Patient and Public Involvement benchmarking report

By Jenny Jopson for the University of Bath, July 2022

Contents

1. Introduction

This report summarises findings from desk and interview-based research into how other higher education institutions in the UK support long-term patient and public involvement (PPI) at institutional level. It is part of the *ParticipatoryResearch@Bath* project.

This report contains key recommendations based on my findings; details of the research methodology which comprised interviews with key people at institutions across the country, and a survey sent to institutions across the UK; a list of people and projects for potential follow up in the future; headline findings from the interviews; and findings from the survey. The full interview notes are saved as separate documents. Some interviewees generously shared resources and these are also saved separately and detailed in the interview headlines section.

2. Patient and Public Involvement or Participatory Research?

Arguably there is no clear definition of each of these terms, and there is much overlap between them. Wellcome's Public Engagement onion, where engagement activities from dissemination to partnership working are visualised as different layers along a spectrum, is a useful reference (see Resources folder).

For the purposes of this report, PPI is taken to mean more formal engagement with patients, people with lived experience (also called experts by experience), or carers. This often takes the form of panels and consultations (approaches that are well established in NIHR-funded research, where PPI is a compulsory part of grant applications), although several people I spoke to expressed ambitions to make PPI more participatory and to use methodologies borrowed from other disciplines.

Readers of this report are encouraged to refer to another document, the 'Participatory Research benchmarking report', which explores how institutions carry out what they variously call participatory research, co-produced research or collaborative research. The findings and recommendations of that report will, I hope, be relevant to PPI practitioners, in addition to the ones detailed here.

3. Recommendations for the University of Bath

3.1 Have a clear strategy backed up by institutional support

- Have a clear definition of what PPI means for Bath, why you want to do it and in what contexts. PPI needs to be relevant and meaningful, and avoid being tokenistic or mandated. Don't force people to do it, or do it just for the sake of it.
- This needs to be supported by Bath's senior leadership. Mike Bell (NIHR ARC West) spoke compellingly about the power of an institutional culture where they are free to get on with things without scrutiny or critique.

3.2 Take time to do things properly

- Acknowledge and accept that good PPI takes time.
- Avoid being tokenistic – generic, tick-box exercises are counter-productive and demotivating for contributors.

3.3 Treat communities with respect

- There is an issue of fatigue, apathy and cynicism among community groups who have been the victim of extractive or repetitive interactions with researchers.[1] Bath should work to sustain relationships over the long term – or if this is not feasible, be clear and up front with communities to manage expectations.
- Follow up with communities, thank them and offer feedback on their contributions.[2]

3.4 Put the right people in place

- Consider having community advocates, embedded within communities of interest, who are paid, or even employed, by the University to make and maintain links.
- Employ PPI specialist(s) who can support the recruitment of participants; organise and facilitate meetings; and maintain relationships between communities and academics; maintain databases; carry out financial admin.[3] (See interview notes for Mike Bell)
- Appoint an academic PPI lead to champion this work. Academics who have a PPI remit may be better able to motivate other researchers than PPI/PE staff who are not also academics (see interview notes for Andy Gibson).

3.5 Fund it

- Set up a seed fund that can be used to fund early-stage conversations and relationship building with communities. At present it is straightforward to write public contributors into a grant application, but much harder to find money to pay people to get involved in developing the applications themselves, or nurture and establish the relationships that need to form before you even reach the application stage. UCL have a fund called Listen and Learn for this purpose. One interviewee (who asked to remain anonymous) told me that they had recently needed to work with a public contributor on a grant application, but couldn't access any funding to pay for the contributor's involvement. They ended up paying the contributor with their own money! They would have loved to have been able to involve the contributor more but couldn't afford to.

3.6 Pay people properly

- Pay people for their time, make the process easy (i.e. minimise admin) and offer a variety of ways for people to get paid that take into account different circumstances (e.g. vouchers, BACS). [4]

3.7 Utilise existing resources

- There's no need for Bath to start from scratch. It doesn't need to have its own network or develop its own training resources or payment policy – these things exist already and can be

---

[1] *"Researchers come in, do the research, then leave and [the communities] never hear from them again. They feel used – people can contribute their health story, can sometimes be very personal, but they don't necessarily get something back from it."*
Jo Stubbs, University of Bristol

[2] *"Always give feedback for everything they've been involved in - biggest complaint I hear from PPI members is that academics never say thank you or tell them how their involvement has contributed"*
Respondent to the PPI survey

[3] *"Ideally have a member of staff who can give 100% of their time to PPI"*
Respondent to the PPI survey

[4] *"Payment is a must… We don't work for free, how can we expect patients to do this work for free?"*
Shoba Dawson, University of Bristol

found through health partner networks like NIHR ARC West and UCLPartners (see Resources).

