

Public engagement Phase 1 Report

We have just completed our first phase of public engagement activities which focussed on exploring citizen's views on sharing their data with a range of health researchers and healthcare professionals via distributed ledger technology (DLT). The key objective for this phase of engagements was to instigate general discussions with the public about any concerns or unmet needs around the current digital health data sharing context. This was undertaken in order to ensure that public stakeholder views and experiences were taken into account as a crucial first step in the co-design process. We also aimed to use these discussions to explore and identify the kinds of choices and privacy options stakeholders may want and need from such a platform before the technical design team began to develop a range of prototypes for use in the second phase of the co-design process.

Developing public engagement materials

Prior to engaging with the public, project researchers identified key features of DLT technology that could support the exchange of health data from a number of public and professional user perspectives. Two researchers then went on to create 'user stories' which highlighted different ways in which people may use the CDIP Platform to make choices about how they may share their health data with different professionals working in health data sharing contexts. These narratives were further explored and refined in collaboration with the remainder of the research team until five potential scenario use cases were identified. These scenarios highlighted three examples in which citizens featured as protagonists and decision-makers in terms of sharing personal health data.

- S1- Secure data exchange between patients & health care providers
- S2 - Data donation
- S3- Citizen Health Certificate

The remaining two scenarios highlighted functions and features which supported professional engagement with DLT and health data recording.

- S4 - Secure Data Transfer of Patient Records
- S5 - Secure certificate recording and management

Finally, all scenarios were then presented to the project's Advisory Board (including professionals with expertise in health informatics and research, bioethics, app design, data governance and computer science) and content was subsequently edited to reflect board member's comments, questions and suggestions.

Focus group format

This phase of fieldwork took place during the Covid-19 pandemic and this has significantly impacted upon opportunities for face-to-face discussion and more interactive workshop engagements. Therefore, researchers chose to utilise video-conferencing technology as the most appropriate way of facilitating remote discussions with the general public. Although a range of different video-conferencing tools were available for use, Zoom was chosen as the preferred medium of communication due to the ability to communicate in real time with a large number of geographically dispersed individuals via computer, tablet, or mobile device. Although this technology can accommodate up to 300 participants, discussion groups were capped at a maximum of six in order to maximise opportunities for participants to express their views. Researchers remained mindful that the lack of a face-to-face alternative may exclude participants with limited or no access to the digital technology required to engage. However, given the restrictions on social contact during this time, researchers chose to go-ahead with remote video conferencing on the proviso that, if or when

social distancing restrictions are lifted, in-person workshops would be offered as an alternative means of engagement. Researchers also undertook individual telephone conversations with each prospective participant in order to ascertain familiarity with the Zoom platform and to offer a one-to-one trial session over zoom prior to engaging in any focus group discussions. In the event, most participants were already very familiar with the Zoom platform technology. A small number of participants stated that they may find this a barrier to participation and elected to have a practice meeting with one of the project researchers. Three researchers were also involved in the facilitation of the focus groups in order that a researcher was readily available to address any technological issues at any point during the discussions. Participants were also encouraged to use the 'chat' facility during focus group discussions in order that they may comment or raise concerns whilst another participant was speaking or if they felt unable or uncomfortable with verbal interaction. Chat comments were moderated by a researcher and any points raised via this facility were introduced to verbal discussions throughout the duration of the focus group.

Pilot work

Researchers undertook a pilot focus group discussion with six PhD students with interests in Law, ethics, AI and healthcare to find out whether or not the materials, timing and format of the focus group designs were appropriate and accessible to a wider public audience. The pilot session lasted for ninety minutes and included a brief explanation of the aims of the CDIP project, followed by an introduction to the basic functions and features of blockchain technology. The possibilities for potential use of the CDIP platform were subsequently introduced by presenting a short narrative scenario on 'Data donation'. Finally, participants were invited to comment on their first impressions of the CDIP platform and data donation use case.

What did we learn from the pilot?

