# Internal Scoping Exercise on Patient and Public Involvement

## May - July 2022

Report compiled by Kim Townsend, Public Engagement Consultant

# 1. Research questions and methodology

This internal scoping exercise has taken place over three months, between May and July 2022, and has aimed to gather insight into the current processes and structures at the University of Bath that support researchers to take a PPI and participatory approach to their work, as well as to investigate the needs barriers, and enablers for those using participatory methods.

The following research questions were explored as part of this exercise:

- RQ 1: Which staff (by faculty/school, job family, grade etc.) are undertaking PPI and PR?
- RQ 2: Why are staff choosing to do PPI and PR?
- RQ 3: What are the current enablers that are supporting PPI and PR at Bath? (Support staff, grants, training, mentoring, community/university networking)
- RQ 4: What external support for PPI and PR are staff accessing?
- RQ 5: What barriers are there to doing a PPI/ PR project?
- RQ 6: What have staff found challenging about PPI /PR?
- RQ 5: What types of community partners are staff currently working with? (local, national, charities, community groups, public sector)
- RQ 6: What types of projects are community groups doing with academics at Bath (subject areas, themes, knowledge and expertise)
- RQ 7: What do staff need to do more/better PPI and PR?

For funding reasons, participatory research and PPI will be considered separately over two reports. This report focuses on PPI at the University of Bath, but has been informed by the entire process investigating both participatory research and PPI.

This report also aims to provide an understanding of the current landscape for those undertaking PPI from EPSRC-aligned disciplines.

The following methods were used to answer these questions

| Method | Details |
|---|---|
| An online survey of researchers using participatory methods at University of Bath | Survey was distributed via<br>• Existing contacts of the PEU<br>• The PEU e-newsletter<br>• The PEU blog<br>• The PEU Twitter account<br>• Departmental email to the members of every department in the University<br>• Email to Research Coordinators in every department<br>• The staff homepage<br>• The University of Bath staff Twitter account<br>• Research Centres with a participatory ethos, particularly those in EPSRC-aligned disciplines. |

| | |
|---|---|
| | - Direct email to all academics who have declared themselves as using participatory methods on the University Research Portal<br>(n = 30 in total, which includes researchers doing both participatory research, and PPI. The participatory research respondents will be considered in a separate report, and so for the purposes of this report n = 13, which is the number of those who said they had done PPI) |
| Semi-structured interviews | - N = 9 interviews in total across PPI and PR<br>- N = 5 interviews with those doing PPI across a range of departments and career level, with a particular focus on those from EPSRC aligned disciplines. |
| Requests for information over email | Every department was contacted via email to their research coordinators to ask for information about their processes and structures that support researchers using participatory methods (n= 3 responses). Given the low number of responses, and the short time-frame for this work, gaps in knowledge were filled using desk-based research and by asking questions in the semi-structured interviews. |
| Desk-based research | Desk based research was carried out to map existing processes and structures that support those taking a participatory approach to their work. A list of academics who have declared that they are using participatory methods on the University Research Portal has been created. |

# 3. Definitions of participatory research and patient and public involvement

## 3.1 How ‘participatory research’ is defined for the purposes of this project

Participatory research is often used as an umbrella term and encompasses a number of different practices. For this scoping exercise, a broad definition of the term was agreed - an approach to research where researchers and people outside academia co-produce knowledge together.

The participants could be patients or service-users in a health or medical context, which is commonly referred to in academia as patient and public involvement (PPI), and so the decision was made to use both terms – participatory research and PPI.

Keeping the definition broad has enabled a wider view of the current landscape of participatory practice at the University of Bath, and has allowed for investigation into what meanings and definitions academics are choosing for their work.

### 3.1.1 Distinctions and overlaps between the terms participatory research and patient and public involvement

As mentioned in Section 2 of this report, for funding reasons PPI and participatory research are being considered separately in two different reports. As such, survey respondents were asked whether they were doing PPI or participatory research. This question threw up discussion and some confusion in the survey answers about definitions of the two, ways in which they overlapped, and what the project team meant by the terms.

> *"I couldn't select both for option 4 but I tried to. PPI and participatory research are different terms for the same thing, perhaps PPI is viewed as more policy minded sometimes but to be honest it shouldn't be."*
>
> *"Participatory research. Patient and public involvement - I'm not really sure what the differences are for these two terms to be able to answer the question."*

In a semi-structured interview, one academic from an EPSRC-aligned discipline said the distinctions between the two from an engineering and physical sciences point of view depend on who the end-user of the innovation would be.

> *"We have to think about who is going to use whatever we are developing and that might not be the patients themselves, it might be the clinician, it might be the healthcare provider. So it's not necessarily just PPI, it's also participatory research, and co-design".*

## 3.2 What the term 'patient and public involvement' means to researchers at University of Bath

In order to explore what meaning academics at the University of Bath gave to the term 'patient and public involvement' the following question was asked in the online survey: "We recognise that the term patient and public involvement can mean different things to different people. Please tell us in your own words how you define patient and public involvement".

Key words from each response have been used to create Figure 1.

**Figure 1: A word cloud showing key words from the definitions of patient and public involvement given by respondents to the survey**

A range of levels of participation were present in researcher's definitions of PPI. Several talked about gaining the input of participants, holding an event where the research can be discussed with patients/public, or getting feedback on their research from patients/public. A deeper level of participation was present in the answers of those who talked about working with people, working in partnership, and involving those whom the research is about. Two responses talked about co-production and co-researchers.

Some of the responses detailed the stages of the project that participants would be involved in, and specified that they would be involved throughout the project, from the design to the dissemination. The idea that participants would be 'shaping research' was popular.

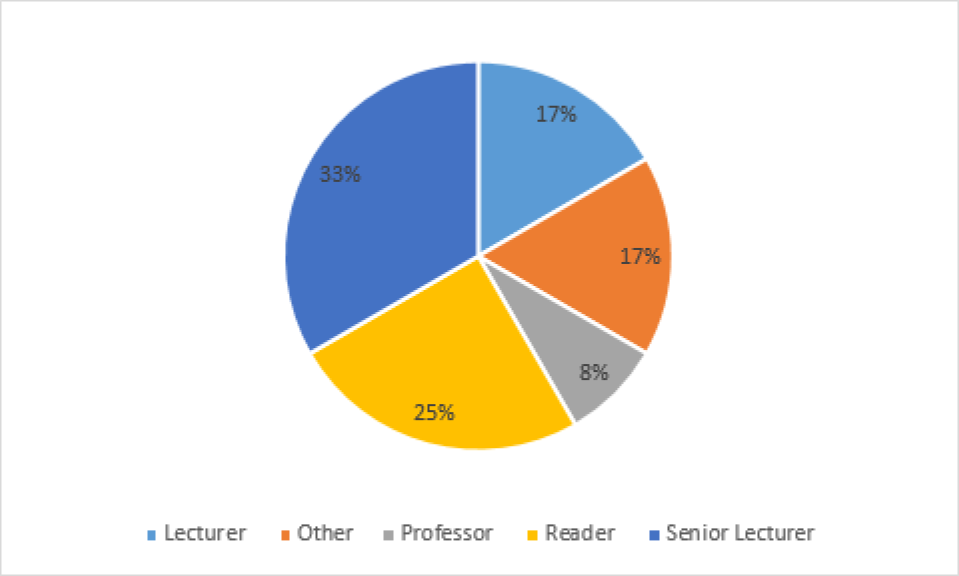
Those who are involved in the research project were frequently described as the 'public' and 'patients'. The terms 'lived-experience', 'those affected by the research', and 'personal experience' were also popular.