3.8 Go to where people are

- For really meaningful contributions it is necessary to go out into communities and find the people to whom the research is really relevant. This is time consuming, resource intensive, and a long-term exercise.
- Do PPI in a way that suits the community rather than the academics – this may not be between 9am-5pm or inside the university buildings! Develop your approach appropriately and ask what is of value to the specific group you want to work with.

3.9 Increase diversity

- Traditionally there has been a problem of 'professional citizens' who are not representative of the local or national population as a whole, which is damaging to research and socially unjust. Bath should work with partners (other organisation's networks, charities) to actively improve the diversity of patient groups. Having a fair and straightforward payment policy will also act to remove some of the barriers to participation by under-represented groups.

3.10 Consider language

- Don't refer to public contributors as 'lay people'. The terms 'communities', 'contributors' and 'experts by experience' are all considered acceptable.
- Avoid acronyms and jargon – for example, most people outside academia think 'PPI' means insurance.
  (See headlines for Mike Bell)

4. Methodology

4.1 Interviews

Interviews were carried out between March-July 2022 with key people at selected organisations. Organisations were chosen on the following basis:

- Sector leaders – recognised as being high performers in the area of participatory
- Comparators – similar to Bath in terms of size and scale; or also in KEF cluster X

Through the interviews I was interested in finding out how universities, and the practitioners who work for them, practically go about encouraging and supporting researchers to do PPI. What are the structures and processes that need to be in place? What challenges do our HEI colleagues face, and how to they mitigate these? What do they consider to be the essential ingredients for quality and meaningful PPI, and what is their advice for Bath?

Interviews were conducted over Zoom, for between 45-60 minutes. Interviewees were told that the findings will be used to inform changes and build an improved culture of support for PPI at the University of Bath. Several of them expressed interest in seeing the results and having further conversations.

4.2 Interview template

Early interviews followed a template of set questions (see Interviews folder). As the project went on, later conversations were more tailored and specific to the expertise of each interviewee.

4.3. Interviewees

- Mike Bell, Patient and Public Involvement Facilitator, NIHR ARC West and Bristol Biomedical Research Centre (BRC)
- Andy Gibson, Associate Professor in Patient and Public Involvement, UWE
- Jo Stubbs, Public Engagement Associate, Elizabeth Blackwell Institute, University of Bristol
- Shoba Dawson, Senior Research Associate, University of Bristol
- Natt Day, Patient Involvement and Engagement Lead, UCLPartners
- Alison Thomson, Lecturer in Patient Public Involvement and Public Engagement in Science, QMUL
- Steven Blackburn, Associate Professor in the Institute of Applied Health Research, University of Birmingham

4.4 PPI survey

A survey was sent out to 11 organisations via individual, personalised emails. The organisations were: Keele, Edinburgh, Cardiff, Exeter, Glasgow, Imperial, Stirling, Sussex, Reading, QMUL and Manchester's Vocal. Five responses were received, from Keele, Edinburgh and Cardiff (two people from both Edinburgh and Cardiff responded individually).

5. Future follow up

I came across lots of interesting people, organisations and projects that I didn't have time to look into further during this project. These could be useful to follow up on in the future.

- **Sarah Sauchelli Toran**, Bristol Dental School – could be useful to find out more about her approach to working with the local community in Barton Hill (see Jo Stubbs interview notes for more details). sarah.sauchellitoran@bristol.ac.uk
- **Norah Fry Centre for disability studies**. Their project 'Getting things changed' was funded by ESRC. It could be interesting to find out more about this (mentioned by Jo Stubbs). The final report can be found here: https://www.bristol.ac.uk/media-library/sites/sps/images/gettingthingschanged/Final%20GTC%20report_web.pdf
- **QMUL** – they were short staffed and delivering a festival during the project. Sarah Barnes, Interim Head of Public Engagement, would be the person to speak to sarah.barnes@qmul.ac.uk
- Jen Wong at Science Gallery London, part of Kings College London, suggested contacting **Bella Spencer**. Bella used to be a young leader at Science Gallery, and is now based at the centre for medical engineering. Her role was public engagement and is now more PPI. She is developing infrastructure to work with communities in a more mutually beneficial way.
- **Sarah Yardley** – clinical doctor in palliative care based at UCL, interested in meaningful engagement and inclusion. sarah.yardley@ucl.ac.uk or on Twitter @lavendercrew
- **Jenny Robertson**, PPI&E Coordinator jenny.l.robertson@ed.ac.uk – completed the PPI survey and indicated she is willing to be contacted for a follow up conversation
- **Tracy Jackson**, Senior Research Fellow and Respiratory PPI Lead, Asthma UK Centre for Applied Research tracy.jackson@ed.ac.uk – completed the PPI survey and indicated she is willing to be contacted for a follow up conversation

