SACRO Public Involvement and Engagement Final Report

October 2023

SACRO PIE Final Report

1.   Background

Summarise the project and its relevance to DARE UK's mission, highlighting the role of PIE in achieving success.

1.1.   What is the project about?

Trusted Research Environments (TREs) play a vital role in enabling researchers to analyse confidential data such as health records then report findings. The Five-Safes Framework is used to ensure data confidentiality and includes Safe Outputs.

Outputs are typically checked by two expert staff before release, which is a significant expense for TRE operators, and can cause a bottleneck for researchers. Meanwhile, the parallel development of TREs and understanding of disclosure-risk, has created a need to consolidate theory and practice to minimise inconsistent behaviour between TREs to retain credibility. Addressing both these issues, this project seeks to reduce the operating costs of TREs, and the time taken to release research results.

The project will:

• Produce a consolidated framework with a rigorous statistical basis that provides guidance for TREs to agree consistent, standard processes to assist in Quality Assurance.

• Design and implement a semi-automated system for checks on common research outputs, with increasing levels of support for other types such as AI.

• Work with a range of different types of TRE in different sectors (health, social data) and organisations (academia, government, private sector) to ensure wide applicability.

• Work with public and patients to explore what is needed for public trust that any automation is acting as "an extra pair of eyes": supporting not supplanting TRE staff, helping them to make easy decisions more rapidly, and therefore focus on more complex or nuanced cases.

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

All work packages encompass the DARE theme of enabling cross-TRE research by establishing mechanisms for aligning measures of risk appetite and management.

1.3.   Why is PIE important in the delivery process?

Public trust is essential for Trusted Research Environments to operate. Transparency in changes to process is part of maintaining the trust therefore the engagement with members of the public, and the creation of a lay document as an output contributes to this transparency.

Understanding what builds trust in the processes will inform the delivery of SACRO as the project team begin to implement changes to the output checking process and create guidance for output checkers.

2.   Aim

Describe the purpose of the 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 public engagement work will produce two outputs, each of which will feed into the project and the wider DARE UK programme.

1.   Literature review focusing on bringing together previous public engagement work around output checking. This ensures the project builds on what has been done in this space. This literature review will be useful for informing the SACRO project direction as well as future related projects for DARE UK.
2.   Consensus statement communicating the SACRO project and outlining principles for output checking. This will support longer term consistency for future work on output checking and create an accessible document for the project.

Additionally as we ran sessions with both public and stakeholders the findings and emerging themes were fed back to the other work packages.

3.   Approach

Elaborate on the strategy and key considerations taken to deliver the activities in a way that is 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?

Members of the public were not involved with the development of the PIE strategy. Due to timescales of funding calls and capacity of Research Data Scotland it wasn't possible to involve members of the public in the proposal although this was informed by feedback from our previous experience both of PIE in general, and on the GRAIMatter project in particular. However, to align with DARE UK focus with embedding public engagement in projects it was considered from the start. We leveraged the availability of existing PIE groups at RDS and the Bennett Institute where participants were already familiar with the idea of TREs. These groups are experienced at advising on practice within TRES so able to comment in detail on the SACRO proposals.

Members of the public also sit on the steering group and have been kept up-to-date and influenced the approach of the project.

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

One of the PIE outputs for SACRO is a consensus statement with input from both public and stakeholders. Process is inspired by Delphi methods with rounds of consultation with each group. The OpenSAFELY Digital Critical Friends group at Oxford was chosen to consult as public members since they meet regularly.

Three members of the public also sit on the SACRO steering group. These were recruited from the OpenSAFELY Digital Critical Friends Group and the Scottish Centre for Administrative Data Research (SCADR) public panel which is jointly run with Research Data Scotland (RDS). These public members attended regular steering group meetings and input into the projects areas of focus.

The consensus statement output is a publicly accessible document.

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

SACRO worked with an established public group at the Bennett Institute in Oxford. Since they already meet online, we attended regularly scheduled online meetings to ensure any accessibility considerations were already met. We met online with the group and also shared the consensus statement with them via email to comment on before meeting with them again. This gave people a range of ways to process the information and feedback.

Additionally the SACRO statement was included as a topic at a SCADR public panel and circulated around the members for comment.

We also feedback to the participants progress and how their comments had been integrated.

3.4. How did you promote your PIE activities?

We were working with the OpenSAFELY Digital Critical Friends group at Bennett Institute based at University of Oxford. The project was discussed twice in advance of the formal meeting with the OpenSAFELY Digital Critical Friends group to give them awareness of the project.

The project communications to a wider audience have currently been carried out through Medium and the DARE UK website.

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

The tight timescales, and the complex subject matter, meant that the most suitable course of action was to work with existing groups such as OpenSAFELY Digital Critical Friends Group & SCADR/RDS Public Panel with existing permissions in place. These groups are well established with a background understanding in TREs so well placed to discuss and comment on output checking.

In addition to engaging with public panels we are carrying out consultation with stakeholders. The themes discussed at both the public and stakeholder sessions will feed into the consensus statement. Stakeholders and the public panel will be asked to endorse the final statement. Outlined below are a list of stakeholders involved:

- ONS
- NHS-Digital
- SAIL Databank
- Eurostat
- Bundesbank
- SDC-GESIS
- ICPSR
- DASH (Aberdeen/Grampian)
- DataLoch (Edinburgh)
- HIC (Dundee)
- eDRIS (Public Health Scot)
- OpenSafely (Oxford)
- Statistics Canada
- The Alan Turing Institute
- DKFZ (Germany)
- The Health Foundation (UK)
- TRE-FX
- UK Longitudinal Linkage Collaboration

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

The OpenSAFELY Digital Critical Friends group were recruited through an open process, with a clear focus on ensuring a representative group based on characteristics such as location, age, gender, ethnicity and disability. The SCADR/RDS panel also has good representation of these characteristics.

