



# **Just Checking**

An evaluation of the Just Checking  
telecare system  
for people with dementia

April 2006

# **EXECUTIVE SUMMARY**

Just Checking is a telecare system to support the care of people with dementia in their own homes. It monitors daily activity. It provides information to carers and care professionals which helps in the planning and delivery of care.

Care professionals use the system for assessment. Family carers use the system to reassure themselves that all is well.

This trial was set up to evaluate the experiences of using the system by:

- professional staff (social workers, CPNs)
- informal carers/family members

The system was installed in the homes of 6 service users with dementia. The system was accessed and used by 4 care managers, 2 CPNs and 11 family carers. The trial ran over 9 months from July 2005 to March 2006.

The main findings were:

## **1. Value to family carers**

Family carers found the information Just Checking provides reassuring, and supportive in their caring role. They want to continue using it and are willing to pay for it. Supporting carers is a key factor in keeping older people at home and independent for longer.

## **2. Promotion of independence**

Information from the Just Checking system gave greater insight on the daily activities of a person with dementia. In most cases the person with dementia had a pattern of activity that was better and more consistent than expected. The trial demonstrated that this telecare system has a role in helping professionals and family carers to allow people to remain independent and more in control of their own lives without too many intrusive visits from health and social care. It supports the wish to remain in the community.

## **3. Collaborative working**

The objective data from the Just Checking system provided more information to be shared and discussed, which underpinned the collaboration between care professionals and family carers.

## **4. Assessment of need, care planning and review**

Just Checking proved a valuable tool for assessment of people with dementia. It provided objective information which allowed professional staff, to see daily patterns, and to make more informed decisions about care needs. Its use led to decisions both to reduce home care visits and to increase such visits. The extra information provided by the system creates an opportunity to meet needs with a

wider range of responses. There is the potential of reducing the reliance on home care.

### **5. Risk Assessment Process**

The Just Checking system provides objective measurements on which to assess risk.

### **6. Preventing or delaying admission to residential care**

The majority of family carers and professionals thought that Just Checking has a role in helping someone to remain in the community. In one case, where the Just Checking system had been in place for 9 months, the family carer was emphatic that the system had postponed a move to residential care.

Important experience was gained on the acceptability of monitoring systems.

The trial results will be used by Warwickshire County Council in planning the deployment of its £771, 000 Preventative Technology Grant.

# CONTENTS

Executive Summary .....	2
Just Checking Telecare System .....	5
What is it? .....	5
What are the benefits? .....	5
Why the trial was run.....	6
Demographics .....	6
Government policy on social care .....	6
Assistive Technology .....	6
Trial Design.....	7
Aim and Objectives.....	7
Methods .....	7
Commercial Interest.....	10
Results .....	11
What users told us.....	11
What else we learned.....	20
Cost Benefit Analysis .....	22
1. Assessment tool for planning care packages.....	22
2. Supporting Carers and Keeping People at Home .....	23
Conclusions .....	24
Glossary.....	26
References .....	26
Appendix 1 Case Studies.....	27
Mrs Y.....	27
Mrs X .....	29
Mrs W.....	31
Mrs V .....	33
Mrs U .....	34
Mr T .....	35
Appendix 2.....	36
Discussion Guide used with Family Carers.....	36
Discussion Guide used with Professional Staff.....	37
Project Board:.....	38
Appendix 3 Consent and Ethics.....	39
Taking Part in the Pilot.....	40
The Ethics of Monitoring People with Dementia .....	42
Ethical Principles .....	42
Warwickshire County Council Guidance and Procedures .....	44

# **JUST CHECKING TELECARE SYSTEM**

## **WHAT IS IT?**

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The Just Checking system records the daily activities of people with dementia, who live in their own homes. It provides information to carers and care professionals which helps in the planning and delivery of care. The aim is to help to maintain the person's independence and ensure that intervention is appropriate.

Small wireless sensors are installed in the main rooms in the dwelling. Data from the sensors is gathered by a controlling modem, and sent via the telephone line to the Just Checking database. There are no video cameras. The system is radio based and there is no wiring.