Bath is particularly interested in learning about examples of PPI with engineering or EPSRC-funded research. Most people I spoke to work in the spheres of NIHR or ESRC funded research, but I did come across a couple of examples that sounded promising:

- **Antonia Tzemanaki,** Lecturer in Robotics, Department of Mechanical Engineering, University of Bristol. She worked with the deaf community on a project that involved teaching robots sign language. She was on parental leave when I tried to make contact. antonia.tzemanaki@bristol.ac.uk
- **Andy Gibson** is working on a project about digital interventions in health, developing a 'conversational AI' (essentially an app) for people with diabetes and will hold workshops to user test the prototype. See interview notes for more details.
- **Steven Blackburn has a** background in engineering (medical devices). He told me that human-centred design is well recognised in engineering circles, and is similar to PPI frameworks in that it considers users in design. There is an international standard for it, he knew it as ISO 13407 https://www.iso.org/obp/ui/#iso:std:iso:13407:ed-1:v1:en This has now been withdrawn, but may have been superseded by this: https://www.iso.org/obp/ui/#iso:std:iso:9241:-210:ed-2:v1:en

6. Useful Links

- 'Enabling meaningful contributions' – report from 2019 http://www.phwe.org.uk/wp-content/uploads/RAND_RR2678.pdf
- 'Enabling meaningful contributions' (shorter version): https://www.thisinstitute.cam.ac.uk/research-articles/involving-patients-public-research/
- UCL Partners PPIE strategy 2022: https://uclpartners.com/about-us/ppie-strategy/
- National Institute for Health and Care Research (NIHR). Payment guidance for researchers and professionals. NIHR. https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392#Involvement_is_not_participation. Accessed April 22, 2022.
- Two publications from Shoba Dawson:
    - Engaging with diverse audiences to raise awareness about childhood eczema: reflections from two community events: pubmed.ncbi.nlm.nih.gov/33468241/
    - Broadening diversity through creative involvement to identify research priorities: researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00244-z

7. Interviews – headline findings

I have summarised the main findings from each of the interviews below. More detail can be found in the much longer interview notes, which are saved as separate documents.

7.1 Mike Bell, Patient and Public Involvement Facilitator, NIHR ARC West and Bristol Biomedical Research Centre (BRC)

About Mike

Mike is a member of the patient and public involvement team and provides support for public involvement for ARC West projects as well as the NIHR Bristol Biomedical Research Centre (BRC). He is a first point of contact for anyone wanting to know what public involvement activities are already taking place.

Interview headlines

- They are training six young people to be peer researchers (EBI project 'Create to Collaborate'). He would like to move more towards co-production than involvement – bringing people in at the beginning of the research process.
- Mike had lots of useful advice for Bath:
  - Have a culture where PPI is adequately resourced, and not overly scrutinised or critiqued. Researchers and facilitators are left to get on with it and spend money as they see fit without having to justify to senior levels.
  - Employ staff to coordinate and facilitate meetings, maintain database, do financial admin.
  - Pay contributors (recommended rate is £25, preferred method cash via BACS transfer). Make it simple for people to get paid – strip away as much admin as possible and send minimal forms to fill in.
  - Boost the diversity of contributor pool by working with partners to actively recruit.
  - Check in regularly with contributors if there is a long gap between meeting and the eventual funding outcome, for example. Follow up with personalised emails to keep them feeling connected.
  - Don't be afraid to ask for help and advice – he is always happy to share thoughts and resources. You are not doing it alone!

In 2021, Mike decided to talk to a group of members of the public, many of whom had not been involved in PPI before, to find out what they want to see in a PPI advert. He recognised that researchers create public involvement adverts all the time, but there had been little consideration of what members of the public actually want, and what would appeal to them. He ran an online seminar in March 2022 to present what he found and help others create better PPI adverts.