# 4. Which staff are undertaking PPI?

## 4.1 Survey responses by job title

The majority of survey responses were from senior academics – Professors, Readers, and Senior Lecturers (66%). 17% were Lecturers, and those who selected 'other' were Doctoral Students, and Research Associate/Clinicians.

**Figure 2: Survey responses by job title**



## 4.2 Survey responses by type of contract

76% of those who answered the survey are on a permanent contract, as opposed to a fixed term contract, or 'other' (for example PhD students)

## 4.3 Survey responses by department and faculty

The majority of responses were from the Faculty of Humanities and Social Sciences. The breakdown of responses per faculty was:

- Faculty of Humanities and Social Sciences – 62%
- Faculty of Science – 23%
- Faculty of Engineering and Design – 0%
- School of Management – 0%

Two of the respondents didn't state which faculty or department they were in.

This heavy weighting towards the Faculty of Humanities and Social Sciences has been echoed in desk-based research, and in the mapping exercise which formed part of this project (see appendix). On the University Research Directory there are more people who say they are doing PPI in the Faculty of Humanities and Social Sciences than any other faculty.

Respondents were also asked which department they were from. Table 1 shows the breakdown of survey responses at department level.

**Table 1: Survey responses by department**

| Department | Number of responses |
|---|---|
| Health | 1 |
| Pharmacy & Pharmacology | 3 |
| POLIS | 1 |
| Psychology | 6 |
| **Grand Total** | **11** |

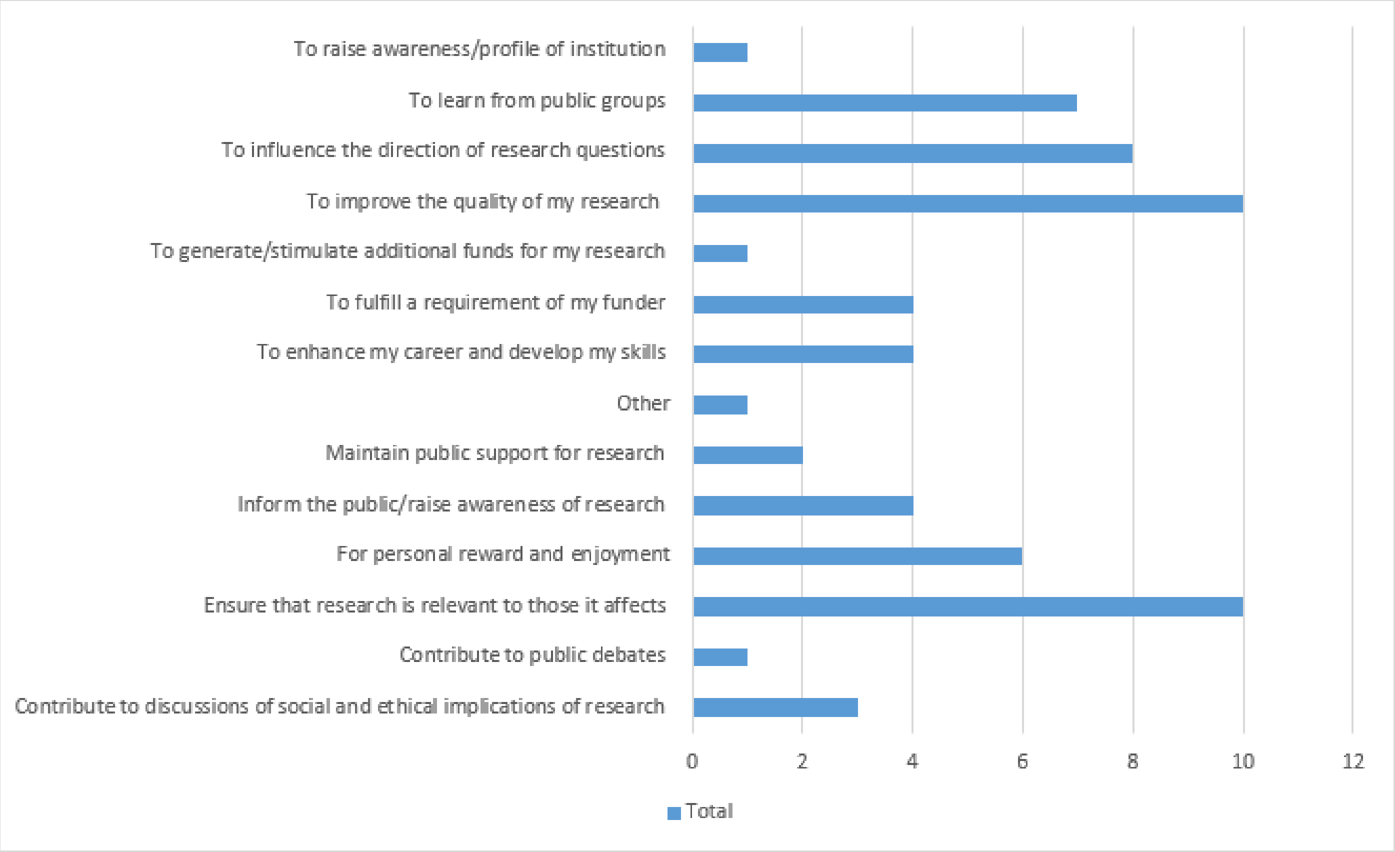
This scoping exercise aimed to shed light on the experiences of those doing PPI from EPSRC-aligned disciplines. Because of the low number of survey responses from this area, it has been necessary to fill in the gaps with semi-structured interviews with researchers from EPSRC backgrounds, and to do desk-based research.

## 5. Why are staff choosing to do PPI?

Survey respondents were asked to choose from a list, which motivations they had for doing PPI. The data-set for this list was drawn from a survey report by a consortium of funders, led by Wellcome Trust, on factors affecting public engagement by UK Researchers. It was felt by the ParticipatoryResearch@Bath team, that the motivations may be similar for doing PPI. Respondents to the survey were given the option to tick ‘other’ if they felt that they had a different motivation for doing PPI, and to give details.

The top two motivations were ‘Ensure that research is relevant to those it affects’ (n= 10) and ‘To improve the quality of my research’ (n= 10).

**Figure 3: Motivations for doing PPI**



One respondent gave an 'other' motivation and that was:

> *"Because it benefits those doing the PPI too."*

An EPSRC-aligned researcher talked in a semi-structured interview about why people in engineering and physical sciences are doing PPI.