A family carer or care professional can log on to the Just Checking website and view a log of activity. For example the system shows when the person:

- Got up and went to bed
- Whether he/she had a disturbed night's sleep
- Used the kitchen
- Left the house and for how long
- Whether there were visitors and how long they stayed

## **WHAT ARE THE BENEFITS?**

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### **Assessment**

The system provides objective information on the daily activities of a person who may have difficulty in communicating information about their normal patterns of life. It adds to the information that is gathered in the assessment process, at initial assessment, review or if problems are reported. It can help to establish if something is happening and how often.

For assessment the Just Checking system is installed for a limited time, such as 3-4 weeks, and then moved on to the next client.

### **Supporting Carers**

The Just Checking system provides information for family carers who are living in a different household to the person with dementia. Carers can log on at home or at work to view the data and reassure themselves that daily patterns are as expected. It enables carers to plan their visits to best effect.

For carer support the Just Checking system is installed for longer periods, sometimes permanently.

# **WHY THE TRIAL WAS RUN**

## **DEMOGRAPHICS**

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The UK has an ageing population. The prevalence of dementia increases with age. As the number of very elderly people increases, so does the proportion of elderly people suffering from dementia. The Alzheimer's Society estimates the number of people with dementia is currently 775,000, of which a third are living on their own. Within Warwickshire it is estimated there are approximately 6000 older people with dementia.

## **GOVERNMENT POLICY ON SOCIAL CARE**

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The Department of Health National Service Framework for Older People (1999) has a strong emphasis on promoting the independence of those in older age, and a specific aim of supporting older people with dementia, and their carers. The 2006 White Paper sets out the Government's aims to promote the independence and social participation of social services users (Department of Health 2006a). Supporting people in their own homes is a key part of this policy. It stresses the need to enable older people to make choices about their own care. Most older people wish to remain in their own home for as long as possible. For people with dementia a move can exacerbate confusion and disorientation.

Social services performance indicators include targets for increasing the proportion of older people supported to live at home, but costs of home care have to be contained. There is a shortage of care workers, both locally and nationally. New ways of supporting older people in their own home, which make the best possible use of human resources, are necessary.

## **ASSISTIVE TECHNOLOGY**

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The Northamptonshire Safe at Home Project (Woolham 2005) used a range of assistive technology to keep people with dementia in their own home for longer. In April 2006, councils with social services responsibilities will receive the Preventative Technology grant, the purpose of which is to initiate a change in the design and delivery of health and social care services and prevention strategies to enhance and maintain the well-being and independence of individuals. The grant is to be used to increase the number of people who will benefit from telecare. Warwickshire County Council will receive £287,000 in 2006/07, and £484,000 in 2007/08.

Warwickshire County Council will use this and other trials to inform their plans for making use of the Preventative Technology grant.

# **TRIAL DESIGN**

## **AIM AND OBJECTIVES**

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The overall aim of the trial was to assess the value of the Just Checking system as part of commissioned packages of care. Specific objectives were:

- to install the system for 3 months
- to record and evaluate the experiences of using the system by two groups of users:
  - professional staff (social workers, CPNs)
  - informal carers/family members
- to identify user experiences which demonstrate the system had value to:
  - informal carers
  - the promotion of independence, and support for the wish to remain in the community
  - collaborative working between professional staff and informal carers
  - the assessment of need, care planning and review
  - risk assessment processes
- to identify tangible outcomes which meet the preventative agenda (preventing or delaying admission to residential care or hospital)

## **METHODS**

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### **Who Was Involved**

The trial involved the following organisations:

- Warwickshire County Council Older Person s Community Care Service (OPCCS) (social services)
- Alzheimer s Society, South Warwickshire
- South Warwickshire Carers Support Service
- Just Checking Ltd

Members of the project team are listed in appendix 2.

There were two parts to the trial.

### **Part 1 Pilot**

Initially the Just Checking system was installed in the home of a volunteer elderly person who did not have dementia, and who could be interviewed with the family carer. The purpose was to enable staff to become familiar with the data that the system produced, and to test the trial methodology. The South Warwickshire Carers Support Service referred the volunteer family.

