Tech-no or tech-yes? Insights from older adults on digital monitoring of physical and cognitive health.

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Introduction

- The numbers of people with dementia in the UK is forecast to increase by forty per cent over the next 12 years (Alzheimer's Society, 2014).
- Early diagnosis of neurodegenerative diseases significantly improves long-term health outcomes (Borson, 2013), thus one of the key challenges is to improve disease detection at the earliest stage possible.
- A second challenge is to closely monitor disease progression and fluctuations to enable the most effective therapeutic interventions.
- Wearable devices, apps and software offer a solution by unobtrusively collecting individualised data about physical, cognitive and functional wellbeing over time.
- Such technology depends on how acceptable such monitoring technology is to older adults

Aim

To determine the thoughts and feelings of older adults (with or without dementia) about the use of technologies for disease detection and symptom monitoring.

Methods

We report on qualitative data collected from three different projects which evaluated the feasibility of using technology for disease detection and monitoring.

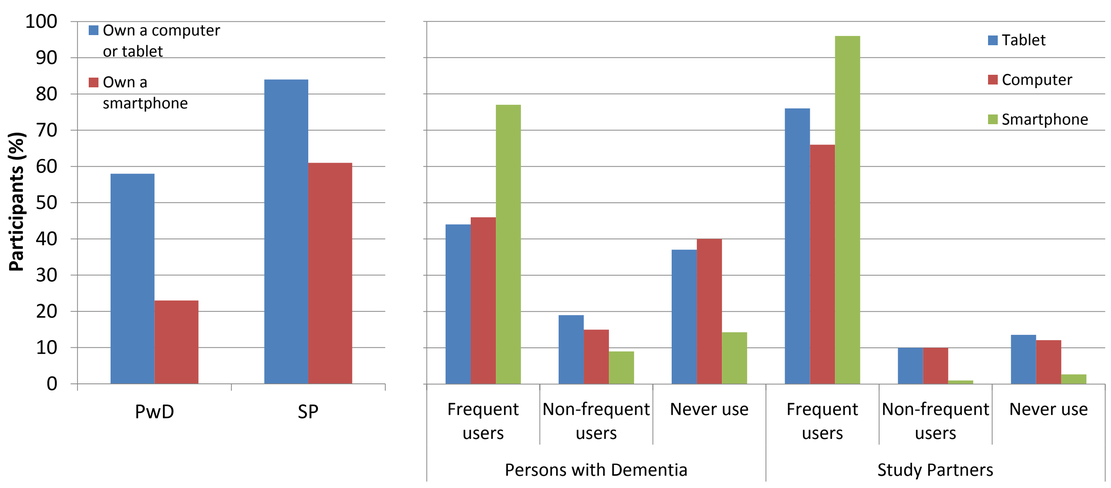
1) The **CYGNUS** project used mobile devices and wearable technology to collect outcome measures for people referred to memory assessment services and their supportive partners. A technology questionnaire was used to determine readiness for the weekly online data collections and mobile device monitoring study (n=273).

2) The Software Architecture for Mental Health Self-Management (**SAMS)** project aimed to detect subtle changes in patterns of daily computer use as proxy indicators of early cognitive decline. A debrief questionnaire was used to determine participants'' preferences for, and the acceptability of, the monitoring software (n=31) and was analysed using a combination of content and thematic analysis.

3) The Symptom Knowledge in Parkinsons (**SKIP)** project aimed to monitor fluctuations in Parkinson's disease symptoms through laptop based tasks and passively through smartphone sensor data. Two focus groups were conducted to discuss the use of technology for disease monitoring (n=6) and data was analysed using thematic analysis.

Results – CYGNUS

- Ownership of home computers/ laptops, tablets and smartphones varied between people with dementia (PwD) and study partners (Figure 1).
- 29% of people with dementia felt confident in using their technology compared to 65% of study partners.
- Common reported concerns in both groups included scams / fraud, sharing personal data, banking and online security.
- Users of technology felt training and reassurance about data security would alleviate these concerns.



How often do you use your computer, tablet or smartphone?

Results – SAMS

Table 1. Summary of participants' views by question

Question	Yes	No
Did you find the SAMS software to be acceptable and unobtrusive?	74.2%	6.5%
Did you have concerns about privacy and/or confidentiality?	25.8%	61.3%
Do you use a smartphone?	54.8%	16.1%
Do you use a tablet?	61.3%	19.4%

Privacy and confidentiality

Concerns about privacy and confidentiality were mainly focused on what the SAMS software could access e.g. banking details. Overall, concerns were alleviated through participation in the study: *"I was initially concerned about the confidentially aspect. My mind was put at rest by the representatives I spoke with on this issue" (LSJ108).*

Device preferences

Some participants preferred smartphones/tablets (12.9%) (to laptops/PCs) whereas others preferred laptops/PCs (16.1%) (to smartphones/tablets). Twenty nine per cent of participants explained that choice of device depended on task and location. On the whole smartphones and tablets were used outside the home or for quick and simple tasks such as internet browsing and checking emails. More complex or longer tasks were done at home on a laptop or PC: *"I need my laptop for word processing, printing. But the iPad is just so easy to use for picking up emails and taking photos. I probably use them both equally, but for the different jobs" (LSJ108).*

Additional tasks

Participants had mixed opinions about the optional diary task, some found it interesting and beneficial, whereas others thought it was time-consuming, daunting or tedious.

Sharing data

Forty two per cent of participants wanted information about any cognitive change to be shared with family and/or their GP. However, twenty three per cent felt the data should just go to the user in the first instance.

Results – SKIP

Readiness

Participants recognised the need for a solution to monitoring symptoms more regularly and more in detail: *"I think when you go to see the specialist or the nurse, and you're feeling quite "chipper", and they ask you how you are and you say "Yeah, I'm great. Not so bad."… whereas 2-3 hours later when your medication's worn off, you're all slumped forward and feeling miserable… It's about trying to get that disparity over to them" (SC103).*

Willingness

Privacy concerns, such as sharing data with clinicians and spouses/carers were not generally an issue for participants, where the benefits of monitoring outweighed the costs: *"It didn't feel as though, "Big Brother's watching you", monitoring what you're doing and where you're going" (SC106)*

Ability

Participants agreed that their physical symptoms could interfere with using technology, such as using a keyboard, mouse or smartphone/tablet touch screen: *"I have a problem with keying because of the tremor in my right hand." (SC104)*

Discussion

- Ownership of devices such as laptops and smartphones, varies amongst the older adult population in these studies.
- Older adults, especially those who do not use technology, have concerns regarding privacy and security, however these can be alleviated through reassurance from researchers , training and allowing time to get used to the device or software.
- Some older adults are willing for data to be shared with family and clinicians, however others would prefer data to go to them first.

Conclusion

The design of detection and monitoring software needs to: be developed for a range of devices; account for concerns about privacy and security; allow the user to determine who can see the data; and keeps up to date with new and evolving technology.

References

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Acknowledgements – A special thanks to all of the participants who gave up their time to take part in these studies.