Fostering Public Confidence: How the TRE-FX Project is Integrating Public Perspective in its Delivery Strategy

The TRE-FX project is a collaborative endeavour involving ELIXIR-UK, HDR UK, the Universities of Manchester, Nottingham, Swansea, Dundee and Birmingham, University Hospitals Birmingham, and leading technology providers. Its primary aim is to showcase how secure Digital Objects can be used to standardise the transfer of queries and results to and from Trusted Research Environments (TREs) for federated analytics. In addition to technical advancements, the TRE-FX project recognizes the importance of public trust and embraces a Public Involvement and Engagement (PIE) strategy to ensure transparency and active involvement of the public in decision-making processes.

Delving into the TRE-FX Initiative

<u>Federated analytics</u> is a methodology that can perform analyses when data is spread across various sources. In the context of TRE-FX we are developing technical prototypes to demonstrate how federated analytics may operate across multiple <u>Trusted Research</u> <u>Environments (TREs)</u>, where there are strict data governance controls in place.

TRE operators face a challenge in that there are now many different types of federated analytical tools that researchers may request to be supported, but for each tool there isn't a standard way of handling data, processing analyses or returning results. To tackle this problem, the TRE-FX project has been developing a framework designed to provide a standardised way for federated analytic vendors (academic and commercial) to interact with TREs. The goal is to demonstrate the technical feasibility of a standard method, which would make it much easier to handle and analyse data remotely. This innovative approach not only helps to enforce data privacy and security but also streamlines and enhances the efficiency of research on sensitive data. Much work is still to be undertaken both technically and with the public before these early prototypes can be used in Trusted Research Environments on patient data.

Public Involvement and Engagement (PIE): Empowering Public Knowledge

Central to the TRE-FX projects strategy is comprehensive PIE, this includes a member of the public chairing management meetings, and presenting at conferences. These activities play a pivotal role in ensuring the content presented by the project is suitable to empower the public with essential knowledge about various aspects of the project, including information about federated analytics, the architecture of TRE-FX solution, how it gathers the required information in line with the Five Safes framework and how it can be integrated with existing TRE services.

Other activities include generating PIE materials that serve as an educational resource for the public, providing insights into the intricacies and benefits of federated analysis. By offering accessible explanations of complex concepts, the project seeks to reduce the gaps between technical language and public understanding, ensuring that the public remains

well-informed and engaged throughout the research journey. By involving the public in this manner, the TRE-FX project advocates for a transparent and collaborative research approach, instilling public trust and confidence. Therefore as the early technical exemplars are developed, it is open to comment and critique from the public.

Focus Groups Assessment: Public Participation in Decision-making

To strengthen its commitment to public involvement, the TRE-FX project has commissioned two focus groups and workshops provided by <u>Alterline</u>. The TRE-FX team do create the content and the questions to be asked, but have no involvement in the running of the events to ensure there is no indirect influence on participants

Through these focus groups, the TRE-FX project seeks to ensure that the public's voice is heard in shaping the project's direction and goals. In addition to gathering valuable insights, the focus group discussions facilitate inclusivity, allowing diverse perspectives to inform the project's decision-making processes.

In its first PIE workshop, the TRE-FX project aimed to solicit public feedback to ensure the clarity and accessibility of project content. Among the critical issues addressed in these discussions were questions related to the authority responsible for determining whether a federated project can proceed, the regulation of data resource access, and the safety and security of project outputs. By incorporating public suggestions from this discussion into the technical design the project demonstrates its commitment to an iterative and inclusive approach.

Building on the success of the first PIE workshop, Alterline is now re-recruiting for a second event, where more complex concepts will be introduced, enabling the public to gain a deeper understanding of the mechanisms proposed by TRE-FX to safeguard data privacy and security during analysis.

Conclusion

The TRE-FX project has sought to include the public voice for transparent and accountable research within Trusted Research Environments through its dedicated engagement in Public Involvement and Engagement (PIE) initiatives. By actively incorporating public feedback, assessing potential risks, and nurturing inclusive dialogues, the project has sought to balance technical capabilities with public and governance based questions. Through the integration of public perspective into both the project operation and design processes, the TRE-FX project paves the way for research that is does not dilute key governance criteria in TREs, but re-enforces those principles whilst providing a standardised mechanism for researchers to undertake analyses across multiple TREs.