

DARE UK



Final Public Involvement and Engagement report: SARA project

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1. Background

A summary of the project and its relevance to DARE UK's mission, highlighting the role of Public Involvement and Engagement (PIE) in achieving success.

1.1. What is the project about?

Semi-Automated Risk Assessment of Data Provenance and Clinical Free-Text in Trusted Research Environments (short name: SARA) is a collaboration involving the University of Edinburgh (through DataLoch), University of Aberdeen (through the Grampian Data Safe Haven, DaSH), Greater Glasgow and Clyde Safe Haven, University of Sussex, and Public Health Scotland.

Currently, a significant demand is placed on data service teams (like staff in Trusted Research Environments; TREs) – including data analysts and information governance specialists – to ensure the linkage of data from across different data systems is accurate and representative of the real world, as well as to minimise the risk of patients being identified (either directly or indirectly) through the data made available to researchers or approved for release from the TRE after researcher analysis. Comprehensive systems are in use to support data service teams already, but many of these are manual and therefore time-consuming. Consequently, there is significant potential to enhance this support by introducing semi-automated processes that would speed-up checks on core aspects of the risk assessment process – and make this more robust – as well as highlight areas where analysts and information governance experts should focus their attention.

1.2. How does it fit into the DARE UK programme?

The prototype dashboards and approaches to understanding privacy risk resulting from this project offer improved support for colleagues in risk assessment and risk mitigation, speeding up the processes in a secure and reliable way, and offering greater potential for improvements to be realised more quickly. Although our focus is on health data, the implications are applicable across the administrative data ecosystem, particularly in harmonising practices for tracking data workflows, assessing privacy risk, and thereby potentially creating alignment of processes across the TRE landscape.

1.3. Why is Public Involvement and Engagement (PIE) important in the delivery process?

To date, ideas around risk assessment and risk mitigations are mostly based on insights from those working within TREs, such as information governance specialists. Incorporating public perspectives from the outset of the SARA project has allowed the team to understand the areas of risk assessment and risk mitigation that are of most concern to (or are less understood by) members of the public, as well as include ideas within decision-making in the design and development of approaches to understanding privacy risks and in the prototype dashboards. Enhancing the trustworthiness of data-access processes by listening and responding to public inputs (and communicating this work to improve transparency) is crucial in securing the social licence to operate.

2. Aim

A description of the purpose of our PIE activities in achieving the project's goal(s) and objective(s) and supporting DARE UK's PIE commitment.

2.1. What does your PIE intervention seek to achieve, and how will it influence your project outcomes and the wider DARE UK programme?

The PIE work package has prioritised securing public perspectives on risk assessment with health data research to inform approaches to understanding privacy risks and the later design of risk-mitigation tools – and other outputs – within the other work packages. The outputs from the overall project will greatly support the decision-making processes of data analysts, researchers, and information governance teams around different risks when working with health data. The next phase will be to improve and refine our approaches and tools, so they can be utilised by research data services (such as TREs) across the UK, and beyond the processing and delivery of health data.

3. Approach

Elaborating on the strategy and key considerations taken to deliver our activities in a way that was robust, measurable and impact-driven.

3.1. Did you develop a PIE strategy and establish a PIE team as part of your project delivery strategy? Was the public involved in the development of your strategy and other decision-making processes?

Our ethos has been to embed PIE as an integral element within the development of risk-assessment and risk-mitigation approaches to the processing of routinely collected data – a daily occurrence within TREs. To ensure PIE expertise was incorporated within our project from the outset, the team has included a Reader in Health Data Science who is experienced in working with public stakeholders and an Engagement Manager who has a breadth of experience in engaging public groups (including young people) from communication through to involvement exercises. The Public Reference Group at DataLoch (one of the project partners) has been informed of developments and contributed to the survey-development process.

3.2. What method was adopted for your PIE activities? (e.g., surveys, focus group interviews, workshops, public events, etc.)

Our principal activities were deliberative workshops and a survey with a representative sample of adults in Scotland.

Working with Ipsos Scotland we have designed and delivered two half-day in-person workshops for two different groups of participants (one hosted in Edinburgh – 22 participants, one in Aberdeen – 17 participants) – preceded by a single half-day online introduction session with all participants – to explore perspectives around risk assessment and semi-automation within health data research services. As part of the development of these workshops, the SARA team designed case study and scenario materials to form the foundation of the deliberations.

The survey was informed by the initial findings of the deliberative workshops and aimed to seek broader perspectives on key themes through the Ipsos UK KnowledgePanel platform. Through this we reached a representative sample of 1,030 adults in Scotland.

