**Charities Research Involvement Group**

**Dealing with requests from researchers who are seeking PPI contributors to get involved in their research**

**Introduction**

Members of the [Charities Research Involvement Group](http://www.slginvolvement.org.uk) are often approached by researchers who want to find PPI contributors[[1]](#footnote-1) to actively involve[[2]](#footnote-2) in their work. Many of our members ask researchers to complete an application form to help them to decide whether to share this request with their networks, and if so what information to share.

The Charities Research Involvement Group has produced this guidance to help our members to produce or improve such a form. We’re making it more widely available so that other charities can use it if they wish. The suggested list of questions for researchers is intended to be as comprehensive as possible – you may wish to develop a shorter list of questions if you are responding to requests from researchers who are only seeking help with a specific activity, such as writing a plain English summary.

This guidance has 4 sections:

1. The topics to cover in the notes for researchers that will accompany an application form
2. Priority questions – these are questions the working group members and PPI contributors felt should be included
3. Optional additional questions
4. Example forms from two member charities

Note that this guidance aims to help you to respond to requests from researchers who want to actively involve people in their research, NOT researchers who are seeking to recruit participants for a clinical study.

Please use and adapt this guidance in any way you wish, but please acknowledge the Charities Research Involvement Group as the source. Note also that some members are using online forms to collect information, whilst others are collecting it using a Word document.

This guidance was produced by:

* Collecting and reviewing application forms and guidance notes currently used by CRIG members
* Asking researchers involved in the UK Clinical Research Collaborations’ PPI Group about what they would want to know about charities and their networks of PPI contributors
* Producing draft guidance and seeking views of PPI contributors
* Revising the guidance and seeking views of researchers

**Thanks**

Thanks to the members of the working group who produced this guidance:

* Heather Bagley, UK Clinical Research Collaboration PPI Group
* Heather Cooper, British Heart Foundation
* Lucy Culshaw, Bliss
* Bec Hanley, CRIG Facilitator
* Laura Lucas, Prostate Cancer UK
* Caroline Schmutz, JDRF

Thanks also to the CRIG members who shared the questions they ask researchers and the guidance they issue about this. Finally, thanks to the PPI contributors and researchers who made helpful comments about these questions.

**Tell us what you think**

If you use this guidance please tell us what you think of it – especially if you feel any of the questions need to be changed or deleted, and/or whether new questions need to be added.

Charities Research Involvement Group

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[www.slginvolvement.org.uk](http://www.slginvolvement.org.uk)

1. **Topics to cover in the notes for researchers that will accompany an application form**

We suggest you include some guidance notes alongside the application form to inform researchers about your organisation and the people you support. This should cover the following areas:

* Some basic information about your organisation, for example:
  + Who you support
  + What research topics you’re willing to support (e.g. research must fit with the charity’s values)
  + Any research you don’t support (e.g. projects by school students, undergraduate projects, service evaluations)
  + Your geographical reach
* How you define involvement (as distinct from participation), and how you can help if they are seeking help with recruitment
* Information about your PPI network (or the people who will be sent the PPI opportunity), for example:
  + Numbers involved
  + Range of conditions/experiences covered
  + Any information you have about the diversity of the people who will be sent the opportunity
* Information about any specific needs of the people you support, for example:
  + Is travelling difficult?
  + Is it better to hold any meetings (face-to face or virtual) in school hours or outside of working hours?
* How the request will be dealt with. This should include information about:
* Who will review the application
* Any criteria used to decide whether to publicise requests (e.g. will you publicise requests from industry, from market researchers or undergraduate students?)
* How the opportunity will be publicised (e.g. in a regular bulletin, on your website etc.)
* How long it will take to deal with the request
* What you ask from researchers, for example:
  + That the form is completed in plain English (for guidance see [this site](https://www.invo.org.uk/makeitclear/))
  + That they share results of the research with you and with people who get involved, once they have been published
  + That they accommodate the needs of PPI contributors
* Any terms and conditions. This might include:
  + Information about whether you charge to publicise opportunities
  + That you are not responsible for anything that happens in the research
  + That by publicising the research you are not endorsing it
  + That your logo should not be used without permission, and that it should be the logo you provide
  + How you comply with GDPR
* Who to contact for more information or advice (especially if the researcher is new to PPI and not yet ready to complete the form)
* Where to go for further guidance about PPI, e.g.:
* Any PPI guidance your organisation has produced
* [The INVOLVE website](https://www.invo.org.uk/)
* The national standards for [public involvement](https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/)

1. **Priority questions for researchers**

These are the questions that working group members and PPI contributors felt should be included in an application form. But please don’t ask particular questions if you know that they aren’t necessary for your organisation.