> *"I know that for people putting in NIHR grants there is a funding requirement. But also, we try to really think about the end user, in particular when it comes to healthcare applications that becomes extremely, extremely important. It's thinking about how to engage with local communities that will end up using the device. So it's not exactly PPI, but it is participatory research, in order to develop something that is fit for purpose and also to understand the needs and what they do and don't want. Another motivation is also thinking about acceptability of new technologies. So sometimes we do PPI because we have to. Other times it's because we actually think it is important if we really want to make an impact without our research."*

Another EPSRC-aligned researcher said that PPI is a way to use funds responsibly:

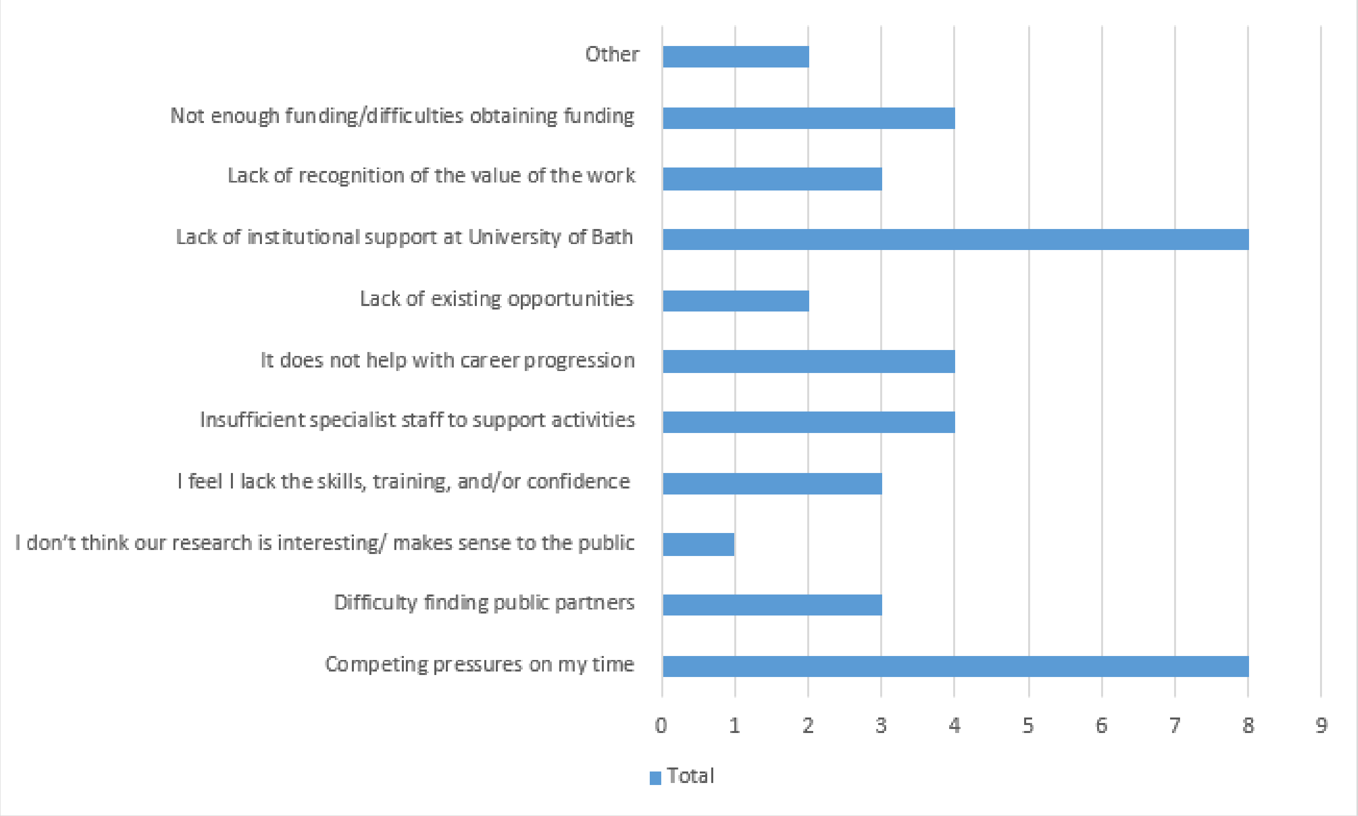
> *"My personal opinion is that we are funded by taxpayers money, so we should really get them involved, and it's a way to get out of the bubble that we live in."*

## 6. What barriers and challenges are there to doing a PPI project?

Survey respondents were asked to choose from a list, which barriers they had faced to doing PPI. The data-set for this list was drawn from a survey report by a consortium of funders, led by Wellcome Trust, on factors affecting public engagement by UK Researchers. It was felt by the ParticipatoryResearch@Bath team, that the barriers may be similar for doing PPI. Respondents to the survey were given the option to tick 'other' if they felt that they had experienced a different barrier to doing PPI, and to give details.

The biggest barriers researchers face to doing participatory research is 'competing pressures on my time' (n=8), followed by 'lack of institutional support at University of Bath' (n=8).

**Figure 4: Barriers to doing participatory research**



Two people selected 'other' and these were the barriers they had faced:

> *"I think there is a lack of co-production methodology/best practice guidance in the literature."*
>
> *"With patient engagement there are difficulties in how they can be 'paid' for their time."*

Barriers to doing PPI were explored in more detail in semi-structured interviews with academics. The top two barriers from the survey will be discussed in the following sections, alongside common themes from the interviews.

## 6.1 Competing pressures on time

The time-consuming nature of involving participants from outside academia in research was the most commonly selected barrier in the online survey. This was described as being particularly difficult at the project design phase, when the work is largely unfunded (with notable exception of NIHR who do fund the project design phase).

> *"It took around 14months of grant writing and ethics protocol development."*

In a semi-structured interview, a senior member of staff talked through the challenges with regards to time pressures when involving participants in developing a bid proposal.

> *"For example, If I want to write an NIHR bid, and I see the deadline is coming up for, I don't know, the end of next month. They will expect there to have been a level of involvement in the bid design. It's relatively easy to pick up the phone to an established group and ask, 'can I meet with you as a group in two weeks time and talk to you about this'. But it's a degree of participation. I think as academics, we tend to perhaps overuse those existing groups then because it's easy. But it's so difficult to do otherwise. Particularly if you've not got any funding.*
>
> *NIHR will now give you a small amount of money to fund that work in the bid development, which is really useful, because I could then employ, maybe one of my PhD students or something, to set that work up. But for me to do it...*
>
> *Ideally you'd want to do a really nice job of having a little core group, and meeting with them two or three times. But in that core group, if you wanted to include people who've got dementia [for example], it could be three or four months just setting that up properly. Let alone setting it up in order to write a bid that has to be in by July the 19th or whatever.*
>
> *When we've done work with carers, to have somebody who is a full-time informal carer come to one of your projects, they generally have to pay somebody to go and sit with the person they care for. And so you're having to think all of that through as well. And I can see why a lot of academics think it's all too difficult.*
>
> *It's just much quicker if I do it myself"*

Another academic talked about how it takes longer to work with people who are not part of the same work environment. There are differences to navigate which can be time consuming, for example, some participants have different availabilities, ways of communicating, preferences of technology – for example not having an email address.

One researcher from an EPSRC-aligned discipline who is involved with co-design of innovations said that working in partnership necessarily takes more time because the project is constantly evolving based on the participation.

> *"Participatory research takes time. And that's because it involves many steps and one of the steps is building trust, building trust takes time.*
>
> *Time is a big barrier. It is something that takes time because we cannot just do one participatory aspect and then go to the next step of the project. The participation informs the next step and the project has to evolve based on the participation.*

> *I don't know personally how to do participatory research from the beginning without causing too many delays on the project itself. We need to somehow tweak things in order to respond to whatever comes out from the participatory research and then feedback."*

This academic went on to say that a lack of understanding about the implications of participation means that researchers are often under pressure to take less time.

