Report for Barnsley Metropolitan Borough Council on the pilot implementation of myhomehelper

Prepared for:

Barnsley Metropolitan Borough Council

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Abstract

Rationale: Living with, and caring for, an individual with a diagnosis of dementia can at times be challenging. Myhomehelper is a service design to support both carers and individuals living with dementia. It acts as an online communication and memory aid.

Design: From November 2014 to September 2015 The University of Sheffield, with Barnsley Metropolitan Borough Council conducted a service evaluation of a pilot implementation of myhomehelper in 25 homes. We used questionnaires and a workshop to gather data on usability, functionality and impact of the service.

Results: In total 25 baseline and 11 post implementation questionnaires were completed. Carers were predominantly female (n=17) and were not confident users of technology. Most carers provided reminders to the person they cared for. Around half felt that they were not coping well and felt emotionally and physically overwhelmed. Three quarters felt anxious or worried most of the time in relation to their caring role and responsibilities, however 80% were happy with the amount of contact they currently had with the person that they cared for; indicating that a reduction in contact was not a motivating factor in using the service. Most carers wanted to use the service as an aide memoir for appointments and medications and to help them feel as though they were doing something to help the person that they cared for. In the post-implementation questionnaires (n=11, 44% response rate) carers reported no change in the amount of contact they had with the person that they cared for over the 12 month period. At the workshop seven carers and patients with a diagnosis of dementia reported unanimous support for the myhomehelper service, reporting reductions in anxiety and increased independence. All carers stated they felt the cost of the system was more than reasonable considering the impact it had made in their life and that of the person they cared for.

Conclusions: Evidence collected indicates that myhomehelper can provide benefit to carers of people with a diagnosis of dementia. Lessons can be learnt from the pilot with respect to future implementation of technology assisted services.
1.0 Background
Dementia refers to a range of irreversible progressive symptoms that currently affects an estimated 820,000 people in the UK at a cost of approximately £23 billion each year\(^1\). Individuals with a diagnosis of dementia may experience difficulties with their memory, concentration and communications; which in turn can impact on their decision-making abilities, independence, behaviours and mood\(^2\). The condition also has a considerable impact on those supporting the person diagnosed with dementia. In the UK there are 670,000 carers of people with dementia\(^3\).

Adopting this caring role currently saves the UK £11 billion a year\(^3\). Family members and friends have to come to terms with the effects dementia has on them and their sense of who they are. Carers of people with dementia often find themselves adapting to constantly changing situations, and they need to cope with both the practical demands of caring and the emotional impact of the person's dementia.

There is a growing need to find accessible and cost-effective ways to support carers in the role that, often, they have no choice but to assume. This document reports on a service evaluation of a pilot implementation of myhomehelper service. Myhomehelper is a service which has been designed to support carers of people with a diagnosis of dementia or other cognitive impairments. Myhomehelper acts as a memory aid and reminder service and has functions including a calendar clock, diary, reminders, news headlines, photos, facebook messaging and skype video calls which can all be accessed, setup and maintained by family and friends over the internet. The intention of myhomehelper developers is to reduce unnecessary contact for carers, increase quality of contact and decrease anxiety associated with a caring role and responsibilities.

Following on from a case study/proof of concept undertaken by the Alzheimers Society in 2012, Barnsley Council Independent Living at Home Service (ILHS) wanted to validate key benefits of the myhomehelper intervention in a larger population. From May 2014 to September 2015, 25 service-users were given myhomehelper, free of charge for a 12 month period.

\(^3\) [https://www.alzheimers.org.uk/statistics](https://www.alzheimers.org.uk/statistics) Downloaded October 2015
The Independent Living at Home Service (ILHS) within Barnsley Metropolitan Borough Council managed and delivered the pilot in collaboration with Simpla Solutions. The University of Sheffield supported the ILHS to evaluate the pilot in order to examine carers’ experiences of using the service.

The project was collaborative effort between several organisations. These were:

- Barnsley Council Independent Living at Home Service
- The University of Sheffield, Centre for Assistive Technology and Connected Healthcare (CATCH)
- Simpla Solutions
- Regional and Local Alzheimers Society
- Barnsley Independent Alzheimers and Dementia Support (BIADS)
- NHS Memory Service
- Barnsley Clinical Commissioning Group

Specifics of the implementation process can be found in Appendix A.
2.0 Methods
A mixed methods approach was adopted for this evaluation of myhomehelper pilot implementation.