3.3. What specific steps or decisions did you take to make your PIE activities inclusive, accessible and collaborative?

We have worked with Ipsos Scotland, an organisation which has substantial recent experience in the design and delivery of deliberative workshops, including several directly relevant to the topic of data-access and confidentiality.

We worked closely with Ipsos Scotland on the content of the workshops and ensuring that the topics were introduced in a ‘public-friendly’ manner. The information session was specifically designed to ensure all participants shared a common understanding of the health data research landscape through recorded, subtitled presentations along with plenty of time for participants to reflect on the information, discuss it with other members of the public, and seek clarification and further information from those delivering the presentations.

Recordings of the presentations were shared with participants after the initial information session to support their learning and reflection.

During the recruitment process, participants were asked for any accessibility requirements they had, with the workshop sessions scheduled outwith the standard 9-5 working week. To support and enable participation in all workshops, and in line with industry standards, participants were each paid an incentive for taking part.

For the survey strand of our work, we secured responses from a representative sample of adults in Scotland through the Ipsos UK KnowledgePanel, an existing public panel. Those who do not have digital access are supported through the provision of tablets, free data, and technical support in the online completion of surveys. For further detail see: <https://www.ipsos.com/en-uk/uk-knowledgepanel>

3.4. How did you promote your PIE activities?

Ipsos Scotland recruited participants for the deliberative workshops on our behalf. This made it more straightforward to reach people beyond the direct networks of the SARA team. We wanted a group of participants that were broadly representative of the local populations, so this required a targeted recruitment campaign as described in 3.5, which we would not have had the capacity to undertake independently.

The survey was circulated through the Ipsos UK KnowledgePanel to reach a representative sample of Scottish adults.

3.5. How did you arrive at your choice of audience, and why them?

For our project, ‘audience’ is not the right term to adopt, since the people we engaged were not passive receivers of information. Particularly through the deliberative workshops, but also the survey, we were seeking the genuine participation of members of the public and actively exploring their perspectives to inform the decision-making in the development of our prototype dashboards.

Since we were seeking a breadth of inputs, we set a target for a pool of participants that were broadly representative of the Scottish population. Due to the in-person elements of the process, participants were also recruited on the basis that they could travel to venues in central Aberdeen and Edinburgh.

For the workshops, we requested that Ipsos Scotland made tweaks to the representation to include greater ethnic diversity than the overall population, and a slightly lower education level to gain a better sense of views across society.

3.6. What is the demographic spread of your audience? (e.g., countries of origin, residence/locality, ethnicity, age, education, income bracket, etc.)

The demographic spread for the workshops was:

Quota	Variable	Target recruits (of 40)	Actual recruits (of 39)
Age	16-24	6	6
	25-34	8	5
	35-54	13	12
	55+	13	16
Gender	Women	20	15
	Men	20	24
Location	Edinburgh	20	22
	Aberdeen	20	17
Ethnicity	Ethnic minorities	7	10
	White Scottish/British	33	29
Education level	Level 4 (degree, professional qualification)	12	16
	Level 3 (NHC / NHD or equivalent)	6	7
	Level 2 (Higher, A Level or equivalent) AND Level 1 (O Grade, Standard Grade or equivalent)	14	15
	No qualifications	8	1

In comparison with the Scottish population, our initial targets slightly over-sampled those from ethnic minorities, as well as those with no qualifications, and under-sampled those at education level 4. The target for the no qualification group proved particularly challenging despite substantial recruitment efforts, so more participants at higher levels were included as a consequence shortly before the workshops commenced.

3.7. How did you translate complex information into public-friendly messages?

The leads of the other two SARA work packages, as well as the Clinical Lead in DataLoch, developed presentations and workshop materials that formed the foundation for the deliberations. These were reviewed by the rest of the SARA team – including the Reader in Health Data Research and the Engagement Manager – who provided feedback that was acted upon. Our collaborators from Ipsos Scotland also provided feedback that informed the further refinement of the presentation and materials. Warnings of potentially distressing topics were also given at the outset of workshops with the option given to participants to (temporarily) withdraw from discussions (or the room) if they wished.

3.8. How did you communicate with your audience during and outside your core PIE activities? (i.e., channels and frequency)

Due to the standards for market research that Ipsos Scotland abides by, the SARA team did not communicate directly with the workshop participants beyond the workshop sessions. At the end of each in-person session, we offered the opportunity for participants to join (or find out more about) public panels that are facilitated in both Aberdeen and Edinburgh by organisations within SARA project team. One of our participants in the Aberdeen session followed up on this suggestion.

3.9. Did you offer any incentives for participation? What were they, and how?

As part of the recruitment process, workshop participants were paid £100 for their time by Ipsos Scotland.