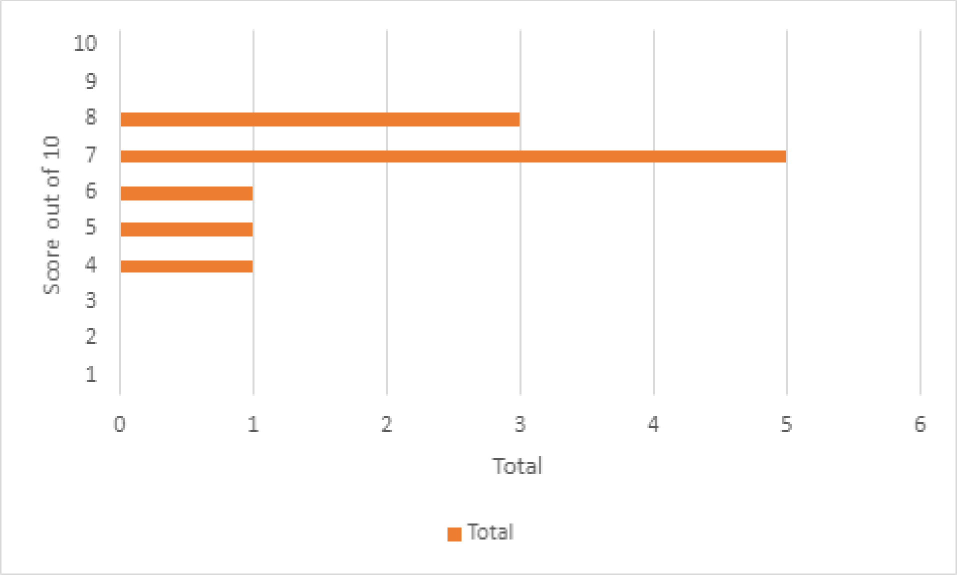
> *"A lot of it is just a tick boxing exercise, without understanding why we are doing it, or what the implications of it are. We do have pressure to get projects running and there is limited time and also limited money and all these things, they take time, then money so. I hope that the university wants to actually go down this route because it believes in it and not just because it wants to tick another box saying that we are doing it."*

## 6.2 Lack of institutional support at University of Bath

The second most commonly selected barrier in the online survey was 'Lack of institutional support at University of Bath'.

In a further survey question, respondents were asked to give a score out of 10 on how supportive both their department and the wider University were of participatory research (10 being very supportive, and 1 being not supportive), and then to give more details if they wished.

**Figure 5: How supportive is your department**



The responses to 'how supportive is your department?' varied based on the department. Some people were from departments where PPI is common, expected, and well resourced, but others found that support was lacking in their department.

Quotes from those who felt that their department was not supportive:

> *"Some of the senior team in my department do not value this aspect of my research, or even present as aware of the importance of PPI work as part of NIHR funded work. It does not seem to factor into their evaluation of research activities."*

> *"My department is very supportive of the idea of PPI, but this is not backed up with practical support - I have to arrange and fund everything myself with no supporting infrastructure."*

Quotes from those who felt that their department was supportive:

> *"The DCLINPSY programme have, for a number of years, been developing their PPE I.e. people with personal experience aspects of both the teaching and research elements of clinical psychology training. Therefore, within this sub team of our department, I feel PPI is well supported and valued. However, this does not necessarily extend throughout the wider department and beyond."*

> *"Very supportive. They provide examples and share ideas."*

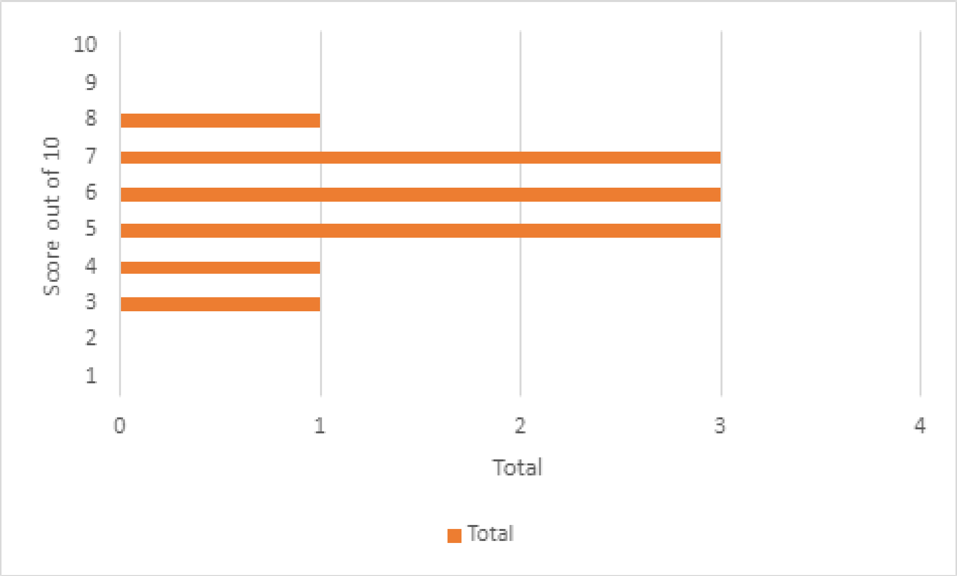
> *"The Department is supportive when it can be- it does not have links with business or groups to facilitate that. It does support colleagues with small pots of funding to engage with non-academics and values this type of work."*

> *"I am in P&P so there is a reasonable amount of this and therefore not unusual and is supported."*

A researcher from an EPSRC-aligned discipline said there wasn't any support in their department, but they didn't expect there to be any either:

> *"I didn't expect my department to have anything related to PPI, I think it's more of a RIS (Research Innovation Services) related thing"*

**Figure 6: How supportive is the University**



Comments about how supportive the University is of participatory research focused on the lack of infrastructure and administrative support, feeling that the work isn't valued, and the lack of support connecting with participants/partners.

Some researchers said there was a lack of understanding of the value of PPI at the University of Bath:

> *"I don't believe that the wider university truly understands the intention or value of PPI work at the broader level, although there are notable exceptions and especially amongst colleagues familiar with healthcare either in terms of research funding or in terms of clinical service delivery."*
>
> *"I doubt the university knows I have done any, so I guess I don't believe it is valued very highly."*
>
> *"It's not well understood and I think can be treated as a tick box exercise which I find frustrating and pointless. It really needs to be given priority and valued by senior colleagues and we need better training and infrastructure around it, not only for researchers but also for those PPI advisors."*

Some mentioned difficulties with navigating university systems:

> *"I didn't find the University unsupportive at all. In fact, finance services were highly accommodating and helpful- it is just that there aren't the right systems in place yet to streamline PPI work- this is where I see investment is needed."*
>
> *"The infrastructure for paying PPI members has hugely improved but is still bureaucratic and anxiety provoking for PPI group members, due to external factors around benefits etc."*