2.1 Survey
A self-complete questionnaire survey was conducted to explore carers’ caring responsibilities, feelings about their role and motivations for using myhomehelper. At the end of the pilot, carers were asked to complete a questionnaire to explore whether the service had been of benefit to them or the person that they cared for.

Baseline carer questionnaires (appendix B) explored:
- Motivations for use of the technology
- Quality of life and/or current carer burden
- Expectations of the technology.

Post-implementation carer questionnaires (Appendix C) explored:
- Use of technology
- Changes in contact

The UoS designed the questionnaires. The ILHS managed the recruitment of users to the service, installation of myhomehelper and data collection.

The UoS coded and analysed data using SPSS 22. Data are presented as frequencies, proportions and qualitative data.

2.2 Workshop
A workshop was organised with a range of stakeholders including service-users and carers, commissioners, healthcare workers, memory support teams, ILHS staff, and Alzheimer’s society representatives, to explore the use of myhomehelper and consider the opportunities for embedding the services in mainstream services.

The interactive workshop was designed to bring together different groups of stakeholders and facilitate them to interact and participate in a collaborative activity. The objectives for the day
were to allow attendees to be better informed about service and products available in the region, be given the opportunity to feedback about the myhomehelper service – benefits and areas for improvement, and to co-design the future of use of technology in the Assisted Living Services.

Appendix D shows the invitation for the event.

During the myhomehelper evaluation feedback section of the event, delegates were asked to consider the following issues:

2. Process – installation, after-care, repairs, trouble shooting...
3. Functionality – usability, design, features (like and dislike)
4. Impact – contact, worry, physical support, confusing...

When considering the design of future services, attendees were asked to consider the following:

- What would you like to see from a technology/assisted living technology service in your area?
- What sort of technology would it provide?
- Who would staff it?
- Who would it be for?
- How would different groups of people access the service?
- How would it be advertised?
- How much would it cost and who pays?
- Who would support people to learn and make best use of it?

All feedback from the event was video recorded and attendees wrote down their thoughts on flip charts and post-it notes. The feedback on the myhomehelper pilot was analysed using thematic analysis. Quotes and comments have been synthesised according to themes. The feedback on future design of services is not reported in this document

4 Data from the event have been provided to Barnsley Council for analysis.
3.0 Results of the survey
In total 25 individuals with cognitive impairments were provided with the myhomehelper service. Twenty-five pre-installation questionnaires were returned to UoS via the ILHS, exploring carers’ thoughts on using the system prior to installation or in the early stages of using the system. Subsequent to this, eleven post-evaluation questionnaires (44% response rate) were completed and returned to UoS via the ILHS.

3.1 Baseline data
3.1.1 Demographics and technology use
The reported age of carers varied from 35 years to 95 years with a mean age of 72 yrs (sd15.5). The majority of carers were female (68%), and often the daughter of the person being cared for (40%) although sons, service managers, wives, granddaughters, friends and siblings also reporting a caring role. Approximately 74% reported no issues with vision or dexterity.

The majority of carers reported themselves not to be confident users of technology (willing but unable, learning the ropes, reluctantly on line). However, nine users did report they were confident in using technology (figure 1).

Figure 1. Reported previous use of technology
### 3.1.2 Caring responsibilities

Table 1 shows the reported caring responsibilities of the carers involved in the evaluation. A large proportion of the carers supported their cared for person by reminding them about appointments and to take medication each day. More than half of the carers in the pilot reported that they physically took their cared for person to appointments a few times a week and took them shopping. A large proportion of the sample cooked meals and provided company each day as part of their caring role. Relatively few carers in the sample provided personal care or helped their cared for person in and out of bed. It is clear there is a spread of responsibilities, with some carers, often living with their cared for person, undertaking a large amount of day to day care.

