Abstract

Pioneering advances have been made in Internet of Things technologies (IoT) in healthcare. This article describes the development and testing of a bespoke IoT system for dementia care. TIHM for dementia is part of the NHS England National Test Bed Programme and has been trailling the deployment of network enabled devices combined with artificial intelligence to improve outcomes for people with dementia and their carers. TIHM uses machine learning and complex algorithms to detect and predict early signs of ill health. The premise is if changes in a person’s health or routine can be identified early on, support can be targeted at the point of need to prevent the development of more serious complications.

Key Words:

Dementia, assistive technologies, machine learning, anticipatory care, internet of things

Key Themes:

- Pioneering digital technologies to help the NHS provide more targeted and sustainable support for people with dementia and other long term conditions
- How digital technologies can fill a gap in care for people with dementia and reduce the burden on carers
- The growing pressure of an ageing population
- How the IoT and machine learning can support early intervention
- Case studies showing how TIHM helps people with dementia to receive prompt support at point of need
Introduction

Integrative digital technologies have the potential to revolutionise healthcare delivery for people with comorbid long-term conditions. Pioneering advances in Internet of Things (IoT) technologies and data analytics are beginning to show promise in the fields of diagnostics and anticipatory care (Catarinucci, et al 2015; Yang et al, 2014). IoT-enabled patient monitoring combines data from digital devices (e.g. monitoring vital signs, behaviour, mood and environment) and uses data analytics and machine learning methods to extract information from raw observations and translate these into real-time actionable insights for clinicians so that they can understand disease progression and deploy support at the earliest point of need to prevent an escalating crisis (Enshaeifar et al, 2018).

An example of such technologies in a real-world setting is Technology Integrated Health Management (TIHM) for dementia. This technology is being trialled as part of the NHS England’s Test Bed programme investigating how new technologies can be harnessed to support people with complex health problems. TIHM deploys Internet of Things technologies to support people with mild to moderate dementia living at home.

TIHM is based on a health monitoring and managing system that gathers continuous information about individuals and their environment using a network of internet enabled devices (sensors, monitors, trackers) installed in the home. Information generated by the IoT system enables a team of healthcare professionals to remotely monitor the health and safety of people 24/7. If a problem is detected by the technology, an alarm is triggered on a digital dashboard and the monitoring team step in to provide support.

The main objectives of TIHM, which involves a collaboration of partners from the NHS, industry, academia and the voluntary sector, are to provide a system that helps to keep people with dementia safe and well in their homes through bettering monitoring of health and improved early
intervention, as well as reducing the burden on carers. At a more strategic level, TIHM is testing the feasibility of a digital care pathway that could provide the NHS with a more targeted, effective and sustainable way to support the growing number of people developing this condition.

**Scope of the Problem**

The Alzheimer’s Society estimates that there are 930,000 people with dementia in the UK and that this figure will rise to more than 1.1 million by 2025. The current cost to the UK economy of supporting people with this condition is more than £26 billion and predicted to rise to £55 billion in 2040 (Prince et al, 2014).

The complexity and cost of managing the health of someone with dementia can be far greater than that of a person of the same age who does not have the condition. People with dementia who are over the age of 65 have on average four comorbidities while people in the same age group who do not have dementia, have two (Poblador-Plou et al, 2014).

The impact on the NHS is significant: one in four hospital beds are occupied by a person with dementia (Lakey, 2012) and 42 percent of unplanned admissions to an acute hospital of people over 70 have dementia (Sampson, 2009).

Supporting a person with dementia takes its toll on carers and 63.5% say they have had no or not enough support (Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital). Also, many carers, 48.4 percent, have a long standing illness or disability (Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital).

Despite the pressure on the NHS, there is evidence to show that if a system were in place to aid early intervention, the number of unplanned hospital admissions for people with dementia could be reduced. For example, research shows four of the five most common co-morbidities people with dementia are admitted to hospital for in the UK are for preventable conditions: a fall, a fractured hip or hip replacement, urinary tract infection and chest infection (Scrutton and Urzi Brancati, 2016).
Typical NHS care for a person with mild or moderate dementia is ‘light touch’ and there is little, if any, routine monitoring of their day-to-day health by healthcare providers. The onus of managing the health of the person with dementia falls on that person and the carer. This means that, despite best efforts, there can be delays in picking up infection and other health-related events (e.g. changes in mobility that can cause falls) that often affect a person with dementia. Diagnostic delays are associated with greater morbidity, carer burden and hospital admission and the more unwell the person with dementia becomes, the less likely it is that their care needs can be catered for in the community.

