

# DARE UK

## Public Involvement and Engagement in Sensitive Data Research: Lessons Learned from the DARE UK Sprint Exemplar Projects

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### Table of Contents

1. Executive Summary .....	2
2. Abbreviations.....	2
3. Introduction.....	2
4. The DARE UK Sprint Exemplar Projects .....	3
5. PIE in the DARE UK Sprint Exemplar Projects.....	4
6. Insights from PIE Leads’ experiences.....	5
6.1. Making sense of PIE.....	6
6.2. Getting PIE buy-in .....	7
6.3. Carrying on PIE activities .....	8
6.4. Reflecting on PIE approaches .....	10
7. Discussion .....	14
7.1. Summary of key learnings .....	14
7.2. Recommendations for future research .....	14
8. Conclusion .....	15
9. Acknowledgements .....	15

## 1. Executive Summary

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In recent years, the collection, storage, and analysis of sensitive personal data have become an important topic of discussion. With the rapid advancement of technology and the growing availability of data, the ethical and social implications of sensitive data research have come to the forefront. As a result, Public Involvement and Engagement (PIE) is increasingly being recognised as crucial to ensuring the ethical and trustworthy use of data while encouraging relevant and high-quality research.

The following report summarises the PIE activities carried out as part of nine DARE UK Sprint Exemplar Projects to promote a better understanding of how members of the public can be involved in and contribute to sensitive data research. It also discusses the characteristics of these activities, including lessons learned from the PIE Leads coordinating their design and delivery.

A set of recommendations are provided at the end of this report. While they are to be considered specific to the contextual circumstances of the DARE UK Sprint Exemplar Projects, they can encourage reflection on how best to involve and engage members of the public in sensitive data research, including the resources necessary to promote meaningful and inclusive PIE activities.

## 2. Abbreviations

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ADR UK	Administrative Data Research UK
DARE UK	Data and Analytics Research Environments UK
GRIPP 2	Guidance for Reporting Involvement of Patients and the Public 2
HDR UK	Health Data Research UK
PIE	Public Involvement and Engagement
UKRI	UK Research and Innovation

## 3. Introduction

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In the field of sensitive data research, the significance of public involvement and engagement (PIE) cannot be overstated. As technological advancements continue to accelerate, the generation, access, and use of sensitive data to further knowledge and enable evidence-based decision-making are becoming increasingly prevalent. However, the sensitive nature of these data gives rise to ethical and privacy concerns.

Within this context, PIE becomes crucial to ensure transparency, accountability, and, ultimately, societal acceptance. While PIE has been known within the field of health and social care research for over two decades, its presence in sensitive data research is recent and still evolving. Consequently, there is little understanding of how best to involve and engage members of the public in this field.

This report aims to address this lack of knowledge by sharing recommendations developed from the experiences of PIE Leads involved in the nine DARE UK (Data and Analytics Research Environments UK) Sprints Exemplar Projects carried out in 2022.

## 4. The DARE UK Sprint Exemplar Projects

DARE UK is a programme funded by UK Research and Innovation (UKRI) to advance the use of sensitive data for public benefit by establishing a coordinated and trustworthy national data research infrastructure for the UK<sup>1</sup>. The programme is organised in three phases, with Phase 1 providing the basis for Phase 2 and 3. Phase 1 – also known as the ‘Design and Dialogue’ phase – is the focus of this report.

HDR UK (Health Data Research UK) and ADR UK (Administrative Data Research UK) led Phase 1 of the DARE UK programme, which included funding nine ‘Sprint Exemplar Projects’<sup>2</sup>. The purpose of these research projects was to uncover and test early thinking in the development of a joined-up and trustworthy national data research infrastructure to support cross-domain analysis of sensitive data at scale for public good.

The nine projects, which crossed different research sectors and UKRI research council remits, were all carried out from January to August 2022, with distinctive aims (see Table 1) in line with DARE UK’s overarching mission. All the projects were required to embed PIE activities throughout the research process to better understand the public perspective on the work underway and identify methods of meaningful involvement to ensure trustworthiness and transparency<sup>3</sup>.