#### Table 1. Table to show the number of carers involved in various caring responsibilities (frequencies)

<table>
<thead>
<tr>
<th>Task</th>
<th>Every day</th>
<th>Few times a week</th>
<th>Once a week</th>
<th>Monthly</th>
<th>Do not provide this care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Housework</td>
<td>4</td>
<td>11</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Shopping</td>
<td>1</td>
<td>16</td>
<td>6</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Taking to/from apps</td>
<td>2</td>
<td>14</td>
<td>3</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Reminders apps/meds</td>
<td>15</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cooking/meals</td>
<td>13</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Company</td>
<td>14</td>
<td>7</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Getting in/out bed*</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>Personal care</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>15</td>
</tr>
</tbody>
</table>

* Row does not equal n = 25 as one response missing

### 3.1.3 Feelings about caring responsibilities baseline

The majority of carers reported feeling cheerful some or most of the time (Table 2). Many felt they communicated well with the person that they cared for and that they were doing enough to help them. However, 19 of the 25 carers also reported feeling anxious or worried some, all or most of the time. Around half of the carers felt overwhelmed by responsibility their caring responsibilities and emotionally worn out. From the self-reported data we can see that half of the carers are managing very well, whilst the other half felt that they were not coping well with the amount and burden of their caring responsibilities.
Table 2. To show the how carers felt about their caring responsibilities (frequencies)

<table>
<thead>
<tr>
<th>Feelings</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing enough to help(^a)</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Communicating well(^a)</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Worried or anxious</td>
<td>1</td>
<td>5</td>
<td>13</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Overwhelmed by responsibility</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Cheerful</td>
<td>0</td>
<td>4</td>
<td>7</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Worn out emotionally(^a)</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Finding caring physically tiring(^a)</td>
<td>7</td>
<td>4</td>
<td>6</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

\(^a\)One missing response

3.1.4. Motivations for using myhomehelper and expectations

Data from the baseline questionnaires suggests that most carers were keen to try myhomehelper in order to support the person they cared for with time of day orientation, appointment reminders and in order to feel like they were doing something else to help support them. Many people wanted to try to reduce their own anxiety, that of the person that they cared for, and try to increase communications. Very few people were concerned with privacy and security issues relating to data sharing on the myhomehelper service. Many people reported that the pilot being free of charge motivated them to take part (Table 3).
Table 3. A table to show the motivations and expectations prior to using myhomehelper (frequencies)

<table>
<thead>
<tr>
<th>Motivation</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce carer anxiety</td>
<td>19</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Reduce others anxiety</td>
<td>17</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Doing something to help</td>
<td>22</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Medication management</td>
<td>10</td>
<td>6</td>
<td>7</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Increase communication</td>
<td>19</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Day to day tasks</td>
<td>19</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Concerns about privacy</td>
<td>2</td>
<td>4</td>
<td>16</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Time of day orientation</td>
<td>20</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Appointment reminder</td>
<td>21</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Free of charge</td>
<td>19</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Pilot new tech/help</td>
<td>16</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

Note: Initial responses were recorded on a 5-point likert scale however due to lack of variance the data have been consolidated.
3.1.5 Contact prior to implementation
We asked carers how often they were called (telephone) by the person that they cared for. Five people told us that this question was not applicable to them as they lived with the person that they cared for and were with them most of the time. Twelve people were called a few times a week and three people were called a few times a day. Only three people reported being called in excess of five times a day. This pattern of contact was mirrored in the amount of times carers reported calling the person they were caring for. Most carers called the person they were caring for a few times a week (n = 12). No one reported calling the person they cared for more than a few times a day. Most carers also reported physically visiting the person that they care for on average 1-4 times a week (n = 12), however six people reported visiting the person they care for in excess of five times a day.

Eighty per cent of carers reported that they were happy with the amount of contact they had with the person they cared for at the time of myhomehelper implementation. This suggests that a change to the amount of contact was not a motivation in using the service. Those who were unhappy with the amount of contact they had, wanted more but were unable to find the time due to work commitments.

3.2 Post-implementation data

3.2.1 Functionality of myhomehelper
Carers were asked which functions of myhomehelper they were most keen to try. The responses were as follows: Calendar clock: 96%; Reminders: 92%; Photos: 72%; Diary: 60%; News headlines: 56%. Only a few people were interested in Video calling: 12%; or Facebook messaging: 8%.

3.2.2 Installation and support of myhomehelper
From the eleven post-evaluation questionnaires returned to UoS it is clear that users of the service were given enough information about how to use myhomehelper at the time of installation (table 4). Some people experienced technical problems with the system, which is to be expected with any technology; however these were dealt with and resolved in an efficient manner. Most people felt the system blended in well in their home environment, however over
half of those who completed post-evaluation questionnaire did report that the system may not fit well within their life.