**How technology can help**

With an ageing population, the need to try and plug this gap in care is becoming more critical. However, workforce supply shortages and a limit on resources mean traditional approaches cannot be relied upon. This is where technology can help.

While the common assumption is that older people are less likely to embrace technology, research and the experience of TIHM suggests otherwise.

The Alzheimer’s Society (ASTRID 2000) highlights the potential of technology to promote the autonomy of the person with dementia and their carers, minimising potential risks for the person with dementia at home, deterring early hospital and care home admission, and generally improving the life of the person with dementia and their carers. A systematic review has identified a number of technologies that have been developed primarily for use with people with dementia. These include; reminders/prompts, safety devices, and reminiscence/entertainment (Bonner & Idris, 2012).

In the case of TIHM, the trial was co-designed with 20 people with dementia and their carers, known as Trusted Users. The Trusted Users’ feedback ensured TIHM was user friendly and gave them what they wanted and needed. Workshops involving people with dementia, carers, clinicians, social care professionals and academics helped to further define the needs of people with dementia living at
home as did a survey undertaken with the Alzheimer’s Society to determine the views of people with dementia and their carers regarding technology-enhanced care.

The TIHM intervention was rigorously examined before being trialled. Its performance was tested in the developers’ laboratory. Next, it was tested in a ‘living laboratory’- a mock-up of a person’s home based at the University of Surrey. Finally, it was tried out in Trusted Users’ homes before being rolled out to participants in the study.

**TIHM for dementia intervention**

408 people with dementia and their carers (204 people with dementia and 204 carers) were recruited from across Surrey and NE Hampshire to participate in an exploratory randomised control trial for six months. Half of homes received the TIHM technology.

Figure 1 below illustrates the high-level architecture of TIHM which consists of four key elements interacting with each other: 1) devices and gateways installed in homes, 2) TIHM backend system including the integration services, storage and analysis methods, 3) the user interface for data visualisation and presenting extracted insights and actionable information (the Integrated View or iView), and 4) clinical pathways where a group of healthcare practitioners monitor the data around the clock, interact with the patients/carers and respond to their needs.
Devices installed in homes comprised: sensors, monitors, gateways. The sensors monitored movement in the home and environmental data, such as temperature and light. Monitors recorded vital sign data: blood pressure, body temperature, pulse, oxygen saturation, weight and hydration. Trackers monitored a person’s movements outside the home.

Data streamed by these devices was integrated and analysed using data analytics and machine learning in an IG compliant backend system. This process transformed raw observations and continuous measurements into actionable information and alerts. However, as the data was provided by a variety of devices using different data formats there was a need to overcome the challenge of data integration and interoperability. To do this a common data model or common language was created using an adaptation of the FHIR standard which is based on the international Health Level-7 (HL7) standard (Enshaeifar et al, 2018).
Machine learning algorithms were also developed to translate data into actionable clinical information. The first set of algorithms was designed to analyse vital sign data enabling the monitoring team to provide a timely response and prevent escalating ill health by detecting unusual changes in device readings. Initial development of the algorithms was based on comparing readings with corresponding baseline thresholds pre-defined by the clinicians and identical for all participants. Over time the machine learning began to identify individual patterns or personalised norms based on the participants’ historical data. This enabled a more nuanced approach which was important for participants who had specific medical conditions.

As well as vital signs monitoring, the algorithms were developed to integrate environmental and behavioural data to provide a holistic picture of health, activity patterns and wellbeing status. Using sophisticated pattern analysis techniques based on combining physical, environmental and behavioural data, the team were able to generate predictive algorithms for early identification of agitation, irritability and aggression (AIA) and Urinary Tract Infection (UTI), one of the five leading causes of hospitalisation in people with dementia (Scrutton & Urzi Brancati, 2016).

Despite the complex layers of data analytics in the TIHM back-end system, the information presented to clinicians and patients is very accessible. The clinical-user interface is known as the Integrated View (iView) and was co-designed by technicians and clinicians to ensure a user-friendly dashboard. The display screen provides a system overview of all patients, represented in separate boxes and with associated clinical, environmental and technical alerts. Clinical and environmental alerts refer to those detected from vital signs, environmental and behavioural monitors as described above, whereas technical alerts flag device faults or errors. A simple red, amber, green alert system was adopted (see fig 2).
Figure 2: Integrated View Front Screen

The iView self-sorts and filters to ensure patients with the greatest needs are at the top of the dashboard. (see fig 3).
The Personal Information Screen includes in the left column (i) personal information, photograph and attachments (e.g. medical records), (ii) personalised thresholds. The middle panel contains (i) generated alerts, (ii) follow-ups and notes, and (iii) patient diary indicating whereabouts and any periods of absence from home such as a holiday. In the right column (i) an observation panel provides the latest readings (this can be interrogated further to present numerical and graphed trend data), and (ii) a location map based on GPS tracking.