Headlines from the session

- Keep it simple – include only the necessary key info in the advert, with link for more details
- Avoid acronyms and jargon – for example, most people think 'PPI' means insurance, 'Public Engagement' sounds like a council meeting
- Language matters – the terms communities, contributors, experts by experience, public involvement in research all considered acceptable. Feedback from contributors is that people don't like being called 'lay people'
- Work to increase the diversity of contributors – recruit them from your personal networks (taxi driver, hairdresser) or work with partners who have access to diverse communities
- Have panels (public, youth etc) to advise on plain language etc.
- Use templates for effective communication – the NIHR have devised some to share
- Refer to plain language guidance documents – again, NIHR has guidance to share
- Employ someone whose role is to broker the relationship between researchers and contributors – for example, a facilitator like Mike

Following the event, ARC West shared these resources:

- Recording of the seminar
- News story
- Page with templates and other materials
- Mike's slides
- Q&A roundup
- Link to sign up for the ARC West email newsletter

There are also many other resources developed by NIHR ARC West that Bath can use (see **Resources** folder), for example:

- NIHR ARC West's contributor database
- Training – videos or a bespoke session by Mike and colleagues (they recently did one for Dundee Uni for free and would be willing to deliver training for Bath)
- Templates (adverts, simple finance forms, evaluation forms etc.)
- Role descriptions for staff

7.2 Andy Gibson, Associate Professor in Patient and Public Involvement, UWE

About Andy

Andy has a social sciences background. His research interests focus on public involvement in health research. He is the academic lead for People in Health West of England (www.phwe.org.uk), a UWE-led collaborative initiative on PPI in research with the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC West), the West of England Academic Health Science Network, the Clinical Research Network West of England, Bristol Biomedical Research Centre and Bristol Health Partners. He also leads the UWE patient and public involvement team based in the Department of Health and Social Sciences.

Interview headlines

- He has noticed that it is easier to get PPI off the ground with NIHR funded research (NIHR ARC WEST projects, for example) than it is at HEIs, because PPI is mandated by NIHR. HEIs aren't mandated to do this.
- There is a language problem / issue of definitions across the sector – often it is unclear what we all mean by the terms we use, which leads to confusion and inefficiency
- Ambassadors – pay (and ideally employ) people who are embedded within the communities you want to work with, and who can provide a bridge between the university and under-represented groups. Long term, sustained relationships, finding out what communities want and giving back. Requires time and money!
- Research Fellow(s) in Public Involvement. It is powerful to have an academic PPI lead, as they are better placed to persuade reluctant academics to include PPI. PPI shouldn't be led solely by people from professional services/PE/Comms backgrounds. His advice to Bath would be to appoint an academic PPI lead to champion this work.
- We need good tools to evaluate this work – he has developed a user-friendly 4-dimensional evaluation tool that is currently being user tested by ARC WEST and will hopefully be made more widely available later this year.
- Improving the diversity of PPI participants should be the next logical step for university EDI strategies (he thinks they are currently too focused on EDI as it relates to staff and students).
- He queries the value of Arnstein's ladder and other hierarchies of engagement. The NIHR used to use a similar, simplified scale to rate projects, but has now dropped it in recognition that it is not always appropriate to aim for the top rungs. "There have some really poor-quality user-led projects"

7.3 Jo Stubbs, Public Engagement Associate, Elizabeth Blackwell Institute, University of Bristol

About Jo

Jo helps researchers engage with the non-academic world. This includes creating conversations between community groups and researchers, working with local partners, and collaborating with public audiences.

N.B. I have included Jo Stubbs in both reports as our conversation covered PPI and participatory research.

Interview headlines

- PE/PPI professionals are needed to facilitate conversations between researchers and communities, and to take things forward afterwards – don't leave it all up to researchers.
- She argues (as have several others) for the need for universities to fund a community engagement officer (or similar) whose role is to be embedded within communities and build relationships, and who can act as a conduit between researchers and the communities they want to reach. This would also help avoid the current problem of community groups being bombarded by too many requests.
- For community engagement and relationship building you have to be a people person and really enjoy the work – and not be too focused on outcomes.
- Good example of an approach that is working – Sarah Sauchelli Toran in UoB Dental School (see full interview notes for more details).
- Also Norah Fry Centre for disability studies. They did a project called 'Getting things changed' – could be interesting to find out more about this.
- Communities can feel used by researchers – people contribute their health story, which can sometimes be very personal, but they don't necessarily get something back from it as researchers don't always follow up or return to share findings.
- More training needed for PE/PPI coordinators re working with vulnerable groups – we are not experts in every vulnerable group. Also safe guarding – coordinators need to set boundaries and protect themselves personally. Qualitative researchers get trained in basic safety for when they are doing research with people with issues – seems like a real omission that PPI coordinators don't get this when they are often coming into contact with the same groups.