## **Part 2 Trial**

The main trial tested the use of the system by families and professional care staff who are supporting a person with dementia, living in their own home.

Participants were:

- selected people with dementia
- relatives/carers of the above
- OPCCS team members (care managers)
- community psychiatric nurses working with the care managers (CPNs)

Inclusion criteria:

- the person in whose home the system is installed had symptoms (or formal diagnosis) of dementia
- the person with dementia lived alone, or spent significant periods of time alone when a carer goes out to work or is not able to support the person continuously
- informal carers/family members were supportive of enabling the person to continue to live in the community
- there was a specific need for information which the system could provide

Exclusion criteria:

- families whose members were without access to the internet/computer

### **Recruitment of Trial Participants**

The OPCCS teams in Alcester, Leamington and Shipston each considered, in the normal course of their work, if they had clients for whom there would be a sound reason for trialling the system. The Just Checking system was not installed routinely with all clients. In each case there was **some concern** about the service user, or limited information about the daily routine of the service user, and clarification was sought.

An inevitable result of recruiting participants in this way was that care managers were likely to approach only the families with whom they already had a good collaborative relationship.

One referral came via the Alzheimer's Society.

### **Installation and Length of Trial**

With each referral the Just Checking system was installed in the home of the person with dementia by a member of staff from Just Checking. The person with dementia was present when the installation was made and an explanation of the system was made to them. In some cases, the explanation was simplified.

A day or two after installation, contact was made with the care manager and the family carer to check that they were able to access the system and to answer any

questions. Participants could only access the data for the person with dementia for whom they had an interest.

The system was then left in place for 4-8 weeks. At the end of this period, family carers and professionals who had used the system were interviewed and a decision made about removing or retaining the system.

If family carers wanted to keep the Just Checking system, they were made an offer in which Warwickshire County Council would cover half the cost of the Just Checking equipment using the Carer Support Grant, Just Checking would cover the other half of the equipment and the family would take on the weekly webservice subscription of £5.

### **Consent**

Consent was sought from the person in whose home the system was installed. In the majority of cases however, the person with dementia was not deemed to have the capacity to give meaningful consent. The system is difficult to understand, particularly if someone has no experience or understanding of movement sensors and internet technology. Furthermore, the consent would be meaningless if the person with dementia was later unable to remember that they had given consent. In most cases therefore, and working to the guidance of the care manager, the explanation was simplified for the service user, and consent was given by the family carer.

Appendix 3 gives details of Warwickshire County Council's protocols for working with people who do not have the capacity to consent, and the ethical principles that were adopted in this trial.

### **Interviews**

The trial sought to record and analyse the views and experiences of users. Given the novelty of this assistive technology system, there is validity in recording the views and experiences of using the system and looking for common themes in order to assess what benefits the system brings. Sometimes new devices are used or seen by users in ways which are not anticipated. This methodology can help to pick up these points.

Each care manager who made use of the system was interviewed using a semi-structured format. In two cases a community psychiatric nurse (CPN) also looked at the data. One of the CPNs took part in the interview with the care manager.

Each family carer(s) who made use of the system was invited to give their views about the system and how useful they found it, via a semi-structured interview, arranged to suit the carer. The person with dementia was also invited to take part in this interview if the family carer thought it would be appropriate. In one case the family carer suggested including the person with dementia in the interview, and in a second case the person with dementia was able to conduct an interview on her own.

Towards the end of the trial, a Just Checking system which had been installed in an earlier trial outside the county, was decommissioned because the service user had moved in to residential care following a bout of serious illness. The system had been in place for 9 months. The opportunity was taken to interview the family carer about her experience of using the system for a considerable length of time, and the feedback included in the results of this trial

The interviews were audio tape recorded and transcribed, and analysed for themes. Copies of the transcripts were sent to the care manager involved with each service user, and to the Service Manager, Adult Services at Warwickshire County Council. Tapes and transcripts are available for scrutiny.