Table 1. Overview of the Sprint Exemplar Projects

Sprint Exemplar Projects	Key aims
<a href="#">TREEHOOSE: Trusted Research Environment and Enclave for Hosting Open Original Science Exploration</a>	Creating an open-source TRE using a secure internet cloud connection rather than a local data centre, promoting research data analysis at scale while maintaining high data protection
<a href="#">PRIAM: Privacy Risk Assessment Methodology</a>	Creating a standard privacy risk assessment framework to ensure secure handling of data managed by multiple organisations and encourage cross-sectors collaborations
<a href="#">STEADFAST: Education outcomes in young people with diabetes – innovative involvement and governance to support public trust</a>	Exploring the best way to involve and engage with young people living with diabetes, their families and the wider public in issues surrounding the use of their data for research and innovation
<a href="#">‘Virtual’ TREs: Creating a federated, cloud-based trusted research environment to facilitate collaborative research between existing institutions</a>	Developing a working platform that promotes research collaborations across academia, public sector bodies and industry by encouraging the use of cloud-based data technologies
<a href="#">Overcoming technical and governance barriers to support innovation and interdisciplinary research in trusted research environments</a>	Investigating the public perspectives on the use of highly secure digital environments (i.e., TREs) by non-traditional researchers to access health and social care data, developing recommendations for future practice
<a href="#">FED-NET: Creating the blueprint for a federated network of next generation, cross-council trusted research environments</a>	Creating a secure way to combine and analyse sensitive data separated by geographical context and data language, tackling technical and governance challenges
<a href="#">Multi-Party TRE federation: Establishing infrastructure for secure analysis across different clinical-genomic datasets</a>	Demonstrating the benefits of establishing infrastructure for secure analysis of clinical-genomic datasets held in different highly secure digital environments (i.e., TREs), promoting collaborations across research councils

<sup>1</sup> <https://dareuk.org.uk/about/>

<sup>2</sup> <https://dareuk.org.uk/our-work/sprint-exemplar-projects/>

<sup>3</sup> <https://dareuk.org.uk/involving-the-public>

<a href="#">FAIR TREATMENT: Federated Analytics and Artificial Intelligence Research across Trusted Research Environments for Child and Adolescent Mental Health</a>	Developing technical and governance solutions to improve young person’s mental health by tackling challenges posed to the access, link and analysis of relevant data secured in different places (e.g., across health, education, and social care records)
<a href="#">GRAIMatter: Guidelines and Resources for Artificial Intelligence Model Access from Trusted Research Environments</a>	Exploring the privacy risks associated with artificial intelligence and machine learning handling sensitive data, developing methods and tools to ensure confidentiality is maintained

## 5. PIE in the DARE UK Sprint Exemplar Projects

The DARE UK programme has adopted the INVOLVE<sup>4</sup> definition of PIE. Therefore, in this report, ‘involvement’ is intended as research carried out with or by members of the public, while ‘engagement’ refers to disseminating information to promote understanding of research and create awareness of related outputs. Based on this definition, it can be asserted that the nine DARE UK Sprint Exemplar Projects included various PIE activities (see Table 2), resulting in multiple and distinct outcomes. These included a greater understanding of project acceptability and challenges, more inclusive and successful recruitment of participants, the identification of new themes among data collected and alternative ways of interpreting them, the development of clear and accessible content for involvement and engagement activities, and the identification of appropriate ways of disseminating findings. Although the context and purpose of activities differed, and more detailed information about their impact can be found online<sup>5</sup>, the experiences shared by the PIE Leads revealed a series of common approaches and challenges, which are discussed in the following section.

Table 2. Summary of PIE activities and related aims

Sprint Exemplar Projects	Public Involvement and Engagement Activities
TREEHOOSE: Trusted Research Environment and Enclave for Hosting Open Original Science Exploration	Two workshops involving members of the public to (a) explore the current understanding of Trusted Research Environments and related key topics of interest; and (b) learn how to ensure accessibility of language in the development of material for information sharing.
PRiAM: Privacy Risk Assessment Methodology	Four workshops involving members of the public gathered in a newly established forum to (a) investigate personal perceptions of privacy risks in the sharing of data, and (b) contribute to developing a questionnaire to collect information from the general public.
STEADFAST: Education outcomes in young people with diabetes – innovative involvement and governance to support public trust	<ul style="list-style-type: none"> <li>- A member of the public was involved in the development of the proposal.</li> <li>- A Public Involvement Advisory Group was established to ensure ongoing collaboration with public members throughout the project.</li> </ul> Nineteen focus groups were conducted, giving members of the public the opportunity to (a) explore issues identified in previous research and related to Information Governance frameworks, differences among the nature of sensitive data and their current and future use; (b) co-develop a toolkit to inform public involvement approaches; and (c) suggest adequate ways of

