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# Utilising connected health and data science to enable dementia research: What do patients and the public think?

## SUMMARY REPORT

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## INTRODUCTION

In 2015 University of Manchester won funding to develop infrastructure and capacity for undertaking dementia research as part of the MRC's Dementias Platform UK (DPUK) award. As part of this, the University was awarded £500k of capital funding to spend on connected health technology to support future dementia research. Ultimately, this stock of devices will support a range of future research projects that will investigate the potential for mobile and ubiquitous technologies to better characterise and predict dementia.

Whilst the research projects that will be enabled by these devices are yet to be conceived, the capital funding must be spent in advance, by the end of March 2016. Thus, timely decisions need to be made regarding the choice of devices to purchase, taking into account the potential variety of topics of dementia research that the devices could support.

The devices to be purchased should be both suitable for data gathering purposes and acceptable to users. Hence, as part of the decision-making process, it was deemed useful to consult patients and members of the public, with a view to gaining advice and input from groups similar to those who might take part in future research. Input from researchers was gathered separately (including a workshop held on 6th October 2015) to establish the technical specifications and data gathering requirements for devices. In this report, we summarise the findings of a series of workshops and meetings with patients and members of the public to explore the acceptability of different devices to users, with the aim of informing purchasing decisions and use of these devices as part of future research.

### Aims

1. To develop guidance for those conducting dementia research indicating the relative suitability and acceptability of a range of devices that capture data from different types of potential users.
2. To inform decisions regarding which devices to purchase for the purposes of supporting an innovative programme of future dementia research.

## THE WORKSHOPS

During the period of October 2015 to January 2016, we held a series of workshops and informal meetings with patients and members of the public to explore the acceptability of different devices to users. This section of the report describes the planning and delivery of these involvement activities.

### Deciding who to involve

To determine exactly who should be involved in our activities, we first considered the types of people who could be asked to wear devices as part of future research projects. We identified four distinct groups of potential users, described as follows:

1. People living with dementia and their carers.
2. People living with memory problems or Mild Cognitive Impairment (MCI) and carers.
3. People living with dementia who are aged 65 years or younger, referred to as young onset dementia.
4. People without known memory problems aged 50 years or older.

To optimise content and delivery, separate workshops were planned for each group of potential users, although inevitably there was room for some overlap (e.g. groups 1 and 3).

### Workshop format and activities

We planned a series of two-part workshops for each group of potential users: two meetings held approximately 1-2 weeks apart, with a short period for testing devices in between. Sessions were designed to be hands-on and interactive, covering the following content:

| | |
|---|---|
| ***Session 1*** *(1-2 hours)* | Introduce types of dementia research and questions, introduce devices, discuss using devices for research, opportunity to handle and play with devices, invite volunteers to take away a device to test out at home. |
| *Device testing period (1-2 weeks)* | |
| ***Session 2*** *(1-2 hours)* | Share and explore experiences of using devices at home, consider which devices might be most suitable for different user groups, reflect on data governance and privacy issues. |

Workshops were facilitated by researchers, who took detailed notes. A series of supporting guides and documents were developed to support the workshops, including:

- Discussion guides – questions and prompts to get discussion going.
- Research scenarios - examples of hypothetical research projects where devices might be used as a basis for discussion.

- Summary information for individual devices –basic facts on features such as functions (e.g. sleep quality, steps), battery life, memory and water resistance.
- Tester feedback – questions for testers to think about whilst testing devices.

Although we had planned to run structured workshops for each group, this was not always feasible. In the case of people living with MCI or memory problems and their carers, we did not attract a sufficient number of people to make it worthwhile running a workshop. In this case, we had 1:1 meetings with individuals instead, which covered relevant topics in a more informal manner. In the case of people living with young onset dementia, due to the relative rarity of this condition, it was more efficient to visit an existing peer support group (Mount Chapel Champions) and speak to people at one of their weekly meetings.

