

DARE UK



SATRE Public Involvement and Engagement Final Report

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UK Research
and Innovation

HDRUK
Health Data Research UK



SATRE 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?

Personal or sensitive data which have been collected for operational, commercial or governmental reasons need to be managed securely and safely for research. This data is held in Trusted Research Environments (TRE). TREs come in different shapes and sizes and all operate differently.

Standardised Architecture for Trusted Research Environments (SATRE) aims to improve consistency across these TREs across the four nations.

What is SATRE doing?

- Engaging with the TRE community and the public to understand what works well, and what doesn't.
- Identifying what it takes to build trust in a TRE, both for the research community and for wider society.
- Being fully open and transparent throughout the project for the benefit of stakeholders and the public.

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

SATRE is establishing the building blocks for a national data research infrastructure responding to the DARE UK programme Phase 1: Design and Dialogue recommendations. We are achieving this via co-development with public, academic and industrial stakeholders and community building with the UK-wide TRE community. It is a response to the reference architecture DARE UK Driver Project call and will, by the end of the project, have developed a TRE specification informed by the needs and requirements of the UK data research community.

DARE UK aims to:

Design and deliver a novel and innovative UK-wide data research infrastructure that is coordinated, demonstrates trustworthiness and supports research at scale for public good.

- Establish the next generation of TREs that will enable fast, safe and efficient sharing, linkage and advanced analysis of data, where it is legal and ethical to do so.
- Enable UK researchers and innovators to securely and efficiently harness the full power of linked datasets, modern digital platforms, tools, techniques and skills.
- Enable research and analysis on a broad range of potentially sensitive data from across the UK research and innovation spectrum.

1.3. Why is PIE important in the delivery process?

The aim of SATRE is to create a community-led standardised architecture for TREs and the public are an important part of that community. Since TREs hold sensitive personal data and provide access to it for public benefit it is important to get their views and reflect them in the SATRE specification.

SATRE has produced a technical and governance specification with a set of principles to guide TREs. Both the specification and the principles will reflect building TREs which can be trusted by the public. Statements will include how TREs should be involving the public in their work as well as transparency.

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 did your PIE intervention seek to achieve, and did it influence your project outcomes and the wider DARE UK programme?

Our PIE intervention aimed to do three things:

- Engage with the public about what are the important aspects of a TRE to build and maintain public trust.
- Ensure the statements around maintaining trust reflect the needs of the public and provide guidance for TREs on how to deliver those.
- Show transparency and openness throughout the project and in its legacy with materials including explainer videos and infographics plus regular blog posts on project activities on Medium.

The standardised architecture for the SATRE project aims to support existing TREs and new TREs to apply best practice and ensure a consistency of language and process. This will make it easier for researchers to access information across TREs. Including practice of public engagement as guidelines within the specification will mean that it will be embedded as best practice in existing and new TREs. Through our public workshops and the inclusion of public members on the project team, as well as drawing on previous reports and public engagement work, we aimed to identify what the public feel is important in a TRE for it to be safe and trusted and ensure that these are included in the specification.

The feedback from the initial two workshops and informal review of literature around public trust influenced the project to include three separate statements around public trust, and feedback informed the wording of a further statement on issue reporting. The subsequent four workshops focused on the wording of the statements themselves and these were rewritten following the workshops taking into account public viewpoints.

Finally, SATRE has produced two videos on TREs broadly and SATRE project which will be of use longer term, beyond the life of the project. One of these is intended for a public audience contributing to awareness raising about TREs whilst the other is focused to those within the TRE community who might use or support the SATRE framework. SATRE also took part in Festival of the Future in Dundee as part of our commitment to talking openly with new audiences.

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?

The SATRE project built upon from the legacy of two previous DARE UK funded project – TREEHOOSE and GRAIMATTER – which had PIE members embedded in the core research team. They and the knowledge gained were intrinsic to the strategy developed during the proposal planning and continue to be active contributors to

project progress. The PIE work package has been led by a public engagement professional from Research Data Scotland and the team includes the two public members on the project team to ensure a public voice embedded in the work.

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

Public involvement is built into the project through the involvement of two public members on the project team. They were involved in scoping the project and the initial bid and attended all project wide meetings as well as relevant work package meetings. This means they fed into all aspects of the project as well as the PIE aspects.