The final consensus statement will be publicly available online and the anticipated audience will be interested parties and stakeholders.

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

The consensus statement is was created by members of the team with experience in public engagement. An artist made a graphic recording of the meeting with members of the public to create a visually appealing and accessible report of the theme discussed.

In addition to the content of the consensus statement we also spoke to the public panel on how to clearly communicate the complex themes. Suggestions including diagrams of the flow of information for output checking and including a few case studies. We checked the consensus statement for clarity with the public and stakeholder groups.

A Medium webpage has been set up to communicate updates [Homepage and settings – SACRO: Semi-Automated Checking of Research Outputs (medium.com)](). We communicate with the public panels via email outside of the meetings.

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

- We communicate with the public panels via email outside of the meetings. To carry out a transparent programme of work a Medium webpage has been set up to communicate updates [Homepage and settings – SACRO: Semi-Automated Checking of Research Outputs (medium.com)]() as well as via the DARE UK site.

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

Members of the OpenSAFELY Digital Critical Friends group are reimbursed for the time they take to attend sessions. They are paid £25 an hour.

Members of the Research Data Scotland panel are reimbursed with Love2Shop vouchers at the same rate.

Members of the public are also paid at the same rate for their attendance at Steering Group meetings.

4.   Activities and Timelines

Explain the schedule of activities you conducted in your PIE process.

What activities were conducted in your PIE process? How were these activities scheduled?

We met with the OpenSAFELY Digital Critical Friends group for two dedicated sessions (in addition to ongoing discussion within their regular meetings) and also involved the SCADR/RDS public panel (via meeting and email). We also met twice with stakeholder groups. Drafts of the consensus statements were circulated for comments.

The timescales for this are outlined below:

Date	Action
March	Attend OpenSAFELY group to introduce concept and organise future engagement
26 April	Attend OpenSAFELY group for initial input from public
April – June	Literature review of existing relevant public engagement and related papers Write draft paper and share with project group for comment
6 June	Stakeholder workshops to present concept and get input
19 July	Take draft back to public group for comment
July - Sept	Complete edits and start to share with wider group of stakeholders for support
11 September	Second stakeholder workshops to present final draft for comment

September-October	Send second draft to stakeholder and public members for comment.
	Integrate comments

5. Monitoring and Evaluation

Describe how you documented, tracked, and assessed your PIE approaches and outcomes.

What key performance indicators did you establish to track your PIE activities?
How did you monitor these activities, and over what periods?
How did you measure the impact of these activities?
How did you monitor your PIE promotion, and how would you rate participation?
How did you collect feedback directly from your audience, and what does this feedback tell you?

Performance indicators include

- Level of engagement from participants in the workshops
- Medium page views
- Reponses to emailed version of the statement

We have held public workshops and engagement from participants was high. This was with an established group therefore we did not include metrics such as attendance.

6. Reflections and Lessons Learned

Review your PIE activities and highlight key learnings and considerations for future practice.

6.1. How were your PIE activities received?

The public panel were very engaged and interested in the projects. There was good topical discussion during the sessions.

Informal feedback via the panel managers has been that the panel has felt positively about the project and how they have been involved.

In addition to the panel meetings five public members gave detailed written feedback on the draft statement,

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

The proposal for PIE work was clear and realistic taking into account timescales and staff time. There are however limitations of working with existing groups in terms of representation and whether they are truly 'lay' public. Findings from the literature review compared with themes discussed in the public panels will further inform the work on output checking going forward.

Identifying common and differing themes from stakeholder workshops and public workshops has been a useful exercise in developing the project. Close working between these two workpackages has helped this happen.

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

Two key takeaways so far we will be taking into consideration are:

- The public's perception of AI & the risks posed with this being particularly topical at present. It is essential to take this into account as part of the project delivery strategy.
- The language being used – ensuring that the language is not too technical/ statistic focused and can be used to communicate widely and effectively.

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

Future PIE work could be enhanced by working across the other DARE UK projects.

Consider whether a wider pool of public participants should be recruited beyond established groups.

7.   Discussion and Recommendations

Provide a general evaluation of your PIE activities and implications on your project and the DARE UK programme.

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

The proposal for PIE work was clear and realistic taking into account timescales and staff time. There are limitations of working with existing groups in terms of representation and whether they are truly 'lay' public.

Identifying common and differing themes from stakeholder workshops and public workshops has been a useful exercise in developing the project. Close working between these two workpackages has helped this happen.

7.2.   What other developments are worthy of note?

In terms of communicating outputs from the project setting up a Medium page allowed for the project to have a neutral place for updates which can be a challenge from cross organisation projects. SACRO developed it's own branding to again have a neutral identity.

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

The PIE and stakeholder work has so far shown clear support for TREs and the principles underpinning the ambition to standardise approaches. There is recognition that SACRO is a part of this ambition and will achieve the aim of improving efficiency of service. The feedback is that SACRO and DARE UK needs to make sure public confidentiality is ensured to maintain public trust.

We are looking at our communication strategy in the second half of the project accordingly leveraging the diverse audiences we have available to us, for example via student cohorts and health-related departments in universities.

7.4. What are your recommendations?

For future projects with time and budget allowing a range of PIE approaches could be considered to ensure inclusive and accessible sessions with a representative audience.

7.5. What are your next steps?

The statement will sit alongside the SACRO tool online and inform future developments.