Table 4. Table to show how carers felt regarding installation and support statements (n = 11)

<table>
<thead>
<tr>
<th>Statements</th>
<th>Strongly agree</th>
<th>Slightly agree</th>
<th>Neither agree nor disagree</th>
<th>Slightly disagree</th>
<th>Strongly disagree</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel I was given enough information about how to use the system</td>
<td>10</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I experienced technical problems with the system</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>I am happy with the level of support I received in relation to technical aspects of the system</td>
<td>10</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>If technical problems occurred I knew who I could ask for support to resolve them</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Technical problems with the system were resolved promptly</td>
<td>8</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I am not sure the system fits well within my daily life</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>The system did not change the character of the home of the person I care for</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

3.2.3 Reported use of myhomehelper
Ten out of the 11 carers who completed the post-evaluation questionnaire found the myhomehelper system easy to use, felt confident using the system and reported that they felt others would also find it easy to learn to use the system. Few people felt that they would need the support of a technical person to continue to use the system and that they didn’t need to learn much about the technology before they used the service (table 5).
Half of the carers who sent back responses felt that they would not use the system again frequently in the future. This decision does not appear to be based on their ability to use the system, or on the complexity of the system, as all but one carer found the system easy to use. When asked what factors determined their use of the myhomehelper system, the majority of people reported ease of use (n = 6) and need for the system (n = 5). A factor that contributed to a lack of engagement with the system was time (n = 4).

With regards frequency of use, three carers reported that they used myhomehelper throughout the day, three engaged with the system a few times and day and one person used it once a day. The other four carers used the system less frequently. It appears that carers’ fall into one of two groups: those who engage at a high level with the system throughout the day and those who do not engage more than a few times a week, if that.

Table 5. A Table to show carers thoughts on the use of myhomehelper (n= 11)

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Slightly agree</th>
<th>Neither agree nor disagree</th>
<th>Slightly disagree</th>
<th>Strongly disagree</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think I would use the system frequently in the future</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>I found the system unnecessarily complex</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>I thought the system was easy to use</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I think I would need the support of a technical person to use the system</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>I found the various functions in the system well integrated</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>I imagine that most people would learn to use the system quickly</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I found the system cumbersome to use</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>I felt confident using the system</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I needed to learn a lot of things before I could get going with this system</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>
3.2.4 Impact of myhomehelper and features used
Of the eleven carers who completed the post-evaluation questionnaires, most reported predominantly using the reminder feature, the diary and date/time/day orientation. Some people reported using the photograph feature, although this was not a commonly used feature.

When asked whether using myhomehelper had had an impact on the amount of contact that carers had with the person that they cared for, ten carers reported that contact had remained the same and one indicated contact had increased, due to a decline in health of the person that they cared for. No carer reported that using myhomehelper had decreased contact with the person that they cared for. One carer stated that they still called the person that they cared for to confirm appointments and check reminder had been seen. One carer reported that, in their opinion, the system had increased the confidence and independence of the person that they cared for.
4.0 Results from the workshop
The myhomehelper workshop was held on Thursday 25th June at Barnsley football club. In total 55 delegates attended from local council, NHS, local service providers, the third sector, emergency services, commissioners, universities, and housing organisations. Seven delegates were carers and patients with a diagnosis of dementia who had been involved in the myhomehelper pilot.

4.1 Expectations and motivations
At the event carers expressed a motivation to use the system due to a free trial option. However they went on to report that, having used the service; any anxieties relating to costs have now disappeared.

One carer thought it would be hard to set up but reported that it wasn’t. They liked that the person they cared for didn’t have to interact with the system at all and the carer found the system easy to use.

One carer was a self-confessed ‘technophobe’ and reported initially that they felt they wouldn’t know what to do. But once they had a demonstration remotely with their Speech and Language Therapist and a representative from Simpla solutions Ltd talked them through it they got the hang of it.