7.4 Shoba Dawson, Senior Research Associate, University of Bristol

About Shoba

Shoba joined the Centre of Academic Primary Care (CAPC) in February 2018. She has diverse experience within primary care research. She is involved in a portfolio of externally funded projects leading and providing expertise on systematic reviews and increasing ethnic diversity in research. Shoba has a special interest in promoting inclusivity and diversity in primary care research. Her core research interests include addressing health inequalities, and patient and public involvement and engagement.

Interview headlines

- If you want to increase the diversity of your participants then make sure you have materials that are relevant and understandable e.g. adverts and forms in different languages

- Visual minutes/live illustration are effective ways to engage and communicate with people who don't speak much English
- Relationships with communities need to be carefully maintained, respectful and not flash-in-the-pan, to avoid distrust and overwhelm
- "Payment is a must… We don't work for free, how can we expect patients to do this work for free?"
- You can't access PPI contributors at the grant writing stage because there's no money for this (only once you have been awarded the grant). She would like a funding pot that people could apply to when writing an application, to cover contributors' time at that stage of the process. This would result in stronger applications.
- We need to move away from the traditional models of recruiting and working with participants – we need to go out into communities rather than expecting them to come to us.
- We need networks of people doing this work – open communication and joined up thinking between organisations who are doing similar things to avoid overburdening and fatiguing community groups who get approached a lot.
- Sustaining the relationships is really important, not seeing interactions with the community as a one-off thing – or if it is, then being clear and managing expectations about what the arrangement is.

7.5 Natt Day, Patient Involvement and Engagement Lead, UCLPartners

About Natt

Natt develops, delivers and evaluates the UCLPartners Patient and Public Involvement and Engagement (PPIE) strategy. This includes developing lived experience communities; creation of a PPIE panel; and working on institutional culture change to enable patient involvement in governance and priority setting. Natt was previously PPI lead in the PE team at QMUL.

Interview headlines

- They don't deliver or facilitate PPI themselves – instead take a capacity building approach
- Strategy published Feb 2022 and developed through a robust collaborative process: https://uclpartners.com/about-us/ppie-strategy/
- EDI – social justice argument for needing proper representation within PPI, so that all needs are considered.
- Existing structures and models don't work for underrepresented communities – we need to go out into communities and find contributors where they are and where they feel comfortable. This is time consuming and resource intensive.
- They have developed a payment policy that other institutions can use to make the case for fair and effective incentivisation and remuneration of contributors. This is in the Resources folder.
- PE teams as capacity building vs delivery roles. Their approach is to empower researchers to do their own PPI, with support (meetings to chat, sense checking adverts) from PE team.
- Need for strategic organisational support for doing PPI (i.e. it is expected of you as researchers within this institution)
- Effective messages she uses to incentivise reluctant researchers:
  - funders require it
  - the institution expects it and has committed to it strategically

- o promotional criteria
- o negative impact on research/career if you don't do it

7.6 Alison Thomson, Lecturer in Patient Public Involvement and Public Engagement in Science, QMUL

About Alison

Alison is a designer and researcher currently based in the Preventive Neurology Unit. Her practice-based research sits at the intersections of PPI, PES, Science and Technology Studies and Design Research.

She aims to articulate how design-led methods can study the notion of 'patient experience' within both healthcare and medical research settings, leading to the design of more inventive service interactions.

Alison studied Design Interactions at the Royal College of Art, before completing her PhD in design-led research at Goldsmiths, University of London. She has collaborated with the Bart's MS research team in the Centre for Neuroscience and Trauma at QMUL since 2012, focusing on interactions between people with MS and researchers studying the condition. Her designs investigate how patient experiences of people with MS might be improved through speculative design, design-research and design-led interventions.

Interview headlines

- Alison has an interesting perspective as she comes from a design/Public Engagement theory background, but is now an academic who thinks analytically and critically about PPI. Not a researcher needing to do PPI for her grants, nor a PE person who is involved on an operational or strategic level, but something else.
- She would like to have a workshop where everyone funded by RE shares what they have done and what they have learnt. She was very interested to hear about Bath's approach. Universities might get individual gains from their RE-funded work but without wider sharing there won't be any larger-scale sector changes – "oh no, here we go again" she thought when the money came through.
- QMUL's approach to using the RE money has been to create a postdoc researcher post for a year. Also 2 x community researchers. Postdoc will be doing an audit of PPI and PR at QMUL and looking critically at what audiences/communities/contributors get out of it. Similar to Bath's approach (internal mapping) but led by an academic researcher.
- In her experience, patients participating in PPI value face to face contact; are motivated by altruism (but the financial side is also important too); and need links between their community and the university to be carefully built and maintained.
- Make finance processes easy, and make sure that payment doesn't cause problems for e.g. disability living allowance.
- Important to do PPI on the contributors' terms, in a way that suits the group rather than the academics – this may not be between 9am-5pm or inside the university buildings! Although some people might like this and see added value in this, so it is important to develop it appropriately, and ask what is of value to the specific group you want to work with.
- EDI is an issue in PPI – you tend to get the same people, with the same perspectives. The focus for the future has to be on diversity. And we need to honestly ask ourselves – what's in

it for them? How do we persuade and enable these traditionally under-represented groups to participate?