<sup>4</sup> INVOLVE. 2018. Patient and public involvement in health and social care: A handbook for researchers. Available from: [https://www.rds-london.nihr.ac.uk/wpcms/wp-content/uploads/2018/10/RDS\\_PPI-Handbook\\_2018\\_WEB\\_VERSION.pdf](https://www.rds-london.nihr.ac.uk/wpcms/wp-content/uploads/2018/10/RDS_PPI-Handbook_2018_WEB_VERSION.pdf).

<sup>5</sup> <https://dareuk.org.uk/our-work/sprint-exemplar-projects/>

	communication with younger generations and possible ways of dissemination of findings.
'Virtual' TREs: Creating a federated, cloud-based trusted research environment to facilitate collaborative research between existing institutions	Two series of sessions involving public members recruited from pre-established groups discussed the acceptability of the project and contributed to the analysis of data collected.
Overcoming technical and governance barriers to support innovation and interdisciplinary research in trusted research environments	Two sessions were designed to ensure an informed contribution to the project by members of the public. The first session focused on introducing key concepts such as health data, health data use, and health data services. Meanwhile, the second one unfolded through small group discussions on case studies designed to encourage reflection on the range and diversity of organisations, researchers, purposes and benefits of data access and deliberation on principles informing approaches.
FED-NET: Creating the blueprint for a federated network of next-generation, cross-council trusted research environments	A series of workshops organised to design with members of the public clear and accessible material explaining the concept of federated analytics and the aims of the project.
Multi-Party TRE federation: Establishing infrastructure for secure analysis across different clinical-genomic datasets	<ul style="list-style-type: none"> <li>- A member of the public contributed to the original proposal at the development stage and provided ongoing support by joining the formal governance board once the project commenced.</li> <li>- Pre-established PIE groups were involved in three activities, including (a) a session that helped develop a shared summary of the project; (b) a focus group that revealed preferences on data access requirements; and (c) an information session that focused on increasing understanding of federation.</li> </ul> <p>Patients and members of the public worked with the research team on the development of a 'Frequently Asked Questions' document.</p>
FAIR TREATMENT: Federated Analytics and Artificial Intelligence Research across Trusted Research Environments for Child and Adolescent Mental Health	<ul style="list-style-type: none"> <li>- A workshop organised during the technology workstream led to exploring the public's acceptability of the project and expectations on technical approaches and safeguards policies.</li> </ul> <p>A workshop in the co-creation stages of the governance workstream gave members of the public the opportunity to provide suggestions on governance approaches, language used for communication purposes, and ways to promote</p>
GRAIMatter: Guidelines and Resources for Artificial Intelligence Model Access from Trusted Research Environments	<ul style="list-style-type: none"> <li>- Members of the public were involved as co-applicants of the project and were then invited to provide ongoing support once this started.</li> </ul> <p>Five focus groups to discuss with a newly established group of public members the technical, ethical, and legal challenges of machine learning, giving them the opportunity to advise on how to overcome those and ultimately affect the development of recommendations.</p>

## 6. Insights from PIE Leads' experiences

The experiences of the PIE Leads in the DARE UK Sprint Exemplar Projects were captured through nine semi-structured interviews conducted remotely by an HDR UK Intern as part of an evaluation study during her internship programme from July to August 2022. These interviews, along with other sources such as surveys, shed light on the innovative and inclusive work carried out by these PIE Leads. Hence the decision to deepen the understanding of their practices by assessing further their experiences through theoretical lenses that could help

unpack the process characterising PIE, identify enablers and challenges, and inform the development of broader recommendations for future research. As a result, in this report, key insights from PIE Leads’ experiences are organised into four overarching themes, drawing from the domains of the theoretical framework chosen<sup>6</sup>. The interpretation of these themes is indicated in Table 3, and the narrative associated with them, including anonymised quotes from the interviews, is reported below.

