedback was very useful in improving the clarity and delivery of the research information to potential participants. We edited the Participant Information Sheet according to some of the suggestions receives from PPI. We added a diagram to describe more clearly what people will need to do if they take part in the study. We changed the technical words with more common explanations and we offered participants the option to come to the study visits accompanied by a friend or relative. We also let people know that we will accommodate the study appointments based on their availability and that there is the option of being scheduled on Saturdays (especially for people who are working during the week). We also simplified the study leaflet in such a way that it is easier to read for a person with xxxx: we added the information in bullet points and made it more presentable.
(Feedback - design of research March 2017)

Detailed - changes
The reviewers felt that the study information sheets were verbose and rather long, and one reviewer suggested that the sheet could be split into two. They also requested for clarification on confidentiality, specifically in regard to information that would and would not be provided to a participant's GP. This study involves an acute [xxx] during an [health procedure], and the previous description of this manipulation was rather stark and 'scary.' We found these suggestions very helpful, and we have revised the materials to incorporate the main three points (i.e., confidentiality, length, description of [procedure]). While we are unable to split the information sheet into two components for ethical reasons, we denote 'Part I' & 'Part II,' where potential participants should get a sense of whether they would like to participate after reading Part I
(Feedback - Ethics Application March 2017)

Detailed - changes
The question about the potential for a conflict of interests on the advisory panel also enabled us to reflect on the role of the panel and how we communicate its purpose more widely. Having that feedback has therefore shown that it is important to keep coming back to what is most important to people who are affected by this research and going through the PPI process hopefully gives us a stronger hand with which to press these points with the wider project team
(Feedback - Research idea May 2017)



Possible PPI Feedback Form – to help prompt feedback

This form can be adapted by researchers or PPI group leads to use freely. However, we would like to keep track of the impact it has had so please let us know if you intend to use it by emailing e.j.mathie@herts.ac.uk

What stage of your research did you ask for PPI input? (i.e. lay summary, patient information sheet)

- Initial design
- Advice on recruitment
- Dissemination
- Review of funding application
- Data collection/interviewing
- Review of application to ethics
- Data analysis

Other

How useful were the PPI comments? Very, Fairly, Not OR Scale 1-10

Has the review from xxxx informed and/or influenced the development of your research application/ideas?	**Please tick one response:** Yes / No
If you answered YES to Qx, please detail how comments from the *PPI group* informed and /or influenced your research or your way of thinking.	**Please give details of specific changes made to your study/research documents:**
If you answered NO to Qx, please detail why you think the comments received from the PPI group haven't informed and /or influenced your research.	**Please outline the reasons why you didn't make any changes to your study/research documents:**

Suggested further questions; What is the next stage of your project?

Date you plan to submit proposal/ethics application (please specify):(remember to feedback)

Date you expect to hear whether successful/not successful: (remember to feedback)

Please return to individual PPI contributor or via PPI lead by

Constructive Feedback:

- Provide support, extra training, examples of previous/helpful PPI input for PPI contributor, so they can learn and know they are on the right track.
- If you can't provide the support or training seek advice from PPI leads.
- Pre-empt need for negative feedback by keeping in touch with PPI contributor, to make sure they know what researchers want.

Seek training on negative feedback.

Examples of how to deliver/phrase feedback. Some examples:

> This is a really good idea, in an ideal world that is exactly how we would change this protocol, however there are all of these governance or logistical or financial issues *(Suggestion from interview)*

> At this stage we don't know what changes will be made but we will let you know by [date] and how it's been included *(Suggestion from interview)*

Further Details about the study:

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http://www.clahrc-eoe.nihr.ac.uk/2016/05/impact-patient-public-involvement-ppi-completing-feedback-cycle/

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