“It looked complicated but once it arrived it was so easy to set up” (ID 1)

Carers reported consistently good phone and email support”

“Setting it up was easy. We had a demonstration. It goes in a room the patient sits in all the time. I put permanent reminders on it. The aftercare…you just call. I didn’t really have to do anything at first. But now have added my own messages afterwards. I rang at first to see if it had come through – which it had” (ID 2)
4.2 Cost

In initial discussion, non-users of myhomehelper stated that they felt the system was expensive for what it offered. However, carers who had taken part in the pilot all agreed that myhomehelper was good value for money.

“If you have a family member calling 70+ times a day the cost of the calls exceeds the cost of myhomehelper” (ID 1)

“It enables the patient to be independent; there is no price on that. Commissioners may find it difficult…but for us X (husband) knows where I am. Before I was at home 24/7 as X was so anxious wondering where I was. But now I can put on (the system) where I am and I can go out (and it will say) on what he should be doing. So he forgets to eat and take meds so I can put that on with an alarm and he knows to look at the screen when the alarm comes on and that is a learnt behaviour. He also likes to know what he has on in a day and at 8am a list comes up – what I am doing and what he is doing and it gives him independence as he gets dressed for the day accordingly without having to ask me – which is empowering for him”. (ID 3)

Some social care staff reported that the cost of myhomehelper was comparable to other telehealth products they were aware of. One manager of care services reported that, although beneficial, the organisation has no way to fund the service once the pilot was over.

“From a clinician perspective, I wasn’t sure who to use the unit with and you need internet access, so I put it in a communal area so staff could get used to it. We needed staff training. So we put it on the intermediate care bedded unit – they were the only ones that had internet. The feedback was very good. We just put generic info up like what time the podiatrist was coming, the hairdresser...when medication was being given out. Staff feedback was that they got fewer questions from relatives so they could spend more time offering other kinds of support. But then we had no money to purchase the unit afterwards, we need economic data to take it to CCG” (ID 7)
4.3 Impact
All of the carers at the workshop and the people whom they care for (who were able to communicate) reported that myhomehelper had had a positive impact on their lives.

“It has been really helpful for my mother, she watches the screen more than the TV” (ID 1)

“It is extremely useful. I have fewer phone calls and my mother seems less stressed” (ID 1)

“X uses myhomehelper to get rid of visitors, as an aide. She says ‘I need to go now as such a thing is about to happen (referring to reminders on myhomehelper)” (ID 4)

“It has reduced panic and anxiety beyond anything I could have imagined and it has allowed me to go out for up to an hour which I just couldn’t do before” (ID 3)

One daughter stated that her mother:

“...feels more independent and she also likes the messages when she arrives home. It reduces feelings of isolation” (ID 5)

The mother stated:

“I find it reassuring. I feel more connected to my family, like I am not alone. I feel supported by her (daughter) but not a burden” (ID 5)

However, one carer reported that although she used the system with the person she cared for, she also felt that she needed to check the reliability of messages and reminders and found herself phoning or popping round anyway to ensure the person she cared for had seen messages.

“You do not know if the patient has followed a message. The only way is to go round and see if they have carried out a task” (ID 2)

4.4 Usability
All users of myhomehelper reported that the product was easy to use.
“The screen is easily seen, it’s very colourful. Even in later stages of dementia, my dad does see the screen and even reads it to me” (ID 6)

None of the users found the system intrusive or an eyesore in their home.

“We love the look of it in our home. X is a young dementia sufferer and so it was great it looked like a digital picture frame and we uploaded lots of pictures of the kids. In between times when there aren’t reminders it a photo frame” (ID 3)