Table 3. Overview of themes

Themes	Interpretation
Making sense of PIE	Sense-making work influencing individual/collective approach to PIE
Getting buy-in to PIE	Relational work necessary to build and sustain PIE throughout the research process
Carrying on PIE activities	Operational work conducted to promote meaningful and inclusive PIE activities
Reflecting on PIE approaches	Appraisal work informing suggestions for positive change

## 6.1. Making sense of PIE

PIE Leads designing and conducting the activities carried out as part of the DARE UK Sprint Exemplar Projects had varied knowledge and experience of public involvement in research. However, they all agreed on the value of public contributions to the research process.

*‘Obviously the people who were involved, the actual members of the public, were just really great. They had really great suggestions, they asked incredibly thoughtful questions, which is exactly what we needed. We needed people to bring up things that we may not have thought about. Because, as researchers, we kind of exist in our little bubble, and there are things that we worry about, but some things just wouldn’t really occur to you.’ (PIE Lead)*

Engagement with members of the public was perceived as an opportunity to provide accessible information about the projects, encouraging a better understanding of the research context and topic as well as addressing related inquiries.

*‘We actually started with something that was almost all public engagement-focused or deliberately communications-focused. Because more than half [of] the challenge in what we’re doing in this project is just trying to explain what even Federation is. [...] So, we gave them a very brief overview of what we knew and then, we spent, I think, about one hour, just doing Q&A [question and answer].’ (PIE Lead)*

While there was consensus on the value of involvement and engagement, several teams lacked experience in PIE and how to carry it out, especially within the short timescale of a ‘sprint’ project. There were concerns about the quality of activities carried out, insufficient resources to do better and a desire for more guidance and support.

<sup>6</sup> Murray, E., Treweek, S., Pope, C., et al. 2010. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC Medicine 8, 63. doi: 10.1186/1741-7015-8-63.

*'I think you assumed we all collectively knew a hell of a lot more about [PIE] than we actually did. I mean, you've got some people on the sprint programme that clearly have done this before and know what they're doing. I think we probably knew the absolute least of anybody. But I know from talking to other groups, I think there was a full spectrum. So, I think nothing has particularly gone badly. But it has been the sense of a frantic race against time to put something in place, calling a huge number of favours even to get what we did off the ground.'*  
(PIE Lead)

Most PIE Leads felt that involvement, as well as engagement, is a learning process, difficult to anticipate or fully address in first instances. However, some of them suggested building a set of standard approaches drawing from sharing lessons learnt. Doing so could support PIE Leads by ensuring clarity of expectations and coherence of approaches.

*'So, we can actually have a centralised vision; come up with clear standards, clear methodology, that people could have adapted rather than just saying, okay, that's what you have to do, make it happen. [...] It's about having a bit more of clear guidelines, expectations, and more of a centralised approach, even if it's people [PIE Leads] coming together.'*  
(PIE Lead)

## 6.2. Getting PIE buy-in

According to some PIE Leads, getting the research team's buy-in into PIE is one of the challenges of embedding involvement and engagement activities in research. Positive leadership was recognised as one of the resources that could ensure an understanding of the value of PIE activities, ensuring this becomes an integral part of the research process.

*'I think, for me, it's all about leadership. If you don't have that leadership at the beginning, you won't get that buy-in from the project team. And if you don't get the buy-in from the project team, none of it works. So, you need the leadership from the very beginning.'* (PIE Lead)

If, on the one hand, the support of the research team could help ensure the conduct of PIE throughout the research process, on the other hand, the collaboration with community groups and charities was deemed crucial to ensure wider and more diverse outreach considering their ongoing engagement with public members and the trustworthy relationship with them.