- Perhaps we should be looking into the community for people who can help us do this work, rather than from within universities – they are arguably better placed to be able to communicate with people who aren't academics.
- They have a very oversubscribed undergraduate Public Engagement module for third years across medical faculties and pharmacology – students are very keen to develop this skill set. She is happy to talk further about this module if we'd like to know more.

7.7 Steven Blackburn, Associate Professor in the Institute of Applied Health Research, University of Birmingham

About Steven

Steven is Associate Professor in the Institute of Applied Health Research, University of Birmingham. An applied health researcher, with specific expertise in Patient and Public Involvement and Engagement. Steven is the lead for public involvement in NIHR Research Design Service (RDS) West Midlands. Current Chair of the national RDS Public Involvement Community and Public Involvement Lead for the RDS National Office, responsible for the delivery of a national RDS Public Involvement Strategy. He has contributed to several NIHR initiatives to improve the quality of public involvement and engagement in research. He, until very recently, led PPI at the University of Keele.

Interview headlines

- He has helped to inform a new funding scheme, the NIHR Programme Development Grants call for Developing Innovative, Inclusive and Diverse Public Partnerships. This will fund a series of awards that will be contributor-led or embrace true partnerships between the public and researchers. The public will not be a sounding board for new research ideas, but actively generate them. Community groups, charities and faith organisations will be encouraged to partner with researchers to co-develop proposals for meaningful projects with a direct impact on them and their constituents. Researchers will then help them turn these ideas into pragmatic proposals. Up to £150k to support work over an up to 18 month period. More information here: https://www.nihr.ac.uk/blog/its-time-for-patients-service-users-and-the-public-to-lead-development-of-new-research-ideas/29669
- His background is in engineering (medical devices) where he was interested in taking a human and patient centred approach. He thinks that too many organisations, companies and technologists come up with a cool piece of kit and then ask "what shall we do with it?" – instead we need to work with people to find out what their needs are, and involve them in designing, prototyping and testing solutions. He sees human-centred design in engineering and NIHR PPI frameworks in healthcare as convergent thinking – both coming to the same realisation of the importance of considering users in design.
- Human centred design is well recognised in engineering circles – there is an international standard for it, he knew it as ISO 13407 https://www.iso.org/obp/ui/#iso:std:iso:13407:ed-1:v1:en This has now been withdrawn, but may have been superseded by this one: https://www.iso.org/obp/ui/#iso:std:iso:9241:-210:ed-2:v1:en
- He sees stress and anxiety from researchers around diversity – they worry about not recruiting the right people and this, he thinks, can be counter-productive as it can lead to a box-ticking mindset. He thinks that the emphasis should be on being inclusive, not meeting

quotas/targets because you don't have much control over who you can recruit. But at least if your approach is inclusive you have a better chance of achieving diversity.

- Being an all round engaged researcher is hard – you need a wide skill set to do this well. You need personality, creativity, an ability to talk and communicate in order to engage with different communities. He sees academics struggling with this – they need more training and support to develop their skills.
- PR is really hard to get funded in the UK because it is not seen as rigorous. Processes need to be made more straightforward e.g. at present application forms are too complex and a barrier for community groups applying.
- Researchers need to be given recognition and capacity to do PPI/PR. At Birmingham they have changed their staff recognition to have PE as one of their three pillars – this is now recognised at annual reviews. Staff need to be given opportunities, time and support to do it.
- Research Design Service North East have recruited research facilitators who are based within community organisations, who have been specially recruited and trained and can help make the connections within the communities when needed.

8. Patient and Public Involvement survey

8.1 About the PPI survey

The survey was open for four weeks between 6 June and 4 July. It was sent to 11 institutions via personalised, individual emails.

The survey received five responses from three institutions: the University of Cardiff, the University of Edinburgh, and the University of Keele.

All respondents gave consent for their contributions to be shared in a way that anonymises their role and institution.