The iView was observed by a Clinical Monitoring Team, made up healthcare professionals, including Nurses and Healthcare Assistants. They responded to unusual observations by following clinical algorithms to determine the most appropriate response to any alert. They also exercised clinical judgement. In the first instance, the team was most likely to follow up a concern by contacting the
carer. Other courses of action included: asking an Alzheimer’s Society Dementia Navigator to visit; a referral to another NHS service; involving social services or the Police and, if necessary, contacting the emergency services.

**Early Findings**

The following three case studies show how TIHM led to important interventions that could have resulted in the development of more serious complications had the technology not been available.

**Table 1: Glossary of terms used in case studies.**

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<th>Term</th>
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<tr>
<td>Clinical alert raised on TIHM for Dementia iV</td>
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<tr>
<td>Follow up call made by TIHM for Dementia monitoring team</td>
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<td>Ongoing advice and support provided by TIHM for Dementia monitoring team</td>
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<td>Alzheimer Society home visit</td>
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Case Study 1: Blood Pressure

Participant Details
Mr S is 78 years old and lives in Surrey with his wife, Mrs S, who is his main carer. He has a formal diagnosis of Lewy Bodies and Alzheimer’s type dementia. According to his latest MMSE memory score he is at a mild stage of his condition. He has a pre-established history of chronic kidney disease stage 3, atrial fibrillation, hypotension, diabetes and glaucoma.

23rd May, Blood Pressure Out of Range Alert
Monitoring team received an alert for high blood pressure. Following the clinical algorithm, the monitoring team contacted the carer and advised her to make an appointment with Mr S’s GP. The monitoring team set a routine follow-up call for 24 hours later.

24-hour Follow-up
At the follow up call the carer advised the Clinical Monitoring Team that Mr S had been placed on beta-blockers for his hypertension.

8th June, Low Hydration Alert
Monitoring team received a low hydration alert and contacted the carer. Following a discussion of current presentation, Mrs S was advised to make a further GP appointment.

24-hour Follow-up
A follow-up call to Mrs S identified Mr S’s prescribed medication was causing frequent urination and dehydration. Mrs S used the trial blood pressure device to provide the GP with several weeks ‘blood pressure readings, resulting in the GP amending Mr S’s medication. The monitoring team were able to view Mr S’s blood pressure and hydration readings returning to normal.
24th July, Missing Person Alert
Mr W left home unannounced. The monitoring team received a GPS alert and contacted Mrs W as per clinical algorithm. She verified her husband had indeed left home. The monitoring team then worked with Mrs W and the Police (as part of a partnership agreement) to locate her husband using the GPS tracker. On finding Mr W, he complained of having chest pains. Based on the medical information provided, in combination with the known history, the monitoring team made a clinical decision and advised calling an ambulance, which met with Mr and Mrs W at their home, and a 24-hour follow-up phone call was organised as part of the routine care pathway.

24-hour Follow-up
On contacting Mrs W, she reported a muscle strain was diagnosed. During this call Mrs W described her husband’s poor sleep pattern, disorientation and their impact on their wellbeing. To support both Mr and Mrs W, the monitoring team made a referral to Social Services for a carer’s assessment and an OT home assessment for Mr W.

Further evidence to show the impact of TIHM on the daily lives of people with dementia and their carers has been provided by the Trusted User Group, all of whom would recommend TIHM. Their comments included: “TIHM has reduced our visits to A&E and put our minds at rest at home if we were concerned”; “TIHM helps to ease the pressure of caring”; “It’s like having a doctor’s surgery in your own home so you don’t have to visit your GP so often”; “It’s very reassuring to know that someone is always monitoring my husband’s health”; “TIHM provided some reassurance. The study was our only means of support.”
Case Study 3: Overdose

11th May, Systolic Blood Pressure Out of Range Alert
As per the clinical algorithm, a member of the team made contact with the carer and asked them to support Mrs L to take a second blood pressure reading. On visiting Mrs L, her daughter realised that an accidental medication overdose had been taken. On speaking to the monitoring team, clinical advice was given to the daughter to support Mrs L to attend their local Accident and Emergency department. A 24-hour follow up call was scheduled.

