Sano

What research participants want

Case study of user-centered design for a participant portal for genomics research.

Contents

Goal of the collaboration

Sano Genetics is developing a ‘participant portal’ in collaboration with Genomics England and Zetta Genomics that will allow participants in genomics research to add additional information about themselves to research databases, and to access new research opportunities based on their data.

The proposed participant platform could be of benefit to many different stakeholders, including patients, caregivers, researchers, and healthcare professionals in several ways including:

1. Improving the breadth and quality of data collected in medical research through participant-generated data.

2. Making it easier to find and access new research opportunities.

3. Giving participants feedback in the form of personalised insights, recognition for the research they contribute to, or connections with their peers.

Due to the interdisciplinary nature of the portal we are developing, we have sought to involve as many different stakeholders as possible in all stages of the development lifecycle through interviews, workshops, and surveys, including:

- Patients and caregivers **(the focus of this report)**
- Experts in law, ethics, and regulatory compliance
- Medical researchers and practitioners
- Genomic scientists
- Scientific communicators
- User experience designers
- Software engineers

Co-development approach and process

To inform the design of the platform, we adopted a co-development model to ensure that:

1. The platform was meeting genuine needs from the perspective of potential users (participants in genomics research).

2. To identify whether a group of potential product features (PPFs) could help to address these needs, and to prioritise these PPFs according to participant feedback.

3. To identify any needs or PPFs that were not considered at the outset of the project.

To do this, we are following a 9-step process for co-development, which is supported by funding from Innovate UK:

1. Identify needs and PPFs to meet those needs.
2. Hold workshops with volunteers with past experience as research participants, including volunteers from the Genomics England 100,000 Genomes Project.
3. Refine and prioritise potential product features based on feedback from the workshops*.
4. Collect data on the refined needs and potential product features through a survey to a wider audience.
5. Produce a mock-up (non-functioning product concept) of the patient engagement platform.
6. Hold a second round of workshops to feed back on the mock-up.
7. Produce a functioning prototype incorporating feedback from the second round of workshops.
8. Make the functioning prototype available to a small group of volunteers from the Genomics England 100,000 Genomes Programme for Alpha Testing.
9. Further improvements on the prototype based on Alpha Tester feedback.

*This report focuses on the output from Step 3 - the workshops with patients and caregivers held in April 2020.

Format of the co-development workshops

The workshops were conducted over Zoom and included both large group and small group discussion, lasting approximately 3.5 hours. In accordance with NIHR Involve guidelines, participants were offered a £100 honorarium for their expertise and time.

Large Group Session 1

Brief introductions from the independent facilitator and the team from Sano Genetics, Zetta Genomics, and Genomics England. Overview of the goals of the project, and the structure of the workshop itself.

Small Group Session

Participants were split into three small groups, and each small group was asked to consider two of the six potential product features (see next section). Notes were taken during these small group sessions by dedicated notetakers with the permission of the participants, and all personal identifiers were removed from the notes.

Large group Session 2

Facilitators from the small groups relayed the feedback, ideas, and any concerns for each of the six potential product features. Further discussion and Q&A was invited from the large group by speaking out loud, or asking questions / making statements through the Zoom Chat function.

After the Session

All participants were sent a short survey after the workshops concluded giving a chance to feedback on all six potential product features and offer any feedback on the structure of the workshop itself.

Notes from the workshops and the post-workshop surveys were used to create this report.

Insights from the workshops

The six potential product features reviewed in the workshops are rank-ordered below based on the favourability to participants in the post-workshop survey. Workshop takeaways based on the notes taken during the workshop by dedicated notetakers.

FEATURE 1

Research Matchmaker

Description:

A system to allow researchers to specify criteria for joining a study (e.g. diagnosis of a condition, or a specific genetic variant) and participants to specify types of research they are interested in. Participants would be securely notified of potential matches to opt-in/out to new research that is potentially relevant to them.

Workshop takeaways:

Participants noted that they regularly ask their doctor if there are any studies they can take part in - but not all doctors / hospitals are research savvy and even those who are will not know everything.

An ‘intelligent screening’ system would be very valuable, and even better if users could set their preferences around type and frequency of notification.

Most participants wanted research to be vetted by a trusted party, such as NHS, NIHR, or an independent ethics committee/board. Researchers should be required to submit a description of the study that is understandable by all.

FEATURE 2

Participant Voice

Description:

A system to allow participants to indicate what kind of research they might be interested in, contributing to research priority setting and early feedback for research proposals.

