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High resolution data from everyday life: coproducing a technically robust and engaging sensing platform

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Objectives

Researchers are increasingly recognising the potential for connected health devices - in particular, wearables and smartphones - to capture high-resolution, multi-dimensional data from everyday life. The Dementias Platform UK project aims to develop research capacity in this emerging area by providing a combination of hardware and software: a pool of devices capable of generating data supported by a 'sensing platform' designed to securely receive, store and link these data with sources, including clinical records and cohort data. We collected feedback from researchers and patients to (i) develop requirements for the sensing platform and (ii) inform procurement of a device pool.

Methods

Separate workshops were held to involve (i) researchers (public and private sector) and (ii) over 30 patients from four potential user groups, including people with dementia. Both groups gave feedback on the suitability and acceptability of a range of wearable devices for capturing data for different study purposes. Additionally, researchers commented on the platform functionality. Patients were provided opportunities to handle multiple devices and test them at home. We captured feedback at workshops using notes, which were collated, shared and discussed among the team. An agile software development methodology was used to respond rapidly to changing requirements.

Results

Patients supported plans for connected health dementia research and, in principle, were willing to wear devices, provided they consented voluntarily and data were stored securely and confidentially. Many patients were prepared to undergo some level of inconvenience, for example wearing devices for longer periods, particularly if given ongoing feedback about research progress, findings and benefits. Researchers and patients agreed the platform should be open to a wide range of devices, available currently and in future. Researchers envisaged using the platform for a range of projects and data types. As a result, we established a device pool (including wearables, smartphones and tablets) and developed a generic, 'device-agnostic' platform to receive and store data. Platform architecture was designed to be as flexible as possible to allow for future modifications.

Conclusion

We found it was feasible to integrate requirements from both researchers and patients when developing a sensing platform for dementia research. By seeking feedback from both user groups, we were better able to attend to device linkage requirements, platform functionality and acceptability, integrating these within development and procurement processes. Furthermore, we identified aspects of research setup and design that could support sustained engagement from participants, thereby improving data completeness and quality.

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