**Advertising**

Posters were designed to advertise workshops to people living with dementia, those with memory problems and those without known memory problems (for example, see Fig. 1). These and other relevant details were advertised in electronic and physical formats via social media (e.g. Twitter), patient and public involvement networks, networks for older people (e.g. Age UK), dementia-specific networks and facilities (e.g. the Humphrey Booth Resource Centre),support staff email distribution lists at The University of Manchester and personal contacts. Attendees were offered £20 per session and refreshments as a thank you.

**Devices**

The following devices (some in a selection of colours and sizes) were purchased for use at the workshops:

- Axivity AX3
- Fitbit Charge HR
- MOTO 360
- Garmin vívofit 2
- Misfit Speedo Shine
- Withings Acitivité Pop
- Withings Pulse Ox

Prior to the workshops, researchers set up and wore a selection of devices to generate dummy data and to familiarise themselves with device set-up procedures, functions and interfaces.


**Figure 1**: Poster used to advertise workshop to people living with dementia and their carers.

## FINDINGS

This section of the report describes who attended the workshops and informal meetings we ran, and what we found.

### Attendance

We involved over 30 patients and members of the public in our activities. Further details about who attended each activity and how they were recruited are provided in Table 1.

**Table 1: Characteristics of patient and public attendees, by workshop**

| | **1. Living with dementia** (Workshop) | **2. Memory problems and MCI** (1:1 meetings) | **3. Dementia <65 yrs** (Activity at weekly support group) | **4. No known memory problems >50 yrs** (Workshop) |
|---|---|---|---|---|
| **Number** | 5 + 4 carers. | 2 + 1 partner. | 8-12 (inc. some carers). | 9 |
| **Gender** | 5 women, 4 men. | 1 woman (and husband), 1 man. | Men and women. | 5 women, 4 men. |
| **Age** | All but one 1 aged >65. | All >65 years. | All <65 years. | Mainly mix of 50-60 and 60-70, at least 1 aged 70+. |
| **Recruited via** | Age UK, Humphrey Booth Resource Centre and Open Doors Network. | Ongoing research study recruiting people with memory problems. | Attending Mount Chapel Champions weekly support group. | UoM PPI networks, UoM admin/ support staff, social media. |
| **Tech-friendly?** | None had smart phones or activity trackers. Most had a basic mobile phone and internet access. One or two had tablets. | Both had a basic mobile phone and internet access. | Few had smart phones. Most had a basic mobile phone and internet access. One had considered using an activity tracker for running. | All but one had smart phones and/or tablets, 2 had experience of using an activity tracker. |

**Figure 2:**

Members of the public trying out devices as part of an interactive workshop.

## Acceptability of connected health dementia research

Across all groups, there was a strong level of support for research using connected health devices that improved dementia prediction, treatment or quality of life for people living with dementia. All of the people we spoke to said they were, in principle, happy to wear a device for at least some period of time and for data about them to be collected as part of dementia-related research. This was providing they were given information about the specific study, had provided their consent and were reassured about confidentiality, data security and anonymity. In addition, many people were prepared to undergo some level of inconvenience to themselves by wearing devices for longer periods, if it helped research and outcomes for people with dementia in future.

## First impressions of devices

Amongst the group with no known memory problems, two had previously used activity trackers in some form and most were aware that they existed. Among people living with dementia and those with memory problems, there was far less awareness of activity trackers and familiarity with computing technology generally. Among these groups, there was no indication that people had previously considered using these types of devices for personal use.

We gave people the opportunity to view, handle and try on a range of devices. People varied in terms of which devices they found most wearable, comfortable and aesthetically pleasing. Notably, people had different requirements for a device if they were using it for personal use, compared to using it as part of a study. They also distinguished between 'active uses' (using it to promote behaviour change) and 'passive uses' (wear it and forget about it).