Respondents included PPI&E Coordinators, a lecturer who brings public contributors in to support teaching, and academic leads working to embed PPI within Centres for health research.

The two respondents from the University of Edinburgh were willing to be contacted for a follow up conversation:

- Jenny Robertson, PPI&E Coordinator jenny.l.robertson@ed.ac.uk
- Tracy Jackson, Senior Research Fellow and Respiratory PPI Lead, Asthma UK Centre for Applied Research tracy.jackson@ed.ac.uk
  She recently gave an interview about her PPI work: Dr Tracy Jackson appointed Centre PPI Co-lead | The University of Edinburgh

8.2 Headline findings

- Recruitment of participants appears to be a common challenge, particularly the administrative challenges of building a database, and being able to access sufficient numbers and types of participants to support the amount of studies being run and their specific requirements.
- PPI is supported by a range of different roles, which varies between institutions. These include Public Engagement staff, PPI specialists and academics with a PPI remit.
- Payment takes many forms. Reimbursing expenses was the most commonly reported way of paying participants, followed by paying a fee/honorarium, and offering vouchers.
- No one reported that a lack of a clear strategy for PPI was a challenge for them, and PPI appears to be functioning well at these institutions. We can infer that having a clear strategy is necessary for good quality PPI, and Bath should consider setting out its vision and objectives for PPI in a clear and defined way.
- Increasing the diversity of participants, embedding PPI in research, and building teams and communities were given as ambitions for the future.
- Advice for Bath included paying people on time; ensuring that academics follow up and feed back to PPI participants; and funding a dedicated member of staff who can give 100% of their time to PPI.
- Sadly no one could suggest examples of PPI with engineering/EPSRC funded research!

8.3 Interview responses

Please note that some numbered questions were follow ups to previous questions, so not all numbers are detailed here. For full survey responses see PPI Survey folder.

Q1 What do you do, and with whom?

Respondents work with patients, carers, family members, people with lived experience, and charities. Most talked about involving people throughout the research cycle.

- "We have public members involved…from research question through to implementation"
- "In our centre we have PPI members involved from idea generation to dissemination. They are co-applicants on grant applications, get involved in study design and analysis, advise on recruitment and are co-authors on papers. They sit on centre management committees and are actively involved in recruiting new staff members etc We see PPI members as colleagues, nothing less."

It is important to recognise that the respondents don't speak for their university as a whole, but their Centre or School. As one respondent said: "PPI is done differently at within each School and department at the university"

Q2 & 3 Do you use the UK Standards for Public Involvement (published by NIHR INVOLVE and Health and Care Research Wales in Nov 2019) as a framework? Do you find them useful?

All said yes, and most said they find them useful. One respondent (an academic lead) commented that the guidelines are useful for "overarching principles, but I think the specifics are sometimes lacking e.g. how to improve diversity and inclusion."

Q4-6 Do you use any other toolkits or frameworks to inform how PPI is done at your institution?

4 out of 5 respondents use the NIHR payment guidance

Other guidance mentioned (No links were included so I have included links that I found myself, with the caveat that this might not be exactly what was meant):

- GRIPP2 impact framework (I couldn't find an exact match for this but found this which could be useful: https://www.england.nhs.uk/sustainableimprovement/impact-framework/)
- Race Equality Framework Race Equality Framework https://www.nihr.ac.uk/documents/nihr-race-equality-framework/30388
- Recently published NIHR/Health Research Authority/Health Care Research Wales guidance for organisations on payment processes https://www.nihr.ac.uk/documents/Payment-for-Public-Involvement-in-Health-and-Care-Research-A-guide-for-organisations-on-determining-the-most-appropriate-payment-approach/30838

Q7 & 8 Do you have your own database/network of patient/public contributors? If not, do you use other organisations' networks?

4 out of 5 respondents reported having their own networks. Other networks used are Health and Care Research Wales Involvement community, and People in Research.

One respondent mentioned needing to use bigger databases to access sufficient people "we run studies on so many different conditions that we need different people all the time". And one mentioned the difficulties of building a personal network of PPI contacts: "we can't get this information directly from the study teams because of GDPR. So they have to ask them to get in touch with us and it doesn't always happen."

Q11 How do you incentivise and reimburse contributors for their involvement?

The most common responses were:

- We reimburse expenses (4 out of 5 respondents chose this option)
- BACS payment (4 out of 5 respondents chose this option)
- We pay a fee/honorarium (3 out of 5 respondents chose this option)

- We offer vouchers (3 out of 5 respondents chose this option)
- Charitable donation (2 out of 5 respondents chose this option)
- We don't pay contributors (1 out of 5 respondents chose this option)

No one reported paying participants in cash or in kind payment (e.g. food, goods).