*Other researchers said there is a lack of supporting infrastructure:*

> *"The University seems vaguely supportive of the idea of PPI, but this is not backed up with practical support - I have to arrange and fund everything myself with no supporting infrastructure."*
>
> *"There's very little existing infrastructure for "general" PPI work, like a panel of people interested in participating and support staff who can help set up PPI activities. There's some support like this in certain specialist areas, but not in my own more general research."*

Some researchers were positive about the support they had received from the University with PPI:

> *"It was great to be able to meet with an impact manager through the university to support the dissemination phase of the project."*
>
> *"I have found (apart from finance processes) that the university is generally supportive of PPI work. The audio-visual department have been extremely responsive and helpful in supporting the making of videos with PPI to disseminate or train (not just for me but also a Phd student), the pre-awards office are very helpful in supporting costings for grants etc."*

Two researchers from EPSRC-aligned disciplines said in semi-structured interviews that they had been able to access some support, but the lack of signposting had made the support very difficult to find:

> *“I wouldn't say lack of support because all I've done is with the help of colleagues at Bath and no one external. It's just a lack of clearly defined roles as to who the advisor is for what. And signposting - lack of signposting. They managed to get the information I needed somehow, but it was a lot of searching in the dark really and trying to find people.”*
>
> *“I would say that overall there is a clear lack of signposting of what support exists for these activities. Processes can be extremely complicated and daunting without the right support so it is important that there are clear routes to what is expected and having the people to support it. At the moment it feels like a case of everyone asking one person in the Dept of Health (Lisa Austin) to help with their PPIs but even that is for those who heard her name through word of mouth.”*

## 6.3 Difficulty paying participants

Difficulty paying participants was a barrier mentioned in most of the semi-structured interviews and frequently in the online survey. An analysis of the responses reveals several problems:

- In order for participants to be paid monetarily for their time they have to register as a consultant with the University, which involves navigating paperwork and University systems. They then have to invoice for their payment, and do their own tax returns. This is not suitable for many participants
- There is the option to pay participants in vouchers, which some researchers felt was demeaning, or not suitable for the work they were doing.
- There are restrictions on how much participants who are in receipt of benefits can earn in both money and vouchers. Sometimes these participants are asking not to be paid.
- The inability to reimburse travel expenses with cash

These quotes from the survey answers and interviews illustrate this further.

> “*I still do not fully understand the processes nor can I explain them to my participants. We have lost individuals in the past because of the university finance processes.”*
>
> *“People have to send an invoice. Can you imagine saying to somebody with dementia - Will you do this activity? And then could you send me an invoice or at least have you filled in the contract? Nightmare!”*
>
> *“It was very challenging arranging payments. Lots of people were concerned about payments impacting on benefits (most group members received benefits). This meant some people opted not to receive payments. Other people preferred voucher payments, whilst others preferred BACS transfers, but this was often complicated with the University systems.”*
>
> *“I am not allowed to have 'petty cash' to pay people back their bus and train fares as the University won't accept this approach - I cannot claim even if I take a picture of the tickets. This means I have paid for participants travel out of my own pocket.”*

Some mentioned that difficulties with payments impact on the diversity of the participants they are able to recruit.

> *“I used to be able to give them vouchers that the university paid for, but now I have to buy them myself. I used to be able to give them bus fair, but now I have to fill in a form to get them electronically paid. And, you know, trying to get people from more diverse backgrounds – I think it’s a turn off. I really would like the systems to be better because I think it would really help us with our diversity.”*

## 6.4 Difficulty finding public partners/participants

Experiences finding public partners tended to vary depending on the research subject and whether there was an existing public panel at the university with access to the right participants, or whether there was an existing relationship with an organisation that could provide access to participants.

> *“I recruited through People in Health West of England.”*
>
> *“I found it easy as I have good links into NHS services regionally, and am linked to coproduction leads in other institutions on Twitter.”*
>
> *“The population is autistic adults, we have a volunteer research register and I advertised with a job role/spec to ask if anyone interested would like to become involved.”*
>
> *“We used our contacts in the particular field and, fortunately, had lots of contacts through departmental colleagues.”*

Accessing more vulnerable groups has been difficult for some researchers.

> *“I have had varied experiences of this. Sometimes approached people successfully. This has been more difficult in some of my work with more vulnerable groups.”*

Others said that finding and then keeping participants engaged is a lot of work

> *“Challenging! I've been working on this for over a decade and finding and maintaining support is hard without having continual administrative support, which there is not.”*

One researcher from an EPSRC-aligned discipline explained what it’s like finding participants for those with EPSRC backgrounds

> *“Everyone goes to Lisa [Lisa Austin, from the NIHR Research Design Service] for their PPIs. I do think that many of the things she does are out of scope in a sense, she does them because she’s interested and she’s helpful. Those who can’t go through Lisa have to use local networks, lets put it that way, they use contacts within the centre – whether or not the contact materialises or provides the support they actually need, that’s a different question. It can be very time-consuming, and I know that some people just decide to not go further”*

Another EPSRC researcher said that the main challenge was in connecting to clinician partners at the RUH, who would then provide the access to patient participants.

> *“There's a huge scope to improve this connecting with clinicians at the RUH. It was awfully challenging. I was very lucky on one of my projects that I managed to get linked with a clinician at the RUH who had access to patients, but on my other project I was very unlucky. I couldn’t*

> *manage at all. Mainly because the person working at the RUH was loaded with too much work, basically, and they didn't find the time to respond."*

A related difficulty is that some academics feel they don't know what they can ask of the charities they are approaching:

> *"I don't know what to ask. I know they're there. I know they're engaging with the public and I know that they'll be a great resource, but how can they help me? That wasn't clear to me. Somehow I need to get educated on that. How to word the e-mail. What to ask of them. How do I offer compensation money."*

### 6.4.1 Methods of finding public partners/participants

There are some existing public panels that are available to researchers at Bath from specific disciplines, for example the People with Lived Experience panel in the Department of Psychology, or the Participate Panel, which is available to researchers using the NIHR Research Design Service. There are many researchers whose work falls outside the remit of these panels.

Survey respondents were asked how they found their public partners/participants. The responses in Table 2 show that most researchers are utilising existing contacts.

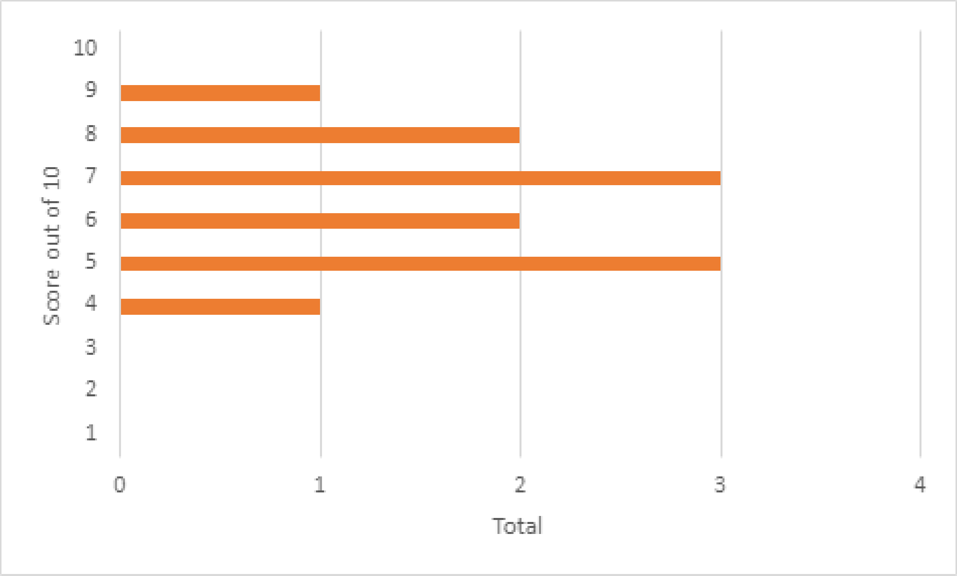
**Table 2: How did you find your public partner/participants?**

| Method | Number of selections |
|---|---|
| I approached them as a cold contact(s) | 1 |
| They were an existing contact(s) of mine/my department | 5 |
| We were introduced to each other by an external organisation | 3 |
| We were introduced to each other by public engagement/involvement specialists at University of Bath | 0 |