24-hour Follow-up
When contact was made, Mrs L’s daughter advised that an ECG had been taken and hypotensive medication prescribed, with a follow-up GP appointment recommended. The GP asked the daughter to supply blood pressure readings for one week, to check the outcome of the medication change.

Ongoing Advice and Support
The daughter contacted the monitoring team and asked for their assistance in providing this information. In addition, the monitoring team advised the carer about safe medication use and storage.

Alzheimer’s Society Navigator Home Visit
The Alzheimer’s Society was also contacted by the monitoring team and asked to visit Mrs L and her daughter to provide refresher training on the use of devices.

Participant Details
Mrs L is 90 years old and lives in Surrey on her own. Her main carer is her daughter, who lives next door. She has a formal diagnosis of Alzheimer’s disease and according to her latest MMSE memory test score she is at a moderate stage of the condition. She has a pre-history of osteoarthritis and hypertension.
Further evidence to show the impact of TIHM on people with dementia and their carers has been
provided by the Trusted User Group, all of whom would recommend TIHM. Their comments
included: “TIHM has reduced our visits to A&E and put our minds at rest at home if we were
concerned”; “TIHM helps to ease the pressure of caring”; “It’s like having a doctor’s surgery in your
own home so you don’t have to visit your GP so often”; “It’s very reassuring to know that someone is
always monitoring my husband’s health”; “TIHM provided some reassurance. The study was our only
means of support.”

Analysis of alerts

There has been an analysis of 16,553 alerts generated by the TIHM system between July 2017 and
March 2018. These were classified according to clinical, environmental and technical domains. The
majority of the alerts generated were clinically related 61%, whereas 26% were technical and 14%
environmental. Breaking this down further, fourteen specific forms of alert were flagged over this
period, with blood pressure, blood oxygen and pulse being the most commonly occurring (see fig 4).
Alerts in green represent those arising from data from multiple combined devices (Agitation and UTI). Alerts in red were the most frequently generated.

**Figure 4: Frequency of alerts**

**Conclusions**

We found it was feasible to deploy a novel IoT enabled system for monitoring and managing people with mild to moderate dementia. Further, it was acceptable to patients and their carers to a) have the system within their homes streaming continuous data from environment-related sensors; b) use wearables to stream continuous data related to patient whereabouts and mobility; and c) augment these with clinical data gained by carers using Bluetooth-enabled devices monitoring health status.

It was evident that patients and their carers built up very positive relationships with the TIHM Clinical Monitoring Team whose communication skills led to them being seen as a friend and their contribution appeared to provide a continuity of care that was seen as otherwise lacking post diagnosis.
TIHM is the first programme of work – in the UK or internationally – that has developed and installed an Internet of Things based intervention to support management of dementia in the community. The full findings will be published in an evaluation report later this year but it is clear the scale of the work undertaken in this study is unparalleled in dementia care. Its achievements reflect the expertise and diversity of the partners involved who have been willing to share their learning to benefit the study.

TIHM has proved that an Internet of Things and machine learning led solution has the potential to provide the NHS with a new digital and data driven type of intervention to support people with long term and complex health conditions. In the future, this type of approach could transform anticipatory care by providing clinicians and patients with real-time information indicating when and where support is most needed. By providing timely and targeted support it should be possible to enable people with dementia and carers to remain in their own homes for longer with confidence and to avoid unnecessary use of more intensive health interventions, like hospital admissions. It also has the potential to reduce routine and unnecessary clinic visits and to help services deploy human resources at the point of need.

During the study, there were examples of Trusted Users and participants sharing historic health data collected by TIHM on their devices with GPs. This meant GPs were provided with accurate information to support faster clinical decisions making – another example of the potential benefit of this technology for NHS services.

The pioneering development of prototype algorithms during the study to detect urinary tract infections and agitation is an exciting area of work that holds considerable potential for the future and could pave the way for further health care developments in dementia and other areas of care. Artificial Intelligence and machine learning offer new opportunities to transform clinical practice. However, it is also important to hold onto the importance of human relationships with patients and
carers. One of the key benefits derived by TIHM is the combination of machine and human intelligence.

The work on algorithms and further refinement of the devices deployed in people’s homes will be undertaken in the second phase of the TIHM for dementia study to be launched later this year. The digital health market is constantly evolving and there will be a need to ensure that the technology used in the next phase is keeping pace with these developments.

The key focus of the next phase of the study will be to further develop the TIHM model so that it can be scaled up and adapted to support people with other long term and complex health conditions as well as dementia.

References


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