*'I think we did very effectively through the community groups we worked [with]. [...] we were able to reach out to five different groups that support outreach to different communities and research [...] Caribbean and African Health Network, South Asian Health Action, Research Black, Chronically Brown and Dietician Ellouise. [...] And I think through these groups we did things that, you know, otherwise we wouldn't be able to do.'* (PIE Lead)



*'For me the standout thing is the collaboration between the University and the Diabetes UK, because there are things that charities do exceptionally well, particularly in terms of reach and engagement and trust with those constituents. [...] So, working together, I think was utterly key.'* (PIE Lead)

While the initial buy-in was a crucial step to ensure the successful recruitment of public members, the ongoing attitude of research team members involved in the PIE activities was considered important in retaining them throughout the projects. Active listening and clarity of expectations were deemed facilitators of the ongoing public commitment.

*'So, you need to make sure that people feel like what they're saying is being heard. [...] very simple things like wow, that's a great question [...] we haven't thought about that, you know, just positive feedback to what they're saying. Not turning down anything or say, no, no, you can't say that, or that's a terrible idea. [...] Even if someone does say something [not feasible] explain, well, actually, that sounds great, but the reason we couldn't do this, or we won't be able to do this is x and y. And people are very receptive to that.'* (PIE Lead)

At the same time, particular focus was placed on the importance of sharing how the contributions received from members of the public have impacted the research project. This would not only guarantee the ongoing buy-in of members actively involved in that project but also impact the general public perception of PIE, building trust by demonstrating a commitment to it rather than a tokenistic attitude towards it.

*'But also, just demonstrating that their feedback has been taken on board [...] So, when someone who hasn't participated in the [public involvement] work, any member of the public would like to access, you know, the [public involvement] section of the project. And we can demonstrate, this is what we've done in detail. This is how we're listening to people. This is how we're incorporated things that people have told us. So, I think that is important to basically build trust, I think with the public is just showing that like, it's not just like a box ticking exercise, like we're actually listening to them.'* (PIE Lead)

### 6.3. Carrying on PIE activities

The operational work characterising the PIE activities was specific to the context of the projects. The activities had various designs and purposes (see Table 2) and took place at different stages of the research process, from the developmental phase (e.g., commenting on the research proposal) to the management (e.g., shaping data collection and analysis) and or dissemination phases (e.g., contributing to developing information sharing material). However, some priorities were common among projects, such as ensuring jargon-free language.

*'We were introduced to a fantastic website called Splasho, which we played in the workshops with the participants. [...] This helped explain it [the project] in the 10,000 most commonly used words in the English language. [...] we made people bring it back to really simple language, and actually, it was really fun.'* (PIE Lead)

Providing public members with the material before the activities was considered good practice, though challenging timewise. Additionally, according to some PIE Leads, there was value in presenting public members with an overview of the PIE plan on the day of the activity, including a clear statement of the aim.

*‘So, part of our engagement included [an] information sheet. So, every participant was issued with a description of the workshop, what will be expected, how information will be used, and all those different things. During each workshop, we provided a presentation that summarised the overall engagement but also details of what activities will be undertaken during the specific workshop.’ (PIE Lead)*

The value of translating lengthy and technical information into clear and succinct manners was perceived as crucial in ensuring understanding and encouraging focus throughout the duration of the activities. Communicating in a variety of formats, such as texts, videos and audio, was also considered a way to be responsive to people’s needs.

*‘No matter what we did, it was always no more visuals or diagrams. Less text and more bullet points, like really simplifying this down. People’s attention is not going to last for like, you know, a whole page of this. [...] have a text version, have a video version, have an audio version.’  
(PIE Lead)’*

When conducting activities remotely, the use of some online collaborative platforms enabled public members to effectively work together in a more interactive way, encouraging various forms of contribution.

*‘We use something called Miro. Have you ever heard of it or used it? So, it’s basically an endless piece of paper. So, you log into a mural board, and you can put slides and you can go through like a normal PowerPoint presentation. [...] So we did the workshops over Zoom and our participants could log in into the board and they could leave sticky notes, they could move things around, they could put arrows [...] or vote on polls and things like that.’ (PIE Lead)*

In relation to the conduct of PIE activities, particular attention was also devoted to their facilitation. In particular, in some projects, the presence of members of the public leading the activities was considered a facilitator of engagement.