4. Activities and Timelines

Explaining the schedule of activities we conducted in our PIE process.

4.1. What activities were conducted in your PIE process?

Our principal activities included deliberative workshops and a survey involving a representative sample of adults in Scotland.

4.2. How were these activities scheduled?

During a work-package inception meeting with Ipsos Scotland in late March 2023, we agreed on a schedule that worked for all parties. The original idea was to have a survey before the workshops, but during the course of the

meeting, it became clear that there was greater benefit in leading with the workshops to have greater awareness of public perspectives prior to the survey development.

Key milestones:

Date	Activity
27 March 2023	Inception meeting between SARA team and Ipsos Scotland
14 April	Agree workshop quotas / dates / locations / recruitment materials
21 April	Agree skeletal design and speaker list for workshops
12 May	Finalise workshop topic guide
16 May	Complete recruitment of workshop participants
21 May	Complete presentation development for workshops
23 May	Deliver online introductory session
27 May	Deliver deliberative session in Aberdeen
31 May	Deliver deliberative session in Edinburgh
19 June	Complete preliminary analysis of deliberative workshops to help inform survey design
27 June	Complete pilot testing of survey questions with DataLoch Public Reference Group
5 July	Finalise survey question design
12 July	Complete conversion to UK KnowledgePanel templates
17 July	Initial draft of report based on deliberative workshops for SARA team comment
19 July	Close UK KnowledgePanel fieldwork window
8 August	Initial draft of combined public consultation report (deliberative workshops plus survey) for SARA review
7 September	SARA sign-off of combined public consultation report

Note: initially, separate reports were planned for the deliberative workshops and survey, but this plan was revised in light of how closely aligned the survey questions were to the final workshop analysis themes.

5. Monitoring and evaluation

Describing how we documented, tracked, and assessed our PIE approaches and outcomes.

5.1. What key performance indicators did you establish to track your PIE activities?

(See also key milestones table in section 4.2.)

Deliberative workshops:

Indicator	Status
One online information session	Completed 23 May 2023
Two in-person deliberative workshops	Completed 31 May 2023

Indicator	Status
Involvement of 40 participants across the sessions	39 participants: the Aberdeen event was impacted by last-minute withdrawals probably due to the anticipated good weather on the day (coupled with the event being scheduled over a bank holiday weekend).

Survey:

Indicator	Status
Three-minute survey involving 6-7 questions	5 questions posed – complexity of these questions meant there was no capacity for more
Responses from a representative sample of 1000 adults in Scotland	1,030 respondents by close of fieldwork: 19 July 2023

5.2. How did you monitor these activities, and over what periods?

Activities were monitored as they were planned and delivered. Progress made by Ipsos Scotland was monitored by the study team via regular meetings and ongoing email communication.

5.3. How did you measure the impact of these activities?

The impact is represented through the recommendations made by participants and survey respondents and how these have informed the final decisions for the dashboards developed in the other two work packages.

From both the workshops and results of the surveys, it became clear to us that those involved felt very strongly about (human) oversight of any automated processes – in effect making them semi-automated and ensuring transparency. Even in the survey, although the preference could be for computers or for humans to have the greatest role, there was undoubtedly endorsement of a combined approach with computers and humans playing active roles.

For the data provenance trace: members of the public were explicit in their need for checks and balances, that automation was only as good as the person designing the trace, and that a fully automated workflow was not a substitute for human review of data throughout processing. As a consequence, we introduced more features within the prototype dashboard that require data analysts and governance staff to review data as it progresses through the workflow and more features to capture information about those reviews/checks. We also changed the design and display of information in the dashboard to account for public perspectives on how the dashboard could be used to collaborate with researchers during data processing without risking individual patient identification (e.g. visually denoting small numbers) and removing passive acceptances in the trace (e.g. green as 'ok' should not be used where analysts should still review the components).

In terms of free-text privacy risk assessment, consultation findings emphasised the important role of the specific research intentions and there needed to be a nuanced position with respect to how data minimisation techniques were implemented to protect identities without negatively impacting the research. While there were particular indirect identifiers that could perhaps (almost) always be removed as the public felt these were just too detailed and likely would not benefit the research – such as descriptions of unusual tattoos – others would have to be assessed against any implications for the intended research. For example, would using the age range of any

children mentioned be suitable as a data-minimisation step instead of retaining the specific ages of children stated in the medical notes? There was also endorsement that specialist expertise ought to be involved in making decisions about what information is or is not relevant to a specific research request. As with data provenance the public also felt that the processes and decisions taken around privacy risk should be recorded and subject to human inspection.

