

Dear Colleagues

Since our last newsletter, distributed in March, the National Breast Cancer Foundation BreastScreen Victoria Cohort Demonstration Project Investigators have been immersed in the process of Consumer Consultation, so apologies for the delay in communication.

A name and logo for the Cohort Project

The first big news is, as you may notice, our new name. One of the strong messages delivered during focus group consultation with 71 women in the Victorian community over February, March and April was that the name of the project was too long, too technical and didn't tell women anything about the aims of the project. In response to this, the Chief Investigator group commissioned a piece of design work and we are really pleased with the outcome.

Lifepool: Australian women finding answers.

Lifepool describes our aims well: The Lifepool Project will enable every woman to contribute precious drops of information to a secure 'pool' of data. This data will contribute to research improving women's health. Approved research projects can dip into this pool of data in a myriad of combinations to answer important questions around breast cancer development, diagnosis and treatment. The logo developed for the Project reflects the way each woman's contribution intersects. As the information is layered, the depth of the resource increases. Our chosen colour scheme links Lifepool to our funding body, the National Breast Cancer Foundation.

Response to Consumer Consultation

The primary aim of the consumer consultation process was to gauge support for the Project and get an indication of how receiving an invitation to participate in the Project might impact on participation in the BreastScreen Victoria program.

We tested Version 1 of the Participant Information and Consent Form (PICF) as well as the Letter of Invitation with each of the first 7 groups for clarity and readability. We asked women to tell us when they would prefer to receive information about the Project.

Women clearly told us that they would be happy to receive a letter of invitation with the confirmation of their screening appointment. They were supportive of the aims of the Project and many (37%) of those surveyed thought that they would be more likely to attend for screening when they learned about the Project.

At the end of each Focus Group session, we quizzed women on their understanding of key elements of the project:

- Would they be asked to approve the use of their information for every research application?
- Did they have to participate in the Project to have a mammogram through BreastScreen Victoria?
- Did they have to donate a blood sample?

- Would a woman's personal identifiers, ie name and address, be known to researchers?
Would these identifying details be known to the Project staff?
- Did they have to have breast cancer to be part of the Project?

Women's responses to these questions told us exactly where we had gone wrong with Version 1 documents. We made changes to the documents to ensure that these key messages were clearly delivered. The last focus group, group number 8, reviewed the changes.

We can report that the work done for the Project by the Health Issues Centre has provided us with invaluable feedback on how to improve Lifepool. We have modified both documents and recognize the value of the consultation process in improving the Lifepool Project. Version 2 of both the PICF and the Letter of Invitation have been reviewed and approved by our governing ethics committee. We have developed pilot recruitment protocols, based on the preferences expressed by women on timing of the Invitation Letter.

Next Steps

We are testing our protocols in a series of carefully controlled pilot projects. Our primary aim is to confirm our Focus Group data which told us that receiving an invitation to participate in Lifepool will not deter women from attending for routine mammographic screening. We will also monitor workload impact on BreastScreen Victoria staff.

When data is analysed from these pilot recruitment projects, we will launch The Lifepool Project with an appropriate degree of celebration.

Members of the Lifepool Management Advisory Committee are engaged in formulating the Stage 2 Information and Consent Form for use when Lifepool invites some women to donate a blood sample and we look forward to keeping you informed of our progress.

Thanks for your support

The Lifepool Team.

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