4.5 Improvements
The following ideas were generated for improvements in the system or service:

- Training – many users mentioned that they would like more time for training and follow up training to maximise use of the product.
- Access to the internet was an issue. Not all carers and managers of services had broadband access and so needed to have it installed before they could use myhomehelper.
- One carer suggested the system could be used in earlier stages of impairment so that the patient has more control over the reminders etc.
- Many people feel the system should be advertised more so that others could benefit
- Streaming of the news was too short in duration.
- But commissioners need to be careful not to replace people with a machine. The machine should never replace the human touch – it should augment it.
- Need to get attention with skype. So need a ring tone.
- Peer support on phone or forum
5.0 Discussion
In total 25 carers took part in a pilot implementation of myhomehelper service through Barnsley Councils ILHS. The majority of carers felt overwhelmed by their role and responsibilities. Most were happy with the amount of contact they had with the person that they cared for, however they were keen to find new ways to support them. Out of the 25 carers, 11 responded to the post-implementation questionnaire. Carers who responded found the myhomehelper installation useful. They were provided with enough information and support and experienced very few technical issues with the system. They found the system easy to use even though they reported not being confident users of technology. The reminder functions and diary were particularly popular. Using myhomehelper did not decrease the amount of contact carers had with the person that they cared for, however, the workshop data did indicate that carers valued myhomehelper. Carers reported that they felt less anxious and gained independence through using the system. Contact may not have been decreased in this pilot because; 1. Contact was reported as adequate to begin with, 2. Without the service we do not know if contact would have increased over the 12 month implementation period as dementia progressed. Therefore we cannot assume that myhomehelper has no impact on the frequency of contact between a carer and cared for person from this data. Overall the carers that took part in the workshop indicated that the myhomehelper service was value for money, however they felt that ongoing training would be of benefit for users. They stated that the service should be advertised more widely so that other could benefit; particularly those with less advanced dementia. Of the 25 initial carers involved in the pilot, eight have self-purchased the myhomehelper service.

5.1 Limitations
There are a number of limitations with this implementation and evaluation that impact on the quality of the data.

5.1.1 Timing of data collection
The University of Sheffield advised the ILHS to administer a base pre-implementation questionnaire before, or at the time of installation of myhomehelper. This approach ultimately was not possible for a number of reasons and instead a baseline snapshot questionnaire was administered for most people once the technology had been installed. The Assistive Technologies Development Manager at Barnsley Council highlighted the following factors as key in the unsuccessful administration of pre-implementation questionnaires: a) The responsibility
for agreeing the final questionnaires and how they were to be deployed wasn’t finalised and put into place even though the majority of clients were on service and should have completed a questionnaire on initial installation with follow up at completion of the pilot period to measure the difference in order to correctly complete the evaluation methodology; b) There was no nomination of overall responsibility and resource for co-ordination of management of the questionnaires; c) Barnsley Independent Alzheimer’s & Dementia Support (BIADS) and Alzheimer’s UK tried to get the evaluation questionnaires to their clients but had resource issues. The Memory team were unaware of the need to provide resource to obtain evaluation questionnaires; d) BIADS & Alzheimer’s UK were unsuccessful with a Council tender to provide local serviced this resulted in even less resource being available due to cutbacks this also directly impacted on the project.

All of the above mentioned reasons created a delay in administering baseline questionnaires. These factors are common in new service implementation and have been previously identified as key barriers to successful implementation of technology-assisted interventions⁶ in the MALT study (Mainstreaming Assisted Living Technologies)

5.1.2 Incomplete data
A mix of management and responsibilities over data collection meant that only 11 post-evaluation questionnaires were completed, from which key data such as date of birth were missing, meaning UoS could not, with any certainty match up pre and post data, as unique identifiers had also been omitted from questionnaires.

As data were missing from the evaluation and we are unsure as to the timings of data collection we cannot determine whether the findings are representative of the sample as whole. It would have been interesting to explore which carers found the system the most useful and examine at what stage of cognitive decline carers see the most benefit from the system, but this was not possible.

⁶ http://malt.group.shef.ac.uk/assets/files/project-end/MALT%20Info%20Sheet%20-%20Factors%20affecting%20Adoption%20FINAL.pdf
5.1.3 Poor response rate at workshop
Seven carers and users involved in the pilot implementation of myhomehelper attended the workshop. We do not know if they are representative of all 25 carer and user dyads that took part in the implementation and so the findings from the workshop must be interpreted in light of this.

5.1.4 Clinical characteristics of users
In this pilot implementation we have no clinical data from the users of the service. Therefore we cannot know where in the disease trajectory they were at the time of the implementation and whether they had any comorbid medical conditions. This limits the generalisability of the findings and means we cannot extrapolate finding to the wider dementia population of Barnsley and beyond.

6.0 Conclusions
Although caution must be applied when interpreting the findings from this evaluation, as the validity of the data in this evaluation was compromised to a degree, the results are positive and provide support for the future use of myhomehelper. An examination of the cost/benefits of the system is still required however. A larger sample and more robust design would allow us to determine who would benefit the most from the system and identify at what point in an individual’s cognitive decline myhomehelper has most potential benefit.