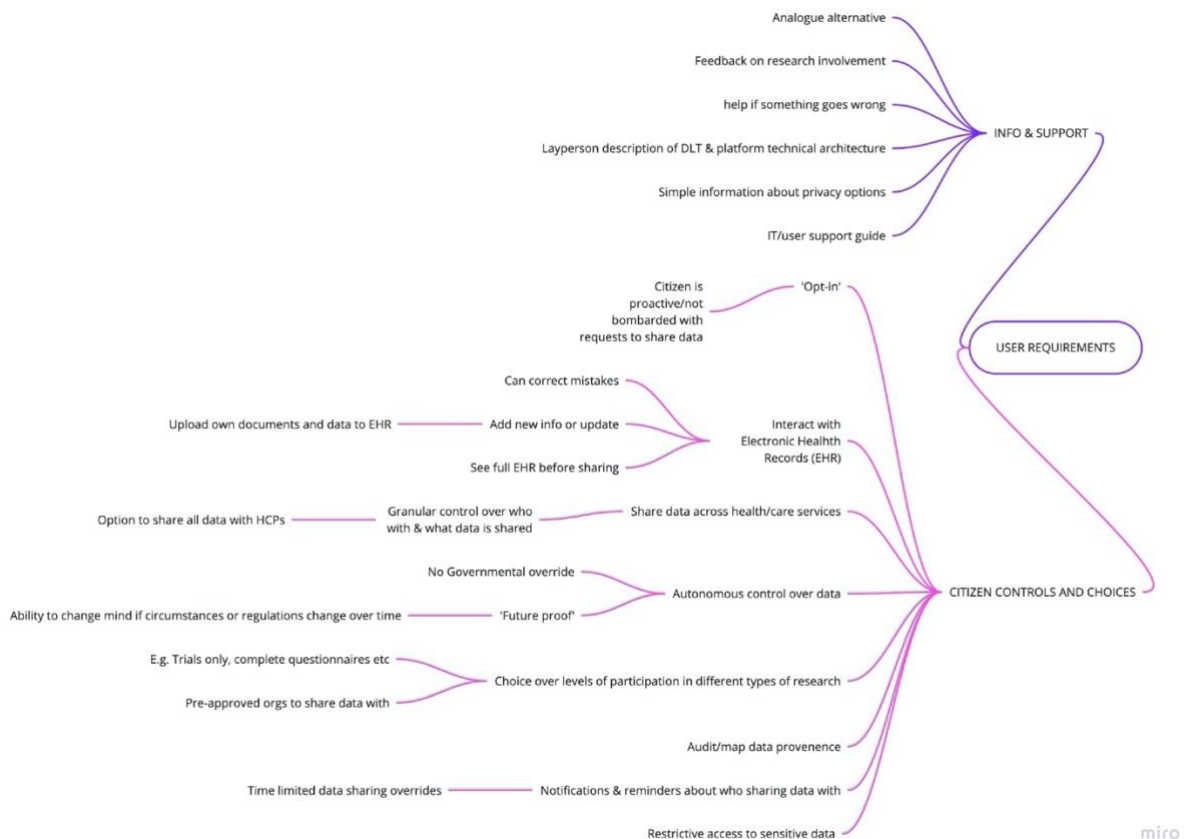
Despite the fact that we were unable to meet with participants face-to-face, on the whole, video conferencing offered a workable alternative. Using three researchers to facilitate the conversations proved to be useful as this enabled minimum disruption when any technological difficulties arose. Pilot group participants commented positively about the timing and content of the focus group format and presentations. However, much more time than originally anticipated was required to explain the underlying technology behind the CDIP Platform design which resulted in significantly reducing time available for group discussion. In addition, despite attempting to present a simplified explanation of DLT technology, as well as illustrating the main features of this through an [animated film clip](#), participants still struggled to fully comprehend some of the technological features and functions underpinning the CDIP platform. We carefully considered this problem in light of the fact that two members of the pilot focus group already had significant technological expertise. Therefore, in order to navigate some of these issues, the research team decided to simplify discussion around the technical framework of the CDIP Platform and omit the film-clip in later discussion groups. The focus group presentation was then significantly edited and explanations of how different forms of digital health data are currently used and shared were presented alongside three different user stories in subsequent focus group discussions. After the presentation of each user story scenario, we asked participants the following questions:

- What are major benefits and drawbacks of this use case example?
- What choices and controls would you like to have over your own health data?
- What information is important for you to know before using a platform like this?

What did we learn from speaking with the public?

During September and December, the research team spoke with 30 members of the general public that were recruited from a range of health research charities and patient and public involvement groups. Participants aged between 20 and 76 years took part in a series of five online focus group discussion groups which lasted between ninety minutes and two-hours. The re-structuring of the focus group format and presentation proved to be much more successful in generating useful points for further deliberation and debate between focus group participants. However, we also remain mindful that creating a more user-friendly explanation of the technological architecture of the platform needs to be further developed for phase two of public engagement activities. The introduction of additional stakeholder perspectives also helped to extend discussions and include debate that related to other additional needs and concerns that public and professional stakeholders may have.

The data gathered from the Phase 1 focus groups resulted in the generation of a comprehensive list of features and functions that citizens would like to be included in the final design.



Participants also identified a number of more general and use case specific benefits of interacting with the CDIP platform.



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This data will now be explored by the technical stream in order to consider which functions are feasible to include and to generate some ‘straw man’ ideas and prototypes over the next two months.

A number of concerns were raised by citizens about who will own the platform and how it will be governed and regulated. In addition, initial data analysis of focus group discussions suggests that citizen’s require further information about the range of different consent and data sharing options as well as assurances about levels of data security and privacy for users of the proposed platform.

What next?

In January 2021, concerns and issues raised by focus group participants will be explored in greater depth by the whole research team in order to decide which design options would be the most productive to develop as design probes to use in our next phase of public and professional stakeholder engagement. We also plan to generate a visual representation of the ‘journey’ that citizen health data may follow as a result of citizens using the platform to share their data with a variety of different stakeholders in the new year.