## 7. How well equipped do University of Bath academics feel to do PPI?

Researchers who responded to the survey were asked to rate out of 10, how well equipped they felt they were to do participatory research. All of the researchers felt positive about their skills. The results, charted in figure 7, show that 92% of participants scored themselves 5 or higher.

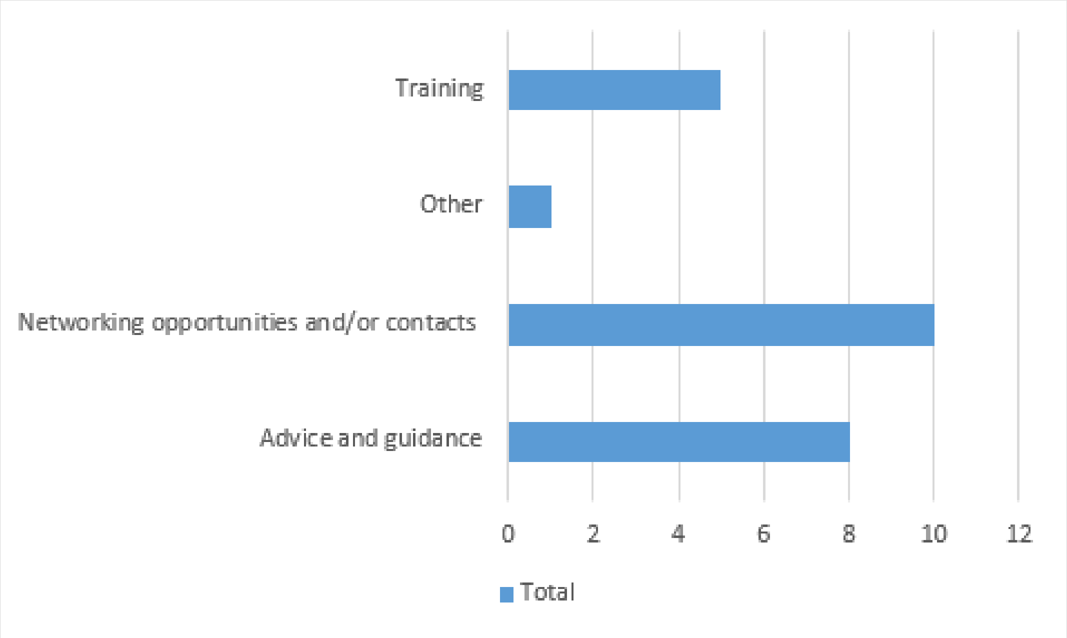
**Figure 7: How well equipped do academics feel to do participatory research, score out of 10.**



## 8. What are the current enablers that are supporting PPI at Bath? (Support staff, grants, training, mentoring, community/university networking)

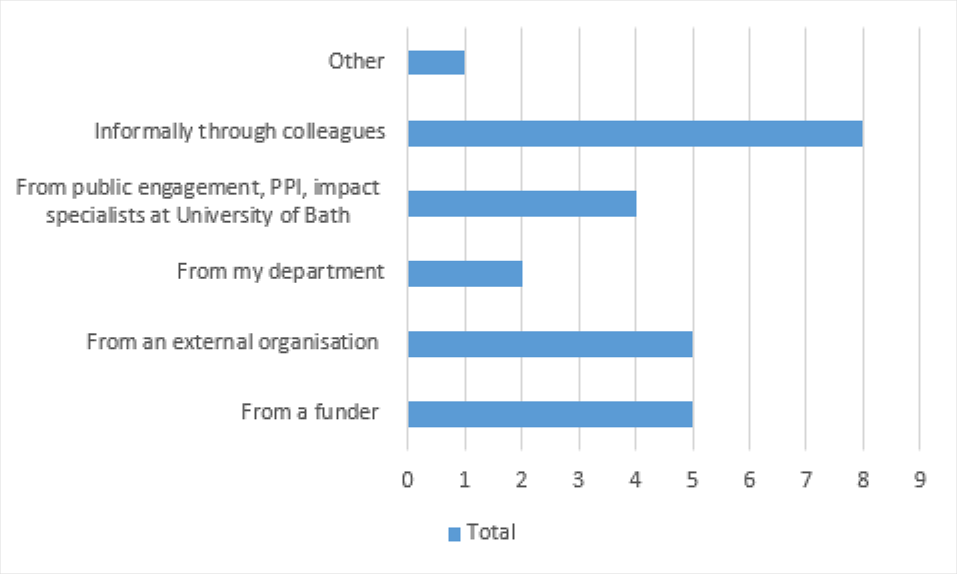
All of the academics who responded to the survey had received some support with their PPI work. 76% had accessed networking opportunities and/or contacts and 38% had had some training as shown in figure 8.

**Figure 8: Types of support researchers have accessed.**



Researchers were asked a further question about the sources they got support from. The majority of survey respondents had received support informally through colleagues. There was a good spread of those accessing support from funders, external organisations, and within the University (from their department or specialist staff) as shown in figure 9.

**Figure 9: Sources of support**



Emails were sent to every department at the University, and desk-based research was carried out, to determine what support was available to those doing participatory research and PPI.

## 8.1 Departmental support

In the psychology department DClin (Doctorate in Clinical Psychology) trainees receive some training in participatory methods as part of their course. There is also a PPE (people with personal experience)

Committee for DClin trainees – this committee advises on all aspects of the DClin (student interview panels, teaching, research projects etc). Weekly emails are sent to the PPE Committee to offer opportunities for involvement. This committee is also sometimes used by research staff. DClin Trainees have to pitch their main research project to a member of the PPE Committee to ensure suitability of their research projects, get feedback on the methods, dissemination etc.

The psychology department also has access to a Research Community Panel and External Advisory Board which can be drawn on for participatory research.

No other support at a departmental level was found.

## 8.2 Research Centres

Many University of Bath research groups/centres include participatory methods, but it is not the focus of any one research centre. Some Research Centres offer seminars, and at times these are about participatory research, for example the Centre for Decolonising Knowledge (DECkNO) recently held a round table series on participatory methodologies.