Workshops were chosen for the wider public involvement into the project. Since the focus of the project is on the architecture of TREs, a workshop gave the opportunity for people to get the background information on TREs and an opportunity for in-depth conversations around their views. With a focus on trust in the final specification SATRE wanted to understand the reasoning behind people's thoughts on the role and set up of TREs.

In addition to public specific workshops the ethos of the project is "default to open" and all activity can be followed live on GitHub and on a dedicated Medium page for regular updates. Non-technical stakeholders and the public could engage directly with formulating the specification through Google docs and accessing an open version of the specification. A project email address was created and disseminated widely for engagement.

To communicate the work of SATRE in an engaging way an infographic was produced at the midway point and two videos at the end of the project (one targeted to members of the public and the other to people within the TRE community). The two public members on the project had input to both the script and the video development.

Initially, in-person workshops were planned for across the UK four nations. A few were planned but difficulties in recruiting people to attend over the summer period as well as logistics led to pivoting to online meetings.

Finally, a minor strand of engagement open to members of the public has been through the Collaboration Cafés. These occur a twice a month targeted to people from the TRE community, a couple of times members of the public have attended to find out more and chat to the team. One session was redesigned to be fully accessible to members of the public. This was promoted to the mailing list of Use My Data (<https://www.usemydata.org/>).

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

We took advice from the experience of the public members of the team to identify the best medium and time to engage with the public. There were five online sessions held at different times of day to take into account people's day and evening schedules, we asked about accessibility requirements at sign up. There were opportunities to participate verbally and with written contributions and to contact the team afterwards with thoughts. The in-person session was held in an accessible location.

The events were led by the PIE team to instil a welcoming, inclusive non-threatening environment. Research team members were not given any special status and all contributions were treated respectfully.

3.4. How did you promote your PIE activities?

Promotion was carried out by all members of the PIE team using channels including existing or past PIE teams such as Co-Connect, TREEHOOSE, GRAIMatter, Dataloch, SCADR Public Panel, EAVEII and ePAMS. We also utilised networks such as RCGP and DARE UK and Research Data Scotland communications channels, as well as promoting on social media and via local community organisations in local areas.

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

Since SATRE is a cross-nation project it was important to have participants in the public group represented from different areas of the UK. This was reflected in the approach to promotion and the participants who took part. The decision was made to hold initial sessions online to engage with a broad geographical spread.

The project team chose to hold the initial sessions early in the project to inform the direction of the specification. The short timescale to recruit and conducting the sessions online meant we recruited via existing channels to ensure turnout and have useful discussions. The four sessions in the latter half of the project were promoted to new audiences and focused on refining aspects of the specification.

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

We did not collect this information in the first two sessions other than asking in the session which nation people were based in. Participants were from England, Scotland and Northern Ireland.

The in person session in Swansea had Welsh participants with previous experience of data projects.

For the latter four online sessions we asked where people were from and whether they had engaged in data projects before. Participants were from England, Scotland and Northern Ireland with a mix of experience of data projects before.

Audience attendance at Festival of the Future included University of the Third Age and Beehive community groups based in Dundee both with people in an older demographic.

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

The presentations and format for the public sessions were created by the Project Lead, Public Engagement Lead and two public members of the project. We created a bespoke presentation and built in opportunities for people to ask questions. We also collected data after the sessions on how understandable the information was and whether it was appropriate level of detail. We edited the presentations after each session based on our reflections.

For our midway communications we engaged an illustrator to create an infographic about the project and what is trying to be achieved. This was developed with the Project Lead for SATRE, Public Engagement Lead for SATRE and Communications Manager at Research Data Scotland. Content was reviewed by members of the SATRE project team including the two public members.

The final video outputs were created by a video agency (Heehaw) with input across the SATRE team.

Embedding public participants into the project meant jargon was identified during meetings and removed from communications.

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

We have a medium blog page to post regular updates to. Updates are also posted on the DARE UK website and communication channels.

We sent a version of the specification to everyone who participated to report on how their views impacted the project.

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

Participants were each paid £50 for participating in the session. This was in the form of Love2Shop vouchers or a supermarket of their choice. This method was chosen as a practical solution which worked for people across Scotland, England, Northern Ireland and Wales. Experience from previous projects found that claiming expenses via University mechanisms was frustrating, slow and error-prone reducing the willingness to be involved to future projects.