5.4. How did you monitor your PIE promotion, and how would you rate participation?

PIE promotion was not monitored since we adopted – through Ipsos Scotland – a targeted recruitment process for the workshops and inclusion of our survey questions into a platform that reaches a representative sample of the adult population in Scotland.

Participation of those engaged through the workshops was excellent. Plenty of questions were asked, and clarifications sought, from those in attendance, which demonstrates the engagement they had for the content. Discussions in the in-person sessions were active with all contributing to the debates. We achieved our response target for the survey and received useful quantitative data to reinforce the qualitative of the debates that took place in the workshops.

5.5. How did you collect feedback directly from your audience, and what does this feedback tell you?

The purpose of our consultation was directly about gaining insights and feedback from participants on real-world examples of privacy risks in medical notes and initial drafts of our dashboard plans. Perspectives gained through the workshops were supplemented by responses to our survey. All of this data directly influenced the decisions made in throughout our development work.

In terms of feedback on the consultation process itself, a post-it exercise asking how comfortable participants would be about health data about them being available for research allowed an end-of-process reflection by participants on what they had learnt through their involvement. This also enables us to infer the range of journeys that workshop participants went through: for example, some were more positive than they had originally been, while others had a more specific range of data they would be comfortable being used for research purposes. This reflects the importance of allowing people time to understand the full scope of what the sharing of routinely collected data (from any field) actually entails and results in, as well as the evolution of participants' understanding and implication of the complex processes and protocols undertaken within TREs.

6. Reflections and Lessons Learned

Reviewing our PIE activities and highlighting key learnings and considerations for future practice.

6.1. How were your PIE activities received?

Seemingly well. The information session helped to ensure that a lot of the potential areas of confusion could be addressed in a relaxed and collaborative format. Discussions of the scenarios went into some depth with participants quickly realising the complexity of the debates, such as the potentially problematic issue of indirect identifiers in clinical free-text: what level of suppression/redaction is necessary while also enabling research to

take place? We observed a number of discussions that explored the nuances of the issues and reinforced our professional experiences that a one-size-fits-all approach is impossible. The presence in the public consultation report of these nuanced debates in the workshops emphasises the high quality of this public consultation work.

In addition, the fact that an Aberdeen participant was sufficiently motivated to join an ongoing patient panel following our workshops reflects well on the SARA project.

6.2. What key implementation successes and challenges arose from your PIE delivery process?

A major success was in the richness of the deliberations and witnessing participants understand the issues in terms of risk assessment and mitigation approaches. This allowed us to not only appreciate the key facets of the topics, but also to develop survey questions that would reflect the experiences of those who would be responding to the survey. The outcomes of our public consultation work have been invaluable for the decisions made in the development of the approaches to understanding privacy risk and prototype dashboards by the SARA team.

As mentioned earlier, a particular challenge were the demographic targets, especially education level. Those with no qualifications may not feel as though the type of topics involved in the SARA project (and perhaps the DARE UK Driver Projects more widely) are accessible for them, no matter how materials are developed. They might also have other priorities beyond the idea of data for secondary use in research that they wish to attend to. Ipsos Scotland mitigated this by including more participants from other levels, trying to focus on levels 1 and 2. Withdrawals from the Aberdeen workshop were mitigated by Ipsos Scotland having a reserve list in place. These practical responses from Ipsos Scotland would have been challenging for the SARA team to deliver directly.

The notion of consent in the secondary use of data frequently arises in discussions of the nature found in the SARA project. Following our previous engagement work, both Ipsos Scotland and the SARA team were expecting this to arise. When consent was mentioned, the Ipsos Scotland facilitators expertly recognised the concerns and directed participants back to the topic at hand in a sensitive and positive way. If they had mishandled this, participants may have felt unheard and withdrew from the discussions; we did not witness this reaction.

The inclusion of our survey questions through the Ipsos Knowledge Panel UK enabled us to reach a genuinely representative sample of the adult population in Scotland. We would not have achieved this diversity, nor magnitude, if we attempted to promote the survey through our own channels.

6.3. What key learnings are important to consider in your project delivery strategy?

Time is needed by experts in the subject content and experts in public engagement in order to facilitate the development of materials that have a better chance of engaging members of the public in the most appropriate ways. Subject specialists are crucial for the insights they bring to the key themes that require exploration, while engagement specialists are a first port of call in simplifying (but not dumbing-down) the resultant materials that will be used with members of the public.

The trialling of materials with members of the public prior to use in the active engagement process is a further step that ought to be included when time permits. This point is particularly reflected within our survey development, where the pilot testing (involving existing members of DataLoch's Public Reference Group) genuinely helped to see potential misunderstandings that we had not anticipated in our original question structure and wording.