In summary, the Just Checking system was installed in the homes of:

- 5 service users who had dementia, 1 of whom is in the early stages of dementia
- 1 service user who did not have dementia (the pilot)
- 1 long term service user from an earlier trial

The data was accessed by:

- 4 care managers and 2 CPNs
- 11 family carers

### **Timing**

The trial took place over a 9 month period from July 2005 to March 2006.

## ***COMMERCIAL INTEREST***

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Just Checking Ltd. is the supplier of the technology and has a commercial interest in the trial. It is covering the main costs of the trial. Celia Price, one of its employees, carried out much of the work in the trial as a piece of research for a masters degree. Bias is minimised by the clear, repeatable design of the study, and by checks on the work by the University College Worcester, at which Celia is undertaking the masters degree. Interview transcripts have been sent to Warwickshire County Council. All the data that is collected is available for independent scrutiny.

# RESULTS

## WHAT USERS TOLD US

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The interviews with family carers, professional staff and service users were analysed. Five themes emerged:

- More information than was available before, and value in making an assessment
- Reassurance
- Helping people with dementia to stay at home
- Ease of use and interpretation of data
- Intrusiveness

Users were also asked about improvements that could be made to the system

### 1. More information than was available before

Every user commented on the fact that the Just Checking system gave them more information about daily activity than they had before, and this was very useful. The information reassures family carers and helps with care planning. The majority of users were surprised at the consistency of the daily (and nightly) pattern of activity of the person with dementia.

#### Family carers

Family carers were interested to see where and how their relative is spending time. Most commented on the fact that the person was more active than they had appreciated. If there were concerns about activity patterns, family carers could see how often something was happening and gauge how important it was, and act accordingly.

*Last week there was a completely unusual night when my mother didn't go to bed. My worry would have been if that had turned into a pattern . . . but the normal pattern soon clicked in, but clearly if there were several days of an unusual pattern that would alert us that something is going wrong. Son*

Two family carers had been concerned about their relative going out on their own. In one case the system showed this happened very infrequently. In the second, the person with dementia went out (to the local shops) and returned every morning at a regular time.

Even if the information was negative, carers could see that action could be taken to try and manage the situation. In one case it was evident that the person with

dementia was leaving open the back door at night. Action was taken to try and reduce the incidence of this happening.

*It helped us to be able to inform the carers and various other people because of course they were only seeing him for a very small part of the time and we were able to observe the activity over a 24 hour period. Daughter*

### **Professional staff**

Professional staff found the information useful in planning care packages. In all cases, the Just Checking system had been installed because there was a concern, or a desire to establish more clearly what was going on in order to be satisfied that the care package was appropriate.

*It shows that you can really, almost within a week, establish what is going on. In a short period of time we've got a fairly clear picture. Care manager.*

### **Outcomes based on the additional information**

Of the four cases that were referred by a care manager:

- two made changes to the care package as a result of the information, (one reduced the number of daily homecare visits from 2 to 1, the other increased daily homecare visits from 3 to 4.
- two were reassured that current arrangements for the person with dementia (neither of whom received homecare) were adequate. In one of these cases some further support for the carer was organised.

## **2. Reassurance**

### **Family Carers**

Every one of the family carers referred to the reassurance that the Just Checking data provided. Peace of mind was a phrase used by most carers. In all cases the person with dementia had a more consistent pattern of activity than the family carers had expected.

Family carers commented on the fact that the person usually got up and went to bed at consistent times, and remained in bed for the night apart from brief trips to the toilet. Concerns about what happened at night were allayed.

*I thought probably she might not be going to bed so we can see she is. Son*

Family carers could also see that daytime routines were occurring as planned. Visits by homecare staff, or activities such as a weekly trip out to a luncheon club could be identified, and the fact that family carers could see that these activities had happened was reassuring. In one case the system showed that home care staff were not always visiting at weekends and action was taken to correct this.

*It s nice to know that on a Friday her lift came at half ten, she s been to the club and she came back at half past two, so we did know that she did go to the club.. it was reassuring to know that things were going on as you d expect. Daughter*

Most family carers commented that the person with dementia was more active during the day than they had thought, which they also found reassuring.