4.0 Resources

Resources produced from the project are:

- Specification for standardised architecture of trusted research environments
- Two videos – one targeted to a public audience and one to stakeholders which will be used beyond the end of SATRE
 - The videos will be hosted on the Health Informatics Centre YouTube channel¹.
- Medium blog outlining project progress
- Infographics

4. Activities and Timelines

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

4.1. What activities were conducted in your PIE process?

- Initial online workshops – focused on broad idea of trustworthiness in TREs.
- Focused online workshops – covering detailed elements of the specification.
- In person workshop – covering detailed elements of the specification.
- Communications – infographic explaining project and how to get involved, two videos outlining the role of TREs and the SATRE project.
- Ongoing meeting with public project members – the public project members attended fortnightly project-wide meetings and all work package meetings regarding PIE.
- Presentation of project at Festival of the Future in Dundee.

4.2. How were these activities scheduled?

Two public workshops were held early in the project. These focused on a broad topic of trust to inform the thinking of the project team in planning the architecture and what is important to build trust.

Four workshops held in the second half of the project discuss more detailed elements of the project and get feedback from members of the public.

Video and presentation at festival were scheduled at end of the project to summarise and present activities.

5. Monitoring and Evaluation

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

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

Performance indicators for public activities and communications include:

- Number of participants signed up to workshop and attending events.

¹ <https://www.youtube.com/@healthinformaticscentre6624>

- Level of engagement from participants in the workshops.
- Feedback from workshops.
- Medium page views.

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

We monitored these activities during and immediately after the sessions in reflective sessions with members of the team.

Medium shows stats from the last 90 days. Page views over the 90 day periods have ranged between 400 – 800 approximately.

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

We surveyed the participants after the workshops. PIE discussions have been used and recorded in changes made to the specification demonstrating direct impact on the project.

5.3.1. Initial Sessions

Our initial two sessions identified what was important for people to trust TREs. From this we heard that cybersecurity, oversight, de-identification of data and transparency were key elements which people cared about. These themes fed into plans for what needs be included in the specification.

- Cybersecurity and Governance are two specific sections within the statement
- Making sure the analysed data removed from the TRE to be used for research does not include identifying features is covered in a section called Output Management (Section 3.3)
- A statement about transparency was included in the specification in Public Involvement and Engagement (Section 4.8)
- A statement about public involvement and oversight of TRE processes was included (Section 4.8)

5.3.2. Follow Up Sessions

In our second set of sessions we looked in detail at elements of the specification and collated feedback. The discussions in those sessions influenced the following changes:

- Upgrading of the Public Involvement and Engagement (Section 4.8) statements from Optional to Mandatory*
Inclusion of a statement for TREs to publicly report on near misses and incidents
- Detail added to the statements on the level of information TREs should include on their website and in what format

We also used the discussions and the questions asked in the sessions to create a video outlining what SATRE does in an accessible way. The script and style was influenced by feedback in the sessions.

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

The initial public sessions in March booked out and there was high attendance rate. In person sessions were planned during August and September but two were cancelled and one had low attendance, the latter sessions in September and October did not book out but had high attendance from those who booked.

Participation from the public varied during the sessions. Participants were encouraged to have cameras on and engage verbally in discussions. To encourage inclusion and accessibility participants could also participate in the

chat section of Zoom. Those that participated actively demonstrated good understanding of the topic area and made relevant points or asked questions. Some opted to not extensively participate.

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

All discussions in the sessions were noted and summarised into anonymous reports afterwards. Each of these reports were shared with the team, uploaded into the project area and referenced when requesting changes to the specification. The chat was also saved from the online meetings to record the questions.

We conducted a survey informally during or after the session asking on how participants found the understandability of the presentations and pre-reading and also their comfort levels in participating.

In the first two online sessions all said the presentations and pre-reading contained the right level of detail. Only one participant did not feel comfortable asking questions in the session, but did not expand on why or how the project team could resolve this.

As the team ran more sessions we edited content based on feedback and reflections on understandability from previous sessions.

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?

Workshops:

There was mixed involvement from sessions. Some participants had to ask clarifying questions on the content and did not actively participate. The majority however did participate and asked questions.

