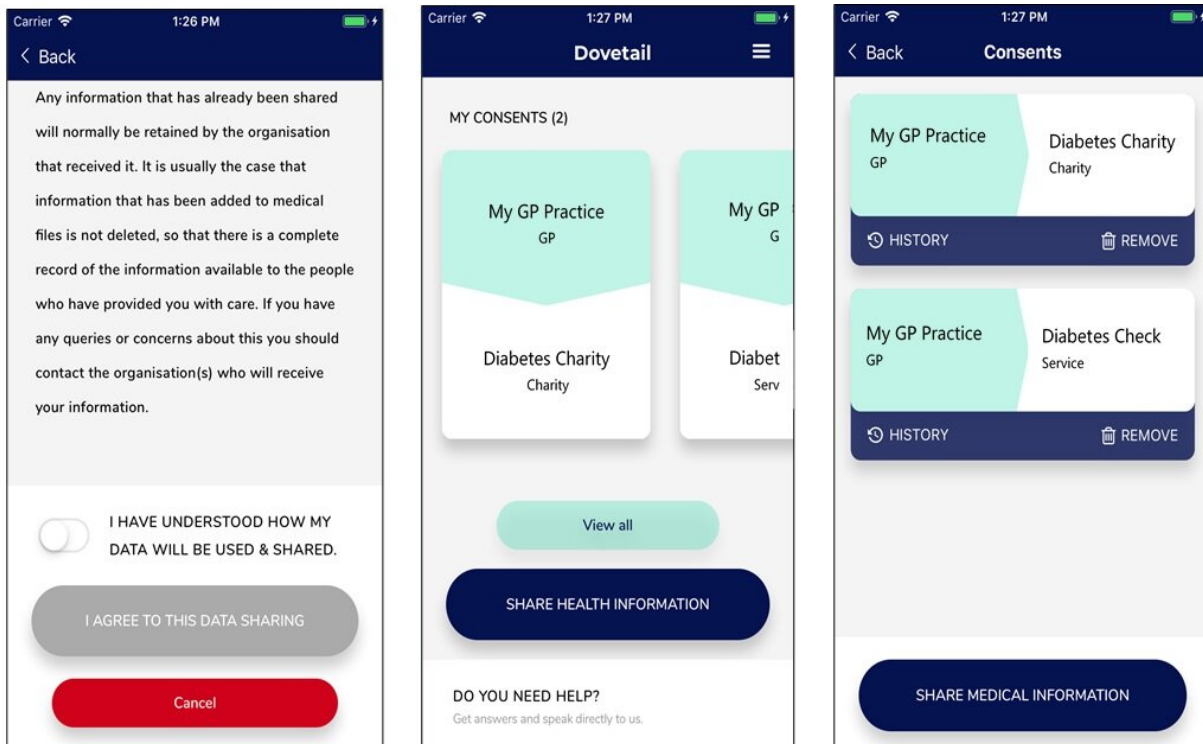


# Patients prefer their consent to share their data and to manage it digitally

May 14 2020, by Alice Scott



Credit: University of Warwick

Patients with diabetes often have to see many different stakeholders who each specialize in different aspects of their treatment. Researchers from WMG, University of Warwick surveyed patients on their understanding of how their data was shared, and found they would prefer to have it

shared digitally using the Dovetail Digital consent application.

There are 4.7 million people in the UK live with diabetes, and will spend a lot of time visiting different specialist in different practices, who each specialize in some aspect of their treatment. Furthermore advances in digital technologies have resulted in innovative applications, which supported by [healthcare professionals](#) enable self-management, empowering patients to take control over aspects of their care. This requires a lot of data sharing, which is currently done by one practice requesting the [medical records](#) off another practice; with the need for doctors [consent](#) to share, this can be a long process to sign off. Furthermore, the process tends to be obscure with the patients forgetting the transfers for which they have given consent, as well not being very easy to revoke consent should the want so. The ability of patients to have control is one of the fundamental ethical and legal rights of the patient, and in many cases is difficult to balance against beneficial but data sharing intensive applications.

However, researchers from the Institute of Digital Healthcare (IDH) at WMG, University of Warwick propose that a new system called the Dovetail Digital consent application is favorable, and have analyzed it in the paper; "Evaluation of patient perception towards dynamic health data sharing using blockchain based digital consent with the Dovetail digital consent application: A cross sectional exploratory study," published in the journal *Digital Health*.

The Dovetail digital consent application is a robust, trusted and flexible mechanism for patients to offer their consent for their data to be shared between GP practices; they can also revoke consent at any point, therefore empowering them to manage their condition within an integrated care setting.

Dovetail sees a mobile application and blockchain-based infrastructure,

meaning they can trace where their data has been shared. Blockchain is a state-of-the-art technology originating in the financial industry, which has allowed implementing healthcare applications with the confidence and robustness found in the financial sector.

To survey whether it would work, IDH researchers asked 23 patients and 13 staff with diabetes, at a GP practice, to complete a series of questionnaires, followed by a focus group discussion, to determine their understanding of current methods to share data in a medical setting, and to see if they recall giving consent.

IDH Researchers then conducted a thematic analysis of the focus group transcripts and descriptive statistics of the questionnaires were performed.

Professor Theo Arvanitis, Director of the Institute of Digital Healthcare at WMG, University of Warwick explains what they found:

"We discovered there was a lack of understanding of existing consent processes in place, in fact many patients did not have any recollection of having previously given consent to their data being shared. When we asked them what they thought about the digital consent application patients overwhelmingly favored the digital consent application over existing practice, as they recognized the value of the capability offered by the application."

Dr. George Despotou, Associate Professor at the Institute of Digital Healthcare and lead in the study comments:

"The study participants welcomed an application that would ultimately contribute to improving their quality of care, whilst maintaining control over their data. In particular the study participants acknowledged the clarity of the consent application, and the ease with which they could

review, as well as revoke existing consents. This was a very promising study on a technology that may be opening the way for highly innovative applications improving quality and efficiency of healthcare services, which patients would welcome, assured that ultimately they are in charge of their data."

**More information:** George Despotou et al. Evaluation of patient perception towards dynamic health data sharing using blockchain based digital consent with the Dovetail digital consent application: A cross sectional exploratory study, *DIGITAL HEALTH* (2020). [DOI: 10.1177/2055207620924949](https://doi.org/10.1177/2055207620924949)

Provided by University of Warwick

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