## 8.3 Doctoral Training Partnerships

Some of the Doctoral Training Partnerships that the University of Bath is involved with provide good support with participation and involvement. The South West Doctoral Training Partnership in Economic and Social Science have a focus on collaboration, and offer a student-led collaboration fund, and an impact fund. The UKRI CDT in Accountable, Responsible, and Transparent AI provide access to research partners, training, seminars, workshops and placements. And the NERC Centre for Doctoral Training in Freshwater Biosciences and Sustainability (GW4 FRESH) offer access to stakeholders for collaborative research.

## 8.4 University-wide support

The Public Engagement Unit offer a Start-Up Fund, which provides up to £200 for relationship building and conversations with new people/partners, that might lead to public engagement activities in the future.

RIS (Research Innovation Services) support academics with research development. They advocate for public participation, consultancy, collaboration, or co-creation (where relevant) and signpost to support for connecting to public partners/participants. For example they will signpost to the NIHR Research Development Service grants, or Health West of England, or charities with patient groups. They have funding available for skills development and have funded academics to go on participatory research or PPI training.

Lisa Austin supports academics who are applying to NIHR through the Research Design Service. She can give guidance on PPI and EDI (Equality, diversity and inclusion), she can access funding to pay participants who are involved in grant applications, and she has set up the Participate Panel - around 100 public participants who are patients, service users or carers with whom academics can be connected for the purposes of PPI.

## 8.5 Funding for PPI at Bath

Survey respondents were asked how their PPI was funded, there was a good spread of answers.

**Table 3: How was your PPI project funded**

| **How funded** | **Sum of Total** |
|---|---|
| It was not funded | 4 |
| Specific grant funding for your participatory research or PPI project | 4 |
| Through research funding | 5 |
| **Grand Total** | **13** |

How PPI projects were funded seemed to be dependent on the stage of the project that the PPI is done. Many academics are doing PPI that is unfunded at the project design stage of their work. NIHR will provide some funding for this early work, and these academics stated in the survey that they had received 'specific grant funding' for their PPI project. Researchers are then able to cost PPI activities into their funding bids; academics doing PPI throughout their project selected in the survey that their PPI was funded through 'research funding'.

Those doing the Doctorate in Clinical Psychology (DClin) are able to use their research budget for PPI activities, and some survey respondents stated that this is what they had done.

### 8.5.1 Difficulties funding the project design phase

Many people talked about the difficulties involving participants in the project design and bid development phase, due to the lack of funding for this work. There are costs involved in using participatory methods at this stage of a project, such as venue hire, refreshments, travel costs, paying partners and participants, and paying university staff who are involved. Only one funder was mentioned who offers funds for the bid development phase; NIHR. Researchers who are applying to other funders are finding it hard to fund participation at this stage of the project. One department coordinator said:

> *"There are no funds specifically for participatory research – this has caused some problems/embarrassment for some people, having to rely on collaborators at other universities to pay PPE [people with personal experience]."*

## 8.6 Strengths of the support offered by the University of Bath

Less than half of the survey respondents answered the question 'What were the strengths of the support you accessed at University of Bath?' (42%) and many of those who answered didn't mention strengths.

> *"People try as individuals but the system is wrong"*

> *"Very little support to have any strengths'"*

However several have mentioned the Public Engagement Unit and the Engage grant to be supportive.

> *"Most of the support I have received on participatory research to date is not at the university of Bath. However, the Engage grant is a huge help to support my work in this area."*

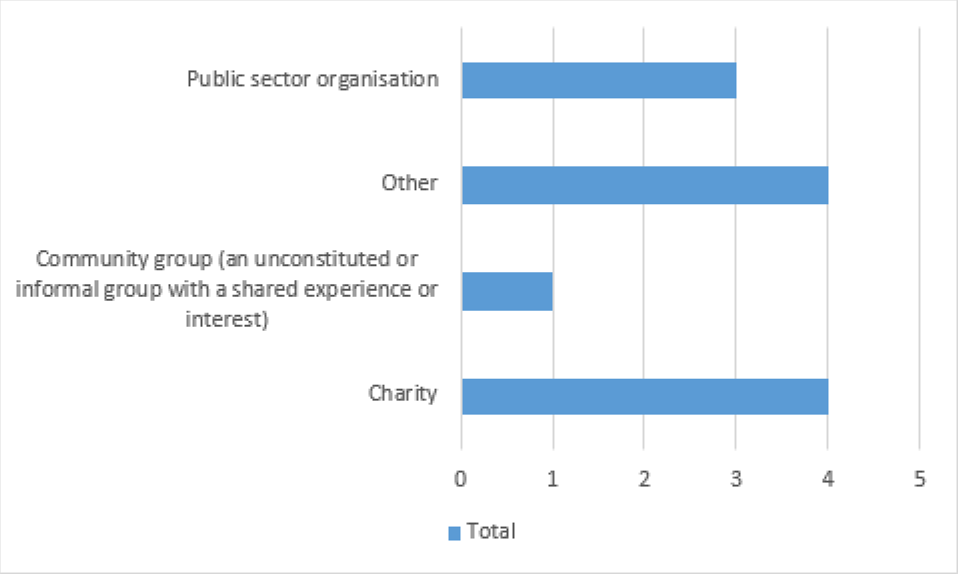
The DClin PPE Committee and the Widening Participation team were also mentioned as having been helpful.

## 9. Who are the public participants working with University of Bath academics? And what kinds of projects are they involved in?

In the online survey, researchers were asked which type of organisation they had partnered with to do their PPI project. This might not have been the best way to frame the question with regards to PPI, as many academics are doing PPI with individuals – often these are individuals who have been recruited to panels specifically for the purposes of being involved in PPI. Some of those who selected 'other' in answer to this question stated that they had worked with individuals.

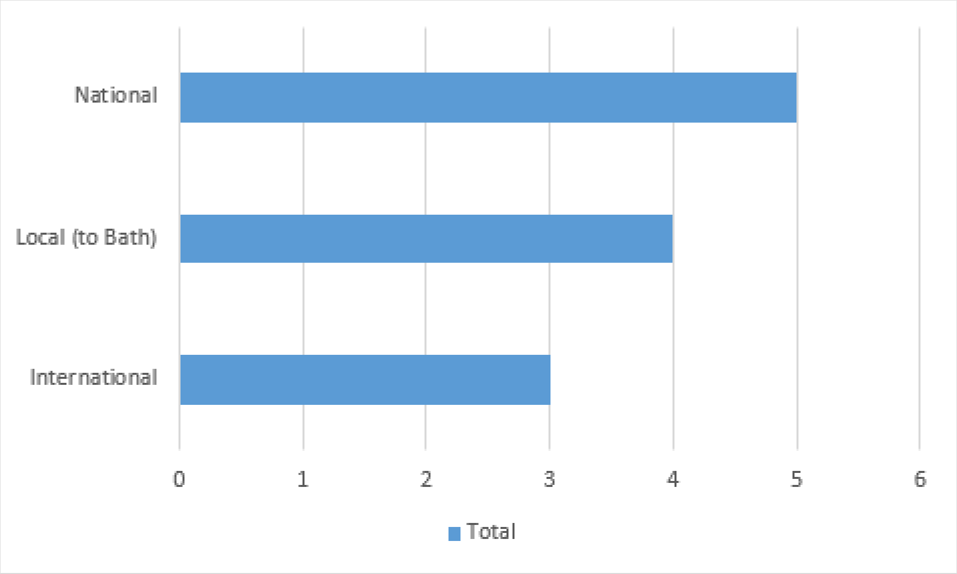
Academics had also partnered with charities, public sector organisations, NHS clinicians, businesses, and SMEs