Workshop takeaways:

Many participants identified this feature as important to ensure that researchers were focusing on the problems that mattered most to patients. Participants suggested implementing virtual ‘focus groups’ that matched researchers and participants together

One concern with this feature is that it must be implemented in such a way that it is not just “going through the motions” - it would be important that the participant’s expertise and time spent translates into something tangible.

FEATURE 3

Research Catalogue

Description:

A system that allows participants to ‘browse’ ongoing research projects they might join which require additional information such as a survey completion or submission of a sample to do additional testing.

Workshop takeaways:

Many participants had searched on search engines, or specialist sites such as clinicaltrials.gov for relevant research. Many responded that they would like to be able to browse research opportunities..

As with the ‘Research Matchmaker’ feature, participants generally felt that a vetting process was essential for the Research Catalogue to be successful.

FEATURE 4

My Contributions

Description:

A system to allow participants to visualise and track their contribution to research.

Workshop takeaways:

Participants felt that they get a fuller experience if you understand what you have contributed to, and that personal acknowledgement would be “amazing”. Many were frustrated with not hearing any findings from research that was ‘negative’. Participants said they don’t see it as negative if a researcher has tried, even if the research results are negative. They recognise the value in the study and see how this contributes to the overall research knowledgebase

Participants knew that it might be challenging to have updates on all the studies they helped by contributing their time/data, but if it were possible it would be much better than a simple yearly newsletter.

FEATURE 5

Wearable Devices / Symptom Tracking

Description:

A system to allow people using wearable devices (e.g. heart-rate monitor watches or other wearable sensors) to link this data with their medical / genetic data in research databases, bringing more information from the ‘real world’.

Workshop takeaways:

Concerns with this feature included the challenge of getting data that is accurate, as well as usability / accessibility. Many participants felt it would be challenging to get enough people using / linking these devices for the findings to be meaningful. Users would need to be able to see the data so that they can also benefit from it - not a “black hole of data”!

FEATURE 6

Data & Reports

Description:

A system to allow participants to receive genetic reports based on their whole genome sequence or other genetic data. The workshop participants considered two potential routes: (1) strictly non-medical reports (e.g. ancestry/ethnicity) (2) diagnostic/medical reports made available through an online platform and added by a medical professional, with the ability to selectively share and discuss these reports with peers / others affected by the same conditions.

Workshop takeaways:

Overall, participants were much more interested in medically relevant reports rather than ancestry/ trait reports that might be interesting, but not particularly helpful from a health perspective.

Participants felt that it was essential that healthcare professionals be in the loop, or at a minimum accessible, to help interpret reports that were medical in nature. Several workshop participants felt there was an opportunity to ‘bridge the gap’ between research and healthcare by making research reports more available to their doctor or other healthcare professional.

Across all six potential product features, and both workshops, several themes arose that applied to nearly all product features.

01. Easier ways to engage with research

Workshop participants wanted to be able to be notified when there was new research relevant to them, and to have the tools to actively seek out research that might be relevant to them. Assuming this research was vetted by an institution or process that they trust, and there were clear benefits to them participants were more than willing to help.

02. Capturing the participant experience

The workshop participants widely recognised that there were ‘gaps’ in the research record that they could help fill, given the right tools. While visits to the doctor might happen every few months, patients or caregivers are often experts in their own right and can provide valuable information through participant-generated health data, or offering corrections to doctors notes.

Tools that allow participants to contribute more to research including at the earliest stages (setting research priorities) and throughout the research process (participant-generated health data) were strongly supported.

03. Transparency and trust in the process

When it comes to researchers accessing their personal data, most participants did not want to be required to approve or deny every potential request for access. Transparency in the process by which access to data is granted and trust in the institution acting as the data steward was brought up by many participants as an essential ingredient.

Conclusion: Putting the findings into practice

Digital technology has potential to dramatically impact medical research through:

1. Changing the way disease is diagnosed or treated by collecting and analysing new forms of participant-generated health data that were not previously possible.

2. Improving the participant experience in research, by providing opportunities to have their voice heard throughout the process, connecting with peers, and to receive data or insights as a result of their participation.

3. Making new research findings faster and more efficient by using software and data analysis to better connect people with research that is relevant to them.

A digital ‘Participant Portal’ that facilitates participant-generated health data, research matchmaking, and more data/insights for participants was recognised by workshop participants as an important step forward.

As we move into the next stages of developing the portal, regular input from participants will continue to be sought, including through a large-scale survey, further workshops to test prototypes of the patient portal, and ‘real world’ testing of the portal by a small number of volunteers.

Finally, we welcome input from anyone reading this report to join the conversation by offering any ideas, concerns, questions, or feedback by emailing us at **contact@sanogenetics.com**

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