**1. Contact details****for Principal Investigator or primary contact**

1.1 Title

1.2 First Name

1.3 Last name

1.4 Email address

1.5 Tick this box to confirm that you are happy for us to share this email address with network members who might want to get in touch with you about this opportunity

1.6 Host organisation or place of work

* + 1. Phone number[[3]](#footnote-3)

**2. Information about the study**

2.1 Project title

2.2 Plain English title

2.3 Please provide a summary of the project **in plain English**, including background, aims, and methods. (200 - 1000 words) For guidance on writing research summaries in plain English, see [this website](https://www.invo.org.uk/makeitclear/).

2.4 How will the study benefit people with/people affected by…? (Max 200 words)

2.5 At what stage is your project? (Please tick any that apply)

Planning stage – funding has not been sought

Project is finalised but funding is not in place yet

Funding is in place (please state funder)

Project is underway

Project is at the final stages

2.6 If ethics approval has been given, please attach the participant information sheet

1. **Deadline for response** **from PPI contributors**
   1. When is the deadline for interested people to get in touch with you?
2. **Role available**
   1. What kind of activities would you like people to be involved in? (followed by tick box list[[4]](#footnote-4)– tick all that apply and include a box and free text for ‘other’)
   2. Do you have a role description? If so please attach.
3. **Time commitment required and when the activity will take place**
   1. What time commitment do you require from people who get involved? This includes how long they will be involved for this project/study (e.g. number of weeks or months) and how often (e.g. number of meetings per year)

5.2 Will the activities take place during working hours, or evenings, or weekends?

5.3 Roughly how long will each activity last? (For example, will meetings last 2 hours or 4 hours?)

5.4 When will the involvement start?

5.5 Please specify any key dates that people should know about, such as meeting dates/deadline dates

1. **Location of involvement**

6.1 Can the activity be carried out from home, or will it require travel?

6.2 If it requires travel, please specify the location

1. **Expenses and payment**

7.1 If the activity requires travel, do you have a budget to reimburse travel costs and other expenses (e.g. childcare or carer costs, accommodation etc.)? Our volunteers should not be out of pocket as a result of their involvement

7.2 Will you be offering payment for involvement?

If yes, please provide details. (See the [guidance from INVOLVE](https://www.invo.org.uk/posttypepublication/involve-policy-on-payments-and-expenses-for-members-of-the-public-including-involve-group-members-february-2016/) if offering payment)

7.3 Will you be offering other incentives for involvement (e.g. vouchers)?

If yes, please provide details

**8. Skills and experience required**

8.1 Are you looking for people with particular characteristics or experience? (e.g. someone with experience of a particular condition/carers/people with previous experience of being involved in PPI)

8.2 Are there any skills that are essential for the role?

If yes, please give details below

**9. Number of people sought**

9.1 How many people are you looking to involve? Please specify for each activity/role

**10. Access**

10.1 How will you make sure that the activity is accessible for the PPI contributors you would like to involve? (For example…[[5]](#footnote-5))

**11. Feedback plans - to and from the people you involve**

11.1 How will you provide feedback to the people who have contributed to your project? (E.g. sharing the results of the research in plain English, sharing the impact of the involvement undertaken, and/or acknowledging the people involved, as a group or individually, in any reports you produce)[[6]](#footnote-6)

11.2 How will you encourage the people you involve to provide their own feedback, so that you can listen to their experience of being involved in your project?

1. **Optional additional questions**

In our review we found these additional questions. The working group members and PPI contributors did not feel they were vital, but you may wish to consider including them if they are relevant for your organisation.

**What can people expect if they get involved?**

What support or information will be offered to people getting involved?

Will there be any training or induction offered?

Will you book people’s travel if required?

**PPI plans and practicalities**

What is your PPI plan for the project?

Have you used PPI in the project to date?

What do you hope to achieve by involving PPI contributors?

If you are looking to involve a limited number of PPI contributors and you are over-subscribed, how will you select people (e.g. at random, by interview, etc.)?

Do you intend to name a PPI contributor as a co-applicant for funding? (If so complete separate section)

Will you need people to sign a confidentiality agreement or no-disclosure agreement?

**Communications**

How will you let PPI contributors know if they have been selected?

Will there be any other (future) PPI opportunities in the project?

Do you have a plan to disseminate results to people affected by….?

Will your findings be open access?

Are there any conflicts of interest that would lead to the exclusion of a potential PPI contributor?

**Relevance to the organisation**

How does the research relate to the charity's research strategy[[7]](#footnote-7)?

How does your project relate to the …. James Lind Alliance Priority Setting Partnership[[8]](#footnote-8)?

How did you find out about the charity's offer to support research?