**Figure 10: Types of organisation involved in PPI**



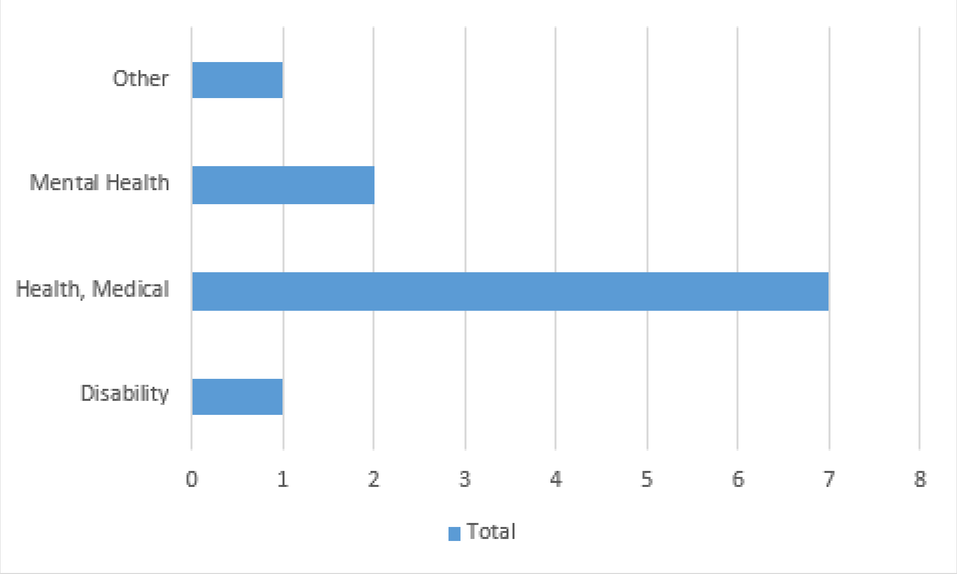
Most of the researchers involved in the scoping exercise had worked with an organisation with a national remit.

**Figure 11: Remit of partner organisations**



All of the projects involving public partners/participants, most commonly focussed on health or medical research., mental health, or disability.

**Figure 12: Focus of PPI projects**



## 10. Recommendations for the University of Bath

In the online survey, respondents were asked ‘What should the University of Bath do to encourage more staff and students to do participatory research or PPI?’. Responses can be summarised into three areas:

1. **Provide support for those using participatory methods**

   *“Include training for PhD students.”*

*"Engage the public outwardly as an institution, perhaps invite the public to sign up to support research, with a centrally managed register of potential volunteers interested in particular types of work or topics, who could then receive information about upcoming PPI opportunities. These administrative tasks take an immense amount of time, but would be very supportive. Have a central university PPI research panel which researchers could consult when trying to set up PPI for a specific project, to advise and mentor how you might go about it."*

*"Engage the community more with the university's research."*

*"Provide resources and expertise - particularly to those new to it."*

*"We should have several Lisas [Lisa Austin, from the NIHR Research Design Service]. Maybe some with different specialties... engagement with patients, engagement with clinicians, preparing things for clinical validation, PPI's, but also more generically. Also having staff that are more involved with local communities and so developing contacts, that kind of thing. They should have people that have at least a clear understanding of the processes, but I think more than that, that actually can support the preparation of PPI to actually get the most out of it. Because she [Lisa Austin] not only gives advice, but she does support as much as she can."*

*"RIS needs to have someone specifically for clinical impact creation. Someone who can connect us with public groups like Participate. Someone who can connect us to clinicians at the RUH. Someone who knows what to expect or what researchers can do in terms of involvement and in terms of engagement. And someone who can link us to charities."*

2. **Remove administrative barriers**

*"Provide the infrastructure to make it easy."*

*"Make processes more straightforward. Ensure that any PPI rep can access involvement and related payment."*

*"Improve the processes for reimbursement in respect of finance."*

*"Develop a clear supportive policy for engaging patients (this may involve some form of 'payment')."*

1. **Highlight PPI**

*"More events and celebration/visibility of the work that is being done."*

*"Reward it as an important part of research work through career progression."*

*"Talk about it, support it, and share the results of the support provided."*

*"Bring more examples."*

*"Make sure it is valued in the same way that we value research 'outputs' (papers)."*

The following sections will expand on these recommendations using material gathered in the wider scoping exercise – the semi-structured interviews, the mapping exercise, and the desk-based research.

## 10.1 Provide support for those using participatory methods

**Consider providing training**

Only 38% of those who completed the survey had had any training in PPI. Academics would like to see training in participatory methods, particularly at masters and doctorate levels, but also for all stages of the academic career.

**Consider providing funding for the project design phase**.

Many funders don't provide funding for the project design phase, despite it being a requirement of some of these funding applications, as well as this being an important stage for participants to be involved in. Those who have received funding at this stage (for example from NIHR, one of the only funders who provide money for this work) have been able to do more meaningful early engagement, have been able to pay participants fairly, and have been able to involve others at University of Bath to alleviate time pressures. Could the University provide funds for this work?

**Consider providing staff who can support PPI**

Through the NIHR Research Design Service some researchers are able to access the support of Lisa Austin, who can help them with planning PPI, connect them with public panels, help them write funding applications, and help them recruit participants as research collaborators. Academics who have accessed this support have faced fewer barriers, and have been able to draw on best practice and expertise in this area. Many researchers, however, are not eligible for this support, and for them it is very difficult to navigate the various university systems, find participants, and access best practice.

Some researchers are accessing support through RIS (Research and Innovation Services), who advocate for participatory methods, and provide signposting to partner organisations and places where participants can be recruited.

Having more staff who can support all researchers with participatory methods would mean that more academics could be supported with, for example, signposting, connecting with participants, giving information advice and guidance, sharing best practice, help navigating university and funder systems, support with applying for funding and demonstrating impact etc.

**Consider providing ways for staff to network**

One of the biggest sources of support that researchers at Bath are accessing is informal support through colleagues. This could be formalised and grown to include more networking opportunities and the sharing of ideas and best practice.

## 10.2 Remove administrative/infrastructural barriers

**Consider working with the finance team to simplify payments processes for those participating in research**

One of the most commonly mentioned issues in this scoping exercise was difficulties navigating finance procedures so that participants can be paid. Having a system that works for a variety of collaborators (those who prefer money, those who prefer vouchers for benefits reasons) would make the research process easier, and would enable researchers to show participants that their contributions are valued.

**Consider improving signposting to sources of support**

Academics who are new to PPI, or who are based in a department in which PPI isn't common, for example those from EPSRC-aligned disciplines, are struggling with a lack of signposting to the support that is available for PPI in the University. Consider providing a guide or online resource that directs researchers to the internal support available.

## 10.3 Highlight PPI

**Consider ways in which academics can feel this work is valued by the University**

Academics would like participatory methods to be promoted and talked about more by the University. This could include highlighting success stories within the University, working with the comms team to publicise this work more both internally and externally, considering reward and recognition, joining in with national and international discussions and networks for PPI, and bringing senior leaders onboard with creating a culture of collaborative research.