*‘They saw us [public members nominated PIE Leads of the project] as being part of the group [...] In the way we talked to them and explained things, they knew. [...] Because they could relate to us and not feel different or somehow [...] how can I say? Intimidated, yes, that’s the word I was looking for.’ (PIE Lead)*

Meanwhile, in other projects, professional facilitation and humble attitude were seen as responsible for the resulting dynamic conversations.

*‘So, rather than I’ll read from the script and now tell me what you think, and everyone just goes, we have no idea what you just said, I tried to go in with very clear understanding of the problem. [...] I suppose I was trying to tell a story trying to prompt questions with genuine answers to and being open to letting the debate go where it needed to be in the moment and being genuinely responsive to people as well.’ (PIE Lead)*

Following the activities, several PIE Leads would dedicate some time to check in with public members who had attended to investigate whether they had a pleasant experience and if there were any unanswered questions. Some PIE Leads would also contact them individually before the activity to ensure attendance was not affected by any accessibility challenges.

*‘One of the things that I do in all of our projects is check in with people after. So, if we have a group meeting, I will catch up one on one with the people after the event, just to help ensure that they understood it that they felt comfortable, that their questions that they wanted to ask were asked and if they weren’t, how could we help them ask those questions in another way? [...] Likewise, in terms of the next meeting, we would often do a quick call with people just before or message them and just say, you know, the meeting is this evening, are you comfortable? Is there anything that you need to know to help you access this? We’re very familiar with the challenges of accessibility to projects [...] and we do our best to make sure that everyone has a fair voice.’ (PIE Lead)*

To encourage the contribution of members of the public on the day, some PIE Leads tried to build momentum and capacity by creating a group chat that helped share relevant material between activities and promoted ongoing support.

*‘I actually set up a WhatsApp group [...]. Because I was trying to build up this engagement of the group and sharing and helping one another to understand anything that may well be trouble in between workshops. So that group has been really, really good. Because we’ve been sharing articles that have been surfacing from the department of health and social care. [...]. So, they’re starting to build up knowledge that was going to be useful to our next meeting. [...] we did maintain effort [between] the workshops to ensure that people, if troubled, answers were provided to them to help them to go to the next workshop.’ (PIE Lead)*

## 6.4. Reflecting on PIE approaches

The importance of developing a PIE strategy alongside the research project proposal was considered an opportunity to ensure the research team members' buy-in and embeddedness of PIE activities throughout the research study.

*'We were able to write the [PIE] strategy as the grant was being developed. So that ensures that their voice is truly embedded the whole way through the project. [...] So, we did a couple of in-depth meetings with that [research] team once we had agreed to support them, to ensure that [PIE] was taken as seriously as it was within the project. [...] So that kind of early strategy for us is really important.'* (PIE Lead)

Meanwhile, early engagement with members of the public was deemed important to successful PIE approaches as it would help better understand expectations and project needs.

*'So, if you're bringing people in to help you with a project, bring them in early, have a very open conversation at the beginning to understand what you want from this engagement, what the project needs, and then most importantly, what they want to get out of project involvement.'* (PIE Lead)

When prompted about challenges experienced in the operationalisation of PIE, all Leads referred to the impact of the limited time frame of a 'sprint' project on the design and conduct of meaningful activities. While the support from other research team members was often cited as a solution to this challenge, it was generally preferred to have a well-defined PIE plan, which included the availability of team members.

*'If we had an ideal plan, when everyone was available, that would have made our lives much easier. And I wouldn't have had to work so many weekends to get the job done. [...] I found the pressure of the sprint quite challenging. And I was ... we were having to work in a very agile way, doing things that we wouldn't necessarily have been doing.'* (PIE Lead)

While the research team buy-in may have helped tackle the lack of capacity in some research projects, the success of PIE was also attributed to the level of expertise of the Lead. However, finding someone suitable for the role when the project had already started resulted in additional pressure experienced.

*'There was, at times, a capacity issue, which we have managed to overcome, because everybody was very committed. [...] but I think it's not just about resources. It's about expertise. And so, you know, in this case, we made sure that we recruited somebody with the right expertise. [...] to get that resource in through the door actually took nearly four months. [...] eight months to deliver this kind of engagement with the quality and strength of the outputs is just a hugely challenging timeframe.'* (PIE Lead)

In addition to reflections on how the limited timeframe affected the working dynamic, PIE Leads referred to several aspects of the design and conduct of activities. For instance, the schedule characterising a 'sprint' research project may have resulted in lost opportunities for meaningful involvement for both the team and the public members.