Q12 & 13 How well do you think this approach works?

All respondents felt that their approaches to payment worked very well or fairly well.

Comments:

- "We try to be flexible depending on the person's situation and needs."
- "Not all public members want to accept payments. We use vouchers in certain instances e.g. children involved with PPIE."
- "For almost all studies we include money for PPI 'honorariums' in the grant application and we pay these by BACS."

Q14-16 Who is responsible for the recruitment of patient/public contributors?

Who organises and facilitates meetings between academics and patient/public contributors?

Who maintains the long term relationship between academics and patient/public contributors?

This varied between institutions. Three respondents reported that recruitment, facilitation, and relationship maintenance are all carried out at their institutions by PPI specialists. One respondent reported that recruitment is led by academics at their institution, while facilitation and relationship maintenance is shared between Public Engagement staff and academics. Another respondent reported that Public Engagement staff and academics share all three aspects at their institution.

Interestingly, no one reported working with external partner organisations or consultants on these aspects of PPI.

Q18 What staff roles exist to support PPI at your institution?

'Academics with PPI remit' was the most popular choice, with 4 out of 5 respondents indicating that PPI is supported by people in this role at their institution. Only 2 respondents indicated that Public Engagement staff support this work. Impact Development staff and Research Development staff were also reported to support PPI at some institutions (3 and 2 respondents respectively).

Q19 How is this work funded?

The majority of respondents indicated that PPI is funded as part of research grants (4 out of 5 respondents chose this option). Departmental budgets and PPI-specific grants were also indicated as sources of funding (by 2 respondents each).

Q20 What training and support is available for academics?

The majority of respondents said that they have developed their own training resources (4 out of 5 chose this option). No one said that they deliver training resources that have been developed elsewhere, or use an external trainer. 4 out of 5 respondents also said that they work with academics at the grant development stage to help them include PPI in their funding applications, and work with them post-award to help them develop and deliver PPI.

Other methods of support mentioned:

- Documents developed by PPI staff to help academics at pre and post award stage
- Advice clinics
- One institution signposts their academics to training from UCL and Health and Care Research Wales (HCRW)

Q21 What are your biggest challenges? And which is the single biggest one?

The most common challenge was reported to be recruiting patients/public contributors to take part (4 respondents out of 5 chose this as a multiple choice option). Two respondents also chose this as their single biggest challenge.

Lack of funding was chosen as the single biggest challenge by 2 out of 5 respondents. The remaining respondent chose persuading/motivating academics to do PPI as their single biggest challenge.

Other challenges indicated by the respondents (as multiple choice options)

- Working with contributors with complex needs/access issues (3 out of 5)
- Lack of time (2 out of 5)
- Lack of appropriate or sufficient staff resource (2 out of 5)
- Managing relationships between academics and patients/public contributors (2 out of 5)
- Working with children and/or young people as patients/public contributors (2 out of 5)
- Payment of patients/public contributors (1 out of 5)
- Finding appropriate venues where PPI can take place (1 out of 5)
- Lack of institutional support for PPI (1 out of 5)
- Developing/sourcing training resources (1 out of 5)

No one reported experiencing a lack of a clear strategy for PPI.

Q23 What would you like to have more of?

Top picks were staff and time (4 out of 5 each), followed by funding and institutional support (3 out of 5 each). No one selected physical infrastructure (e.g. buildings, venues).

Q24 What are your aspirations for the future?

- "A more diverse network of public contributors and for PPI to be an integral part of PPI [sic] that all researchers take responsibility to do"
- "To grow our PPI Team to support our whole school, rather than just our centre"
- "PPIE becomes valued by all academics and is not tokenistic"
- "To embed PPI into the research culture of the School as well as it is embedded within education and better demonstrate impact of PPI"
- "To build a PPI community in our Centre, so that members of the public are not in silos on their studies; to involve more diverse member of the public; to do PPI research"

Q25 What advice or recommendations would you offer the University of Bath?

- "Make sure you fund your PPI. Ideally have a member of staff who can give 100% of their time to PPI"
- "Always pay PPI members on time and for everything they do. Always give feedback for everything they've been involved in - biggest complaint I hear from PPI members is that academics never say thank you or tell them how their involvement has contributed"

- "Speak regularly to academics and public members to explain the value of PPIE for getting research into practice"
- "Reach out to external networks/third sector to recruit PPI representatives"
- "Have a clear strategy and goals for the next year, three years"