Many of those who did participate found it a positive experience and were pleased to see the project actively making the effort to involve members of the public.

Embedding PIE on the project team:

The two public members have given positive feedback on their experience of being embedded within the project, noting that their input has been taken on board and influenced the project. The rest of the project team has welcomed their input and involvement.

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

Successes include

- Representation across the UK nations
- The input we have had from the two public members on the project team at all regular meetings and some Collaboration Cafes means that PIE has shaped all work packages and development of the specification across the project
- Identifying broad themes of trustworthiness from public workshops combined with stakeholder survey responses helped prioritise what is required within the specification
- A glossary of terms developed between SATRE and TRE-FX to help consistency of language. This is supported by a public member working across DARE projects.
- Tying in with existing Festival of the Future programme to reach new audiences. Members of University of the Third Age attended festival session and interested in future PIE activities.

Challenges included

- communicating the technical work of the project both to the lay project team members and also for the public workshops.
- The scope of SATRE is broad so communicating the work and receiving input into the project in a short online session was also challenging.
- Recruitment of participants, particularly for in-person events.
- Use of GitHub for interacting with other workpackages. This was a new tool for the public members of the team and PIE lead to use so took some upskilling. Although an open repository it's not an intuitive tool for members of the public so additional considerations were needed in linking to the readable draft specification and ensuring regular blog posts on medium covered the progress of the project.

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

We took the following key learning from our experience running PIE in this project:

- Seek support with recruitment from external agencies
- Repeat sessions with participants could result in more in-depth conversations with more time to understand content
- Longer project length to be able to plan an engagement programme and run public sessions out side of summer holidays
- Inclusion of communication expertise and time to support communication of SATREs work is important
- Recognising the time required to plan, develop and run public engagement sessions, particularly in person
- Involvement of public participants on the project team works to embed a public voice at all levels and across all work
- When on a short project timeline connecting with existing groups can help recruit
- Build in a project wide communications plan to feedback to previous participants
- For an aligned programme work, such as DARE, shared or common resource across funded projects would be an efficient use of resource and avoids duplication/misalignment/inconsistencies. This could be a hybrid model of support with centralised resources from agency or access to large public panels, but individual PIE leads on the project to shape and deliver the engagement.

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

For future PIE activities:

- Having a PIE coordinator/lead is crucial to good delivery. If organising events within the project, admin or PIE support for arranging events and processing participant payments
- Ensure sufficient PIE and comms time has been allocated
- Embedding public participants on the project team and in project/proposal planning ensures meaningful PIE activities are done right first time
- Detailed plan from the start on the public workshops to allow ample time for recruitment
- Consider using external agency to support recruitment to workshops.
- Consider the accessibility of online tools

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?

Timescales and staffing means the PIE process has had practical ambitions of delivering small workshops whilst recognising the limitations of small groups. However, the project has been ambitious in maintaining a cross nation reach and making plans to recruit people without a background in data. Challenges arose in recruitment and delivery of in person sessions. The project team were flexible in plans to pivot to a different approach.

The success of having two public members on the core project team (and involved in more than the PIE aspects) has been noted as being down to a welcoming and inclusive culture by the whole project team. Public members particularly noted the efforts of the Project Lead in including them and creating that culture.

With a short-term funded project legacy is always a concern so having a medium site and video output gives us a location for ongoing engagement in our work.

7.2. What other developments are worthy of note?

Creation of a logo and setting up the Medium page has been useful in establishing a separate identity for the project to reflect cross organisation working and a public space to link to updates.

Originally the SATRE Specification was a technical specification and expanded to include governance and other areas. Following on from the initial workshops and informal review of literature three statements focused on the public were included.

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

The public engagement work has helped inform what is essential for TREs to consider to maintain public trust and reflects their views.

7.4. What are your recommendations?

Recommend that as the SATRE specification is taken forward ongoing PIE is budgeted and built in so public input into the statements and principles are included.

We also recognise that working with other DARE projects to pool insights and resources from the projects will be useful.

7.5. What are your next steps?

- Ensure PIE is built into the future iterations.
- As TREs start to evaluate themselves against the specification monitor how the PIE statements are interpreted

8. Acknowledgement

We thank all the members public who got involved and contributed to the SATRE projects' programme of public engagement. Without their inputs the project would have had less impact and be less relevant to the wider UK research community.

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