Overall, people indicated they were more likely to wear a device when:

- The aim and purpose of the research was clear and researchers would justify why they needed the data (especially more sensitive data, such as GPS).
- They personally supported the aims of the research, or perceived potential 'benefit' to patients and/or themselves.
- The device told the time in a simple format, thereby replacing a wristwatch.
- The device tracked sleep as well as physical activity.
- The device enabled personal feedback, especially on the wrist.
- The device was unobtrusive, low maintenance, waterproof and robust.
- The particular research project required them to wear devices for shorter periods of time.


**Figure 3:**

A range of devices were demonstrated at workshops and loaned to testers.

## Tester reports

At the end of sessions, we offered people the opportunity to borrow a device to test out at home. The purpose of this was to give people more of an insight into the issues that future research participants might encounter and the wearability of devices. Overall, devices were loaned out 14 times for testing: four testers were living with dementia, three had memory problems and seven had no known memory problems. All of the devices we presented were tested by someone except for the Axivity AX3; nobody volunteered to test this as it gave no opportunity for feedback to the individual tester. All of the testers in the group with no known memory problems had a smartphone/tablet and synched these with the borrowed devices. None of the group living with dementia had a smartphone and so devices were synched with a University tablet instead (not loaned to them and synched with the device at the follow up workshop).

At follow up sessions, we asked for feedback on how testers found the experience of setting up, wearing and using the device. Key points are summarised below:

- **Set up** – People who had less familiarity with technology and/or were unused to smartphones required more help to set up their devices. Those who chose to set up their own devices encountered few problems. Some issues were found with the MOTO 360 (due to extra apps being required to maximise functionality) and the Fitbit Charge HR (when loading it onto a tablet rather than a phone). The individual who borrowed the Withings Pulse Ox could not test their device as it failed to sync with the app.
- **Wearability** – No problems were reported with the Garmin vívofit 2, the Withings Activité Pop or the Misfit Speedo Shine (provided the activity clip was worn to keep it securely in place). Two of the four people who tested the Fitbit Charge HR reported skin problems and had to stop wearing it. The Moto 360 was considered bulky. Some people wearing non-waterproof devices worried that they would forget to take it off when performing certain daily living tasks (e.g. showering, washing-up and cleaning). Those who already wore a watch preferred devices that showed the time, and could therefore replace a watch, or could be feasibly worn as well as their own watch.
- **Feedback and interface** – Testers generally preferred devices that gave some feedback on the wrist. Those living with dementia and their carers required some help to navigate the interface and interpret the data, especially that provided via the app. People were very interested in their sleep data, in particular. Some older people struggled with viewing data on smartphone screens, preferring larger tablets.
- **Data accuracy** – Accuracy seemed to be better when devices were synched to the tester's own phone/tablet. All of those testers in the group who were living with dementia experienced some data losses or irregularities including missing activity data and inaccurately recorded sleep patterns. The time reset with some devices if not synched regularly with a phone/tablet.

In summary, although many had not previously considered using activity trackers, most found them wearable for the duration of the testing period. Some became very attached to their devices and the data they generated (indeed, two subsequently bought their own devices). A few could not tolerate wearing a device due to skin conditions.

## Issues and considerations for conducting research involving connected health devices

During sessions, we explored with attendees how the devices could be used as part of research and the opportunities and challenges that may arise as a result. Key points included the following:

- Support for setup and possibly provision of a mobile phone may be required to support participation from some participants. A smartphone (or tablet) was seen as necessary to 'unlock' the value of regular feedback from devices. It would be unreasonable to expect participants to visit a specific location to sync the device and upload data.
- The testing period revealed some unexpected findings for individual testers. Some people enjoyed using devices much more that they expected. Others were unable to tolerate certain devices, sometimes for clinical reasons (e.g. skin irritation).
- Some people worried that the devices might draw attention from others, leading to questions that could lead to their health status being questioned or revealed. There was some concern about attracting 'unwanted attention' if devices looked out of place or couldn't pass for a watch.
- Questions were asked about how researchers would access data from devices. The data being collected was mostly perceived to be low risk and not highly sensitive. The exception to this was detailed GPS data, for which more careful justification would be required. People generally trusted researchers with their data. They thought it was acceptable for participants to share their data with third-party companies (e.g. Withings), if necessary for the research, providing participants were informed of this.
- Some people asked about what would happen if a device picked up an irregularity that could indicate a health problem, such as very high heart rate – would the participant be alerted or advised to visit their doctor? There was an expectation that researchers should intervene if there were clear signs of treatable health problems requiring attention.
- Some people discussed the possibility of longitudinal study designs that required participants to wear a device every year for a set period of time (e.g. 1 month every year). Wearing a device for a shorter period annually was preferred to wearing a device continuously.
- Even though studies in this area may be focused around apps and digital devices, it does not necessarily follow that all follow up, contact and support should also be digital. People living with dementia and their carers indicated they preferred the telephone and face-to-face contact to email. The need for reliable telephone support was seen to be important in supporting people to maintain and use devices.
- Carers were seen to be instrumental in maintaining the ongoing participation of some people with memory problems in studies.
- People were interested in research. Providing updates on the progress and outcomes from the research could be an incentive for wearing the device for longer, making participants feel valued and encouraging support for the research. Some people welcomed the idea of personalised feedback on their outcomes over time, or in comparisons to other participants in the study.
- Some older people warned against stereotyping: although many did not *choose* to engage with technology, this did not mean they couldn't use it if they wanted/needed to. Others were very technically able. People wanted to be considered as individuals.

## RECOMMENDATIONS

**When purchasing devices, it is recommended that:**

- More than one type of device should be purchased. Where possible, a variety of straps (or belt mounts, if available) should be purchased in different colours, sizes and materials, to improve wearability.
- A stock of phones and/or tablets should be purchased to enable people who do not own their own suitable device to participate.
- Devices to be worn for longer periods should be waterproof and should have a long-life battery.
- Wrist worn devices should, ideally, clearly show the time and pass for a watch. If they do not display the time, devices that pass as bracelets or can be worn discreetly elsewhere (e.g. using an alternative belt clip mount) are preferable.
- Devices, and any associated 3rd party software applications, are checked before purchase, and henceforth on a regular basis, to ensure that they provide the necessary security to protect personal data and ensure privacy.

**When conducting research using connected health devices, it is recommended that:**

- Any software, whether existing or new, that is used to store or process personal data should be fully compliant with modern security standards to provide the necessary security to protect personal data and ensure privacy.
- Information provided to prospective participants should include information on:
    - How data is transferred between the device, researchers and any third parties.
    - What happens if researchers pick up something irregular, indicating a potential health problem.
    - Prospective benefits to individual participants and future patients.

- Set up of devices should include:
    - Offer of one-to-one support to set up the device.
    - Offer of phone/tablet, where feasible.
    - Demonstration of how to charge the device, if needed.
    - Follow up visit/call shortly after to check they are able to use the device.

- Researchers consider offering a trial period in advance of the research to get people familiar with using the device, without pressure to participate in the study. Offering prospective participants a choice of wristbands and allowing users “trial periods” to try out wearing the device in advance of the study may help to allay misgivings, address any teething problems in a low pressure way and possibly increase recruitment and retention.
- Where individuals have carers and want them to be involved, researchers make provisions to enable this (e.g. scheduling appointments at times when carers can attend). This applies to the process of recruiting participants, following them up over time and reporting on the findings of studies.

- Participants should be offered feedback on study progress and outcomes throughout the study. This should be offered in a choice of formats, not just email.
- Researchers consider offering a telephone number of a person/office who is available during working hours and can offer help if they have problems with their device.

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## FURTHER INFORMATION

This report summarises findings from a variety of activities with different groups of patients and the public. A number of related resources are available on request including reports describing individual workshops in more detail and copies of supporting materials (e.g. discussion guides and research scenarios). In addition, a number of patients and members of the public who participated in these activities were interested in being contacted about future involvement opportunities. For further information please contact:

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