

## Patient and Public Involvement (PPI) Services for Academia and NHS

### What is PPI?

Patient and Public Involvement, or PPI, is the inclusion of patients, carers, and the public in research – not as people being researched on, but as equal partners providing their experiences, insights and skills. There is increasing evidence of the significant impact that involving people can have on research. Public involvement in your research can improve your chances of funding success, enhance study design and recruitment, and ensure you are conducting relevant research that has an impact. Involving patients can help pinpoint what is important to people with a particular bowel condition, and provide understanding about what it feels like to have a serious bowel condition or to be part of the care support system for those living with such conditions.

### Why Bowel Research UK?

- We coordinate patient and public involvement activities through our **People and Research Together (PaRT) network**, made up of over 1,000 bowel cancer and bowel disease patients and carers who have expressed interest in helping researchers like you.
- Bowel Research UK has a **track record** of successfully involving patients in research. We have been entrusted with leading on PPI for AMELIE (Anchored Muscle cELls for Incontinence), a 5-year collaborative research project funded by the European Union Framework Programme.
- Our Patient and Public Involvement Manager Sam Alexandra Rose is a three-time cancer survivor and patient advocate with a **deep understanding** of what is important to patients and how to engage with them.

### Our PPI Services

Our PPI services include:

- [Advertising involvement opportunities](#)
- [Co-ordinating focus groups](#)
- [Serving as a co-applicant](#)
- [Other ongoing PPI support](#)
- [General consultation](#)
- [Sitting on PhD student interview panels](#)
- [Website creation and management for individual studies](#)
- [Social media management for individual studies](#)
- [Other ad-hoc support](#)

Read more about each service below (click on the link to go straight to the service in this document) and see the table on page three for associated fees.

### Advertising Opportunities

We are always happy to advertise focus groups, surveys or other activities on social media or in the PaRT newsletter free of charge if there will be no further PPI involvement from ourselves.

## Focus Groups

We can recruit and co-ordinate attendees; arrange a date and time for the focus group meeting; attend and record the meeting; supply the recording, transcript, and minutes; and disseminate agendas, outcome and results as appropriate. If required, we can provide co-ordination and consultation in an additional preparation meeting where the PPI Manager provides support such as advice on facilitation, guidance in structuring session and choosing questions, or other bespoke assistance. The timeline from initial conversation to conducting the focus group is typically six to eight weeks.

## Serving as a Co-applicant

If you are applying for funding at another institution, PPI Manager Sam Alexandra Rose could be a co-applicant on your research application. Sam has personal experience of bowel cancer, duodenal cancer, womb cancer and constitutional mismatch repair deficiency (CMMRD). She can therefore provide her own patient perspective and experience, as well as PPI expertise and access to others with lived experience in the PaRT network.

The specifics of the co-applicant role will depend on the needs of your research, but may include:

- Reviewing the plain language summary of the study and editing unnecessary jargon
- Helping to set the agenda and chair meetings such as Patient Advisory Group meetings
- Producing patient-facing materials such as leaflets or posters
- Providing the patient perspective in trial management groups
- Recruiting or interviewing patients for a study
- Distributing surveys or disseminating findings to the general public
- Helping to create a plan and budget of PPIE activities across the lifecycle of the research

The cost will depend on how many days per month you expect the role to require. See the table below for example costings, based on full-time equivalent (FTE) depending on the amount of time you require per month (one day per month minimum).

% FTE	Days Per Month	Annual Cost	Day Rate
3.33%	1	£2,100	£175
5%	1.5	£3,150	
6.66%	2	£4,200	
10%	3	£6,300	
15%	4.5	£9,450	
20%	6	£12,600	

## Other Ongoing Support

Similarly to above, we can provide ongoing services as PPI lead, including putting together Patient Advisory Groups and organising regular meetings and project input such as document reviewing. This is charged at the rates outlined in the above table.

## Consultation

If you are not currently engaging patients in your research, are just getting started, or would like to know how you can improve your PPI, we can support you. We can help you to understand and

implement PPI and begin embedding patient engagement within your organisation. We can also offer consultation for specific activities, such as co-ordinating a focus group.

#### Sitting on PhD student interview panels

We can attend interviews for prospective PhD students for studies. Our PPI Manager can sit on the interview panel, as PPI-related questions and provide feedback to ensure new hires understand the value of PPI in research and is aligned with the mission and values of the charity and the study.

#### Website creation and management for individual studies

With the help of third-party agencies, we can create and manage small websites for individual studies to assist with dissemination of research outcomes and updates.

#### Social media management for individual studies

We can create social media channels and regularly update them with news and information about your study, including PPI opportunities and general public engagement to highlight your work.

#### Other Ad-hoc PPI Support

We can provide other ad-hoc support for the duration of your study. Activities may include:

- Reviewing documentation
- Attending Patient Advisory Group (PAG) meetings, steering groups or other events
- Disseminating research

#### Fees

<b>Fees</b>	
<b>Standard Rates</b>	
<b>Hourly Rate</b>	£95
<b>Day Rate (Excluding co-applicant or ongoing services – see table on page two)</b>	£650
<b>Services</b>	
<b>Focus Group Co-ordination</b>	Charged at day rate as required (1-2 days anticipated)
<b>Ad-hoc Project Support</b>	Charged at day rate as required
<b>Serving as a Co-applicant or providing ongoing project support (e.g. as PPI lead)</b>	£175 per day (Based on FTE equivalent, see table on page two. One day per month minimum.)
<b>Sitting on PhD student interview panels</b>	Charged at hourly rate as required (2 hours anticipated)
<b>Website creation</b>	Please enquire
<b>Advertising only (social media and/or newsletter)</b>	Free

We will be happy to discuss your project and provide a quote for your specific needs.

## Exceptions and Exclusions

**Pre-funding:** We may work with academia free of charge if the project is pre-funding, providing that Bowel Research UK will be retained to give paid support if and when funding has been achieved. For example, we may be able to co-ordinate a focus group for free for a study where the PPI Manager at Bowel Research UK is a co-applicant.

**Conflict of interest:** We are unable to provide PPI support beyond advertising for anyone who is currently in the process of applying for funding with Bowel Research UK as this is a conflict of interest. Similarly, the PPI Manager cannot act as a co-applicant on research applications submitted to Bowel Research UK. However, outside of the grant application process, we are able to provide support for any study regardless of whether funding is provided by us or another body.

**Remuneration for participants:** Any reimbursement to patients, experts by lived experience or members of the public is separate from our fees and the responsibility of the researcher. We advise researchers to follow NIHR guidelines on remuneration for patients and the public. The PPI Manager's travel expenses for any in-person meetings would also be additional and reimbursed to them personally.

## Get In Touch

For more information about any of our PPI services, email [sam@bowelresearchuk.org](mailto:sam@bowelresearchuk.org).