*'Timeframe was, undoubtedly ... [a challenge]. [...] In an ideal world, what we would have done was we would have had the survey, got the outputs of the survey, understood those and use that within the planning of the workshops. So, then we were able to focus more on particular aspects that we wanted to explore.'* (PIE Lead)

*'So, the project timelines are really tight. And that meant that you had to really push people to take part and to turn things around in a short period of time. Normally, if we were producing public documentation, like the brochure, we would give people a lot more time to work on it.'* (PIE Lead)

All PIE Leads tried to ensure diversity among the public members invited to collaborate with the research team on the projects. While partnering with charities or using pre-existing relationships with community groups were considered facilitators, the time spent connecting with people and gaining their consent to work with the team was considered a challenge.

*'I will start with that one. Because I think the one thing I hadn't realised before [...] all of the work [that goes into] recruitment. Everything else is fine and easy. You're attending meetings, preparing materials [...] recruitment is hard and time consuming. And it takes so much, so many different teams, so many different skills, so many different checks [...] and the effort is getting that right.'* (PIE Leads)

Once a diverse group of people was recruited to participate in PIE activities, particular attention was also focused on ensuring accessibility in the language used to communicate information and facilitate group discussions and the methods of involvement used. For instance, some PIE Leads shared how using some online collaboration platforms may facilitate young people's engagement but not necessarily their parents.

*'The parents definitely struggled with it a bit more than the young people. So yeah, something to kind of consider going forward that like parents might be not as kind of either not keen on it, or just like even if they want to participate, I don't quite get the hang of, you know, intuitively how it works.'* (PIE Lead)

Meanwhile, in circumstances where people with visual impairments are involved, some adaptations in the format of the material provided may be needed.

*'We did have some other interesting, and new for me, accessibility challenges with this and that one of the members of the public who came along is visually impaired. And so, we did have to work to make sure that the resources that we were providing for that member were different and adapted [...]. And that was quite new for me. I wouldn't say it was difficult [...] but it kind of adds another layer of doing what you're doing on top of the language that you're using in the first place.'* (PIE Lead)

Moreover, when involving people with different PIE experiences or knowledge of sensitive data research, PIE Leads may benefit from spending time engaging with them and addressing uncertainties or nervousness.

*'In any group of members of the public, you have people that, you know, they're brand new. They've done hardly any public involvement before. Data is almost entirely new to them. [Then you have] members who have been with us over eighteen months of other data type projects [...] And they bring knowledge that is related to data, but not necessarily to this project.'* (PIE Lead)

The suggestion put forward by all PIE Leads to ensure inclusive practice was to understand people's needs and negotiate the best way forward, as one size does not fit all.

*'So, I think it's, you know, meeting people where they are, on their own terms, and engaging with them in ways that they want to engage rather than the ways that we think they should engage.'* (PIE Lead)

The number of people involved in the PIE activities across the projects varied, with some Leads reflecting on the resources necessary to ensure ongoing involvement and engagement. In addition to the limited timeframe earlier discussed, some PIE Leads mentioned the costs associated with it.

*'Should we have had greater than 10 people? Should we have gone through a much bigger group and broke those into smaller focus groups? [...] the challenge with the project, of course, is the limited resourcing available. We could have spent all the money on doing public engagement, but, you know, you had to size it, it was a sprint.'* (PIE Lead)

The reimbursement of members of the public for their contribution was little documented in the reports, though mentioned by some PIE Leads when discussing the large amount of funds allocated to the activities. Some Leads expressed their disappointment in the payments to public contributors not being processed in a timely way by their institutions, with a consequent negative impact on how future PIE opportunities would be perceived.