1. **Example forms**

We’ve included two forms as examples. **Asthma UK** uses an online application form. The link is here: <https://www.asthma.org.uk/research/researchers/involving-people-with-asthma/request-for-research-involvement/> and their guidance notes to accompany the form are here: <https://www.asthma.org.uk/research/for-researchers/involve-people-with-asthma/>

**British Heart Foundation** uses a Word document. This is over the page.

**Promoting an**

**Involvement Opportunity**

Do you have an engagement opportunity that you’d like us to promote to our network of heart patients? If so, please complete this form and tell us how you plan to engage patients and why this will be beneficial to your project.

Please answer all of the questions as fully as possible.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Name** |  | | | |
| **Organisation** |  | | | |
| **Email Address** |  | **Telephone Number** | |  |
|  | | | | |
| **PROJECT OVERVIEW** | | | | |
| **Name of Project** |  | | | |
| **Please tell us a little bit about your project including the project aims.** | | | | |
|  | | | | |
| **Does the project require ethics approval?**  If yes, please attach a copy of the ethics approval documents | | | **Yes / No** | |
| **What do you want to achieve by involving heart patients? What are your key questions?** | | | | |
|  | | | | |
| **What are your timescales for the project?** Please note it can take up to four weeks to assess and advertise an opportunity. | | | | |
|  | | | | |
|  | | | | |
| **TYPE OF INVOLVEMENT** | | | | |
| **What activities will participants be involved in?** Please tick all that apply | | | | |
| **Attending a focus group (one-off)**  **Joining an ongoing panel**  **Joining a committee / steering group**  **PPI representative in research**  **Research participant**  **Completing a questionnaire** (please provide a copy of the questionnaire)  **Reviewing and commenting on resources**  **Providing an account of their experiences**  **Attending an event**  **Other – please expand in the space below** | | | | |
|  | | | | |
| **ELIGIBILITY CRITERIA** | | | | |
| **What key criteria should those taking on this role meet, including any specific experiences?**  **How many people are you looking to involve?** | | | | |
|  | | | | |
| **What time commitment do you require from participants?** This includes how long they will be involved (e.g. number of weeks) and how often (e.g. number of meetings per year)  **Do you have any information regarding location, dates and time** (if applicable)**?** | | | | |
|  | | | | |
|  | | | | |
| **SUPPORT AND INFORMATION** | | | | |
| **Will you be paying expenses and / or booking travel in advance if required?**  **Will you be offering any payment or incentive?** | | | | |
|  | | | | |
| **How, and in what time frame, will you respond to let people know whether they have been selected to be involved in this opportunity?** | | | | |
|  | | | | |
| **What information will you provide to those who would like to know more about the project and possibly your organisation?** Please attach any patient information sheet or similar documents. | | | | |
|  | | | | |
| The following question applies to those who would like to involve participants in an ongoing capacity. **What support and / or training will you be providing to those that get involved?** | | | | |
|  | | | | |
| **How will you be feeding back the outcomes of the project to BHF and project participants, including how their involvement has made a difference?** | | | | |
|  | | | | |

**Please tick the box if you are happy for participants to contact you directly if they have any questions or would like to express an interest in being involved**

**Thank you for completing this form.**

Please note that by submitting this form you acknowledge that BHF will be acting in a signposting capacity only. Therefore, anyone who chooses to get involved following our advertisement of this project will not be representing the views of BHF but their own experiences.

We’ll review your form as soon as possible and will let you know if we are able to promote it to our network.

In the meantime, if you have any questions or would like any guidance on completing the form please do not hesitate to get in touch.

**Email:** [heartvoices@bhf.org.uk](mailto:heartvoices@bhf.org.uk)

**Phone:** 0207 554 0426

**Post:** Heart Voices - Patient Support and Engagement Team

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1. We’ve used the term ‘PPI contributors’ to describe the people our members seek to support. We recognise that different terms to describe these people – e.g. patients, carers, service users, people affected by…. etc. By using the term ‘PPI contributors’ we are seeking to distinguish this group from people such as clinicians or others who may have a professional interest in our work [↑](#footnote-ref-1)
2. We are using INVOLVE’s definition of involvement – see <https://www.invo.org.uk/frequently-asked-questions/> [↑](#footnote-ref-2)
3. For the charity’s use only. We will not share your phone number unless you ask us to do so. [↑](#footnote-ref-3)
4. Note: there are example lists in the two forms included at the end of this guidance [↑](#footnote-ref-4)
5. Add examples that are most relevant for the people you involve – e.g. if your activity is face-to-face, how accessible is the venue for disabled people? Will you fund carers to attend any events with the person they care for? If people need rest breaks, have you allowed for these in your planning? Will funds be available for an interpreter/translator, if people need this? [↑](#footnote-ref-5)
6. You could use tick boxes here [↑](#footnote-ref-6)
7. Add a link to your research strategy [↑](#footnote-ref-7)
8. Add a link to a list of the relevant JLA priorities [↑](#footnote-ref-8)