



digi.me

Data sharing for Harvard research project

A longstanding research project based at Harvard University in the United States has been exploring how it can partner effectively with digi.me.

The project's participants are drawn from the Nurses' Health Study 2, which runs jointly across the Harvard T.H. Chan School of Public Health and Brigham and Women's Hospital, an affiliate of Harvard Medical School.

The health study has been going since 1989 and has over 100,000 nurses taking part from all over the US. They receive questionnaires every two years asking them about their behaviour, lifestyle and health, as part of the study's overarching goal to further understand how to prevent chronic disease through lifestyle and behavioural changes.

Professors Laura Kubzansky, Lee Kum Kee Professor of Social and Behavioral Sciences at the Harvard T.H. Chan School of Public Health and Fran Grodstein, formerly of Harvard Medical School and now Adjunct Professor of Epidemiology at the Harvard T.H. Chan School of Public Health, are working with some of the study participants to understand what positive benefits certain attributes, such as having a positive outlook or being optimistic, can bring to health outcomes.

As part of this, they began wondering about the idea of using social media to assess some of the attributes they were interested in. For the cohort they had in mind, who are in their 50s and 60s, this meant getting their consent to study the language of their Facebook posts.

They obtained funding for the project, but then the Cambridge Analytica scandal broke, and access to Facebook data was shut down. At “a complete loss – how were we ever going to do this project?” they learned about digi.me through a personal contact of Professor Kubzansky’s with expertise in companies dealing with data privacy issues.

Digi.me, said Professor Grodstein, was “just ideal for us as we’re always concerned about participant privacy, security, and confidentiality. “Government has lots of rules for human research, our institutions have lots of rules, and we as researchers impose really high standards on ourselves to ensure privacy to as high a standard as possible for all the information the participants so generously share with us.”

Digi.me was a “beautiful solution” and she and Professor Kubzansky worked with the digi.me team on a customised version of the main app, so that participants could, completely securely, send their Facebook data directly to the researchers. Professor Grodstein said: “Digi.me really is an ideal platform for this kind of research, with the ability both to transfer large amounts of information, and do it in such a secure, private way. All the digi.me parts worked beautifully and were an ideal fit for our needs.”

Professor Kubzansky added: “We were also very impressed with everyone we worked with at digi.me who were highly responsive to our concerns and requirements and routinely made themselves available for troubleshooting and evaluating how processes were working. “We would absolutely work with them again if we had similar needs.”

An independent Institutional Review Board, which assesses how ethical research studies are, approved the use of digi.me for providing a secure and confidential way to transfer information and had no concerns about the platform.

The researchers are now exploring how they can work with other cohorts, and other social media platforms, to get more of the kind of data they are interested in, with full consent from those with whom they are working.