*'We've got people still waiting for payment from the first meeting. [...] trying to get them [public members] paid, it's been absolutely rubbish. And I'm really embarrassed about it. And I think it shows really poorly on [PIE Lead] and myself. And it will potentially affect us recruiting those people in the future [...]. This is just an ongoing issue with university payment for lay members.'* (PIE Lead)

## 7. Discussion

### 7.1. Summary of key learnings

This report provides an overview of the PIE activities carried out as part of the nine DARE UK Sprint Exemplar Projects conducted in 2022 (see Table 2). It refers to the impact of PIE on each of these projects (see narrative in section 3) and gives insights from the PIE Leads involved in their design and delivery. These PIE Leads had varying levels of experience of involvement and engagement in research but seemed to agree on its value and understanding as a learning process, with some underlying the need for opportunities where to share practices to promote meaningful PIE within the limited timeframe of a ‘sprint’ project.

Positive leadership was seen as essential in ensuring an understanding of the value of PIE among research team members, making it an integral part of the research process. While the collaboration with charities and community groups was deemed crucial for wider outreach, setting clear expectations of involvement and addressing issues as they arise were seen as essential for retaining public members throughout the research projects. Sharing information on the progress and impact of involvement was highlighted as important in maintaining buy-in and building trust.

The PIE activities carried out in the DARE UK Sprint Exemplar Projects had specific designs and purposes, taking place at different stages of the research process. Nevertheless, common practices included ensuring accessible language, providing material in different formats, and offering support to public contributors throughout the PIE journey. While reflecting on approaches chosen, some PIE Leads underlined the importance of an ongoing assessment of methods of collaboration chosen to ensure inclusiveness.

The development of a PIE strategy alongside research proposals was seen as important for buy-in and embeddedness. Early engagement with the public was also key to successful PIE approaches. However, the limited time frame of ‘sprint’ projects posed a challenge to be overcome with the support of a coordinated team and expert PIE Lead. Ensuring flexibility of approaches was perceived as crucial as the timely reimbursement of honoraria.

### 7.2. Recommendations for future research

There are various reasons and methods through which members of the public can get involved in sensitive data research and engage with key issues in this field to contribute to improvement (see Table 2). Such a participatory approach to research conduct can bring about multiple benefits, as highlighted in section 3. Therefore, it is vital to ensure the progress of current PIE practices. To guide future research endeavours, Table 4 presents a set of recommendations based on the insights gained from the experiences of PIE Leads organised according to four overarching themes: ‘making sense of PIE’; ‘getting buy-in to PIE’; ‘carrying on PIE activities’; and ‘reflecting on PIE approaches’.

Table 4. Recommendations for future research

Themes	Recommendations
Making sense of PIE	Providing a platform for PIE Leads involved in sprint projects to share knowledge, allowing for collective learning and problem-solving.
Getting buy-in to PIE	<ul style="list-style-type: none"> <li>- Ensuring effective PIE leadership within the research team, including clarity of vision and direction on how to achieve it.</li> <li>- Seeking collaboration with local organisations to access the community and engage with them appropriately.</li> <li>- Setting clear expectations of involvement and addressing concerns</li> </ul>

	expressed, being open and transparent about possibilities. Promoting ongoing communication of PIE progress and impact to public members involved.
Carrying on PIE activities	<ul style="list-style-type: none"> <li>- Developing clear material for PIE activities, reminding public members of the purpose and progress of the project as an ongoing practice.</li> <li>- Negotiating with public members involved how best to collaborate, ensuring accessibility of methods chosen.</li> </ul> Ensuring adequate support to public members before, during and after PIE activities take place.
Reflecting on PIE approaches	<ul style="list-style-type: none"> <li>- Developing a PIE strategy as early as possible, reflecting on the resources available/necessary to ensure meaningfulness.</li> </ul> Being flexible in PIE approaches, ensuring ongoing assessment of methods used and timely reimbursement of honoraria.

## 8. Conclusion

This report provides an overview of the PIE activities conducted as part of the DARE UK Sprint Exemplar Projects, while documenting the experiences of the PIE Leads coordinating the design and delivery of these activities. It contributes to the sensitive data research field by giving insights into how to involve and engage members of the public, as well as identifying strategies to address challenges. Although further evidence is needed to gain a greater understanding of good PIE practice in sensitive data research, the learnings and recommendations presented in this report can prompt critical thinking among those interested in planning and conducting meaningful and inclusive PIE activities in sensitive data research.

## 9. Acknowledgements

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