6.4. What key considerations will be crucial for future PIE activities in a similar context?

In addition to section 6.3, careful consideration and planning is required around any PIE objectives. The roles that members of the public can be offered in work of a highly technical and complex nature needs to be proportional to the time available for members of the public to gain an understanding of the concepts involved. Also, there needs to be some clarity around the boundaries for the engagement – what the possible impacts of the engagement process could be – so that all involved have a shared expectation of what could result from the process.

A way to speed-up the process is the inclusion of public participants who are already engaged in public forums around research and research data and therefore have relevant experiences. However, caution is advised for the representativeness of these particular participants: their experiences could be a boon for the project, yet also be a limitation given their record of involvement may colour the perspectives they bring to the debates at hand, and not be truly representative of the broader population.

7. Discussion and Recommendations

A general evaluation of our PIE activities and implications on our project and the DARE UK programme.

7.1. What is your overall assessment of the PIE process?

We are very happy with our PIE work package. Working with Ipsos Scotland has once again highlighted the benefit of working with an organisation that is experienced in consulting the public on a variety of topics. They have brought an external view to our work, which has helped to advise on the overall structure of the consultation we are conducting, as well as offer valuable feedback on the materials themselves. Ipsos Scotland also has existing protocols for engaging a representative sample of the UK population, which assists our objective of gaining inputs from across society on how we ought to approach our risk assessment and risk mitigation approaches. These practical advantages would not have easily been secured by the SARA team directly. Furthermore, the involvement of facilitation specialists, who are not directly connected to the themes/project at hand, enables discussion and debate more easily than if the SARA team were delivering these sessions independently.

For the majority of TREs, we anticipate that securing the support of specialist services like Ipsos Scotland would not be possible without external funding due to the costs involved.

7.2. What other developments are worthy of note?

Our public consultation has produced some incredible insights that have contributed to our decision-making as intended. However, related questions have come to mind which have not been possible to address within the current public consultation. These questions include:

- What level of error in (semi-)automation might be acceptable?
- What level of human oversight of the computer/analyst involvement is required? (Is it possible to quantify this?)
- What type of specialist(s) should be assessing relevance of data to a specific research focus and whether the (semi-)automation has been done correctly?

- How would views of relevance of data to a specific research focus and the potential for identifiability be different if the exercise was repeated with clinical researchers, or in a forum where researchers and members of the public deliberated together?

It would be valuable to expand our foundation work by exploring these more specific questions that reflect the edges of where our current public consultation reached.

7.3. What are the implications for the project and the DARE UK programme?

We managed to squeeze in a deliberative process within the available time, but this is a pressured undertaking and therefore the scope of the deliberations was quite specific. For broader insights to be secured, and more detailed questions and scenarios to be explored, there would need to be more time and funding to support either more workshops with the same format so that more participants could be involved in the workshops, or a greater number of workshops so that participants could be introduced to core concepts and then deliberate over a greater number of related topics.

7.4. What are your recommendations?

Future DARE UK-funded schemes would benefit from greater time-windows that would allow more diverse possibilities for engaging members of the public with the themes at hand. These public exercises could then more easily precede other aspects of work, so that these other aspects have a greater chance of being informed by public perspectives from the outset, rather than a later stage, which might therefore limit the influence that public perspectives could bring.

Alternatively, there could be a diverse public group set-up at the DARE UK Programme level which could be involved with the technical work taking place within each project. This would reduce recruitment overheads overall and lead to members of the public having a greater insight of what is taking place across the programme, which may generate more powerful and informed insights. However, care would need to be taken to ensure that this centralised group was still actively involved with the individual projects, otherwise there could be a separation caused by project PIs thinking solely about the technical work since they think that the PIE angles are being handled separately.

7.5. What are your next steps?

In terms of PIE, beyond the DARE UK reporting, we are exploring avenues to share the learning that has been possible through our public consultation. As well as news items through partner websites that will include the final public consultation report, we are also investigating the merits of publishing a paper focused on the consultation within a journal such as the International Journal of Population Data Science. This paper will focus on how the contributions from our public participants were directly incorporated within our outputs, which is fairly novel in the data science field. Our aim will be to offer a case study on how we effectively achieved this, to act as an exemplar for others.

In terms of our commitment to Public Involvement and Engagement, we will continue our attempts to secure additional funding and/or work collaboratively through other organisations – such as Research Data Scotland – to answer further important questions (some have been summarised in section 7.2) that will allow us to evolve our services in a manner that will justify our claims to have a social licence to operate.

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