*It shows you that Mum doesn t sit in a chair all day. She is more active and doing things, and pottering about. That s good because I thought she sat and vegetated. Daughter.*

### **Professional staff**

Professional staff were also reassured by the system s data that the person appeared to be managing well, often better than expected, and that this relieved some of the worry for family carers. Professional staff are clearly aware that the anxiety that some carers feel adds to the stress of being a carer.

*It has shown that the family perhaps don t need to be as anxious . Care manager*

*If it s giving peace of mind to the carer then that would reduce the concerns and strains. Care manger*

*The main thing is that it put your mind (to the son) at rest. Care manger*

In most cases the care manager used the Just Checking system data in discussion with the family carer(s). There appeared to be a good collaborative relationship between the care manger and the family carer (this is probably self selecting in the trial: referrals were most likely to have come from care managers who already had a collaborative relationship with family and felt able to ask the family to try this new system). Nevertheless it seemed that the information from the Just Checking system added a further dimension that could be discussed between the two parties.

## **3. Helping People with Dementia to Stay at Home**

### **Family carers**

Three of the family carers made comments about the system helping to keep someone at home.

*Yes definitely. I think it does (help her mother to remain at home). I think it does, I think it would, yes. Daughter*

The family carer of the longer standing installation (9 months) was emphatic about the system s role in enabling her father to remain at home

*I am in no doubt that without using the Just Checking system we would probably have had to go down the route (of residential care) far sooner, because having the information enabled us to know what was happening.*

*It all ties in with peace of mind. If you can see what's happening, however remotely it is, then information is power, and if you've got that information then it informs the decisions that you make.* Daughter

One family carer (the daughter of the person with dementia) has a brother who lives in New Zealand, who also logs on each day to view the data for their mother. The daughter has indicated that she feels the system has helped to share the load with her brother, that it gives him more to talk about when he speaks to her on the phone every few days, and this supports her in her onerous caring role. Support for carers is often key to helping people to remain at home. Furthermore, if and when her mother's mental health deteriorates to a point at which she cannot remain at home, the Just Checking data will show this objectively and she and her brother will make a decision jointly.

### **Professional staff**

Three out of four of the care managers thought that the Just Checking system could help a person with dementia to stay at home. Although none of the participants were at a point where the care manager felt that they should be moving to a residential home, care managers could see that the system could have a role in informing such a decision.

*This helps me (to make a judgement) .. it has alleviated any worries I have.*  
Care manager

*Hopefully it means we can keep Mrs XX at home for longer, now we've got a bit more assurance of our facts.* Care manager

Again this is very much tied in to having more information and the family being reassured that the person is managing at home, (and possibly that risks are being managed).

*Often it's the family's concerns that lead to a position where it seems unsustainable for someone to remain at home. I'm just thinking back at other people I have known where really, I have thought well actually they could have stayed at home longer if the anxieties of the family were lessened.*  
Care manager

## **4. Ease of use and interpretation of data**

### **Family carers**

Family carers were given a sheet with the website address and instructions for logging on to the Just Checking website. All family carers reported that the system was easy to use, and none needed any help in accessing the data via the website.

*Very easy. You just go straight in and there it is.* Daughter

While the system needs some knowledge of the household to interpret the data, this knowledge is with the family carers. All family carers were able to interpret the data

with ease. In the follow up contact made a day or two after the system was installed, there were only one of two questions from carers to clarify that they were interpreting the data correctly.

*You can see exactly where she is and what her movements are at night . Daughter*

Two family carers suggested improving the system so that it could zoom in to give closer examination of data, so that they could be sure of a sequence of events. This suggests that the carers were examining the data to a high degree.

### **Professional staff**

Professional staff universally said they found the system easy to use.

*I was quite surprised actually. Log in, put in your password and you are there. Nice and easy. Just what I need. Care manager*

On interpreting the data, there was no help required on how to interpret the data; this seemed to be obvious to everyone. There were some comments about the difficulty in establishing the sequence of events if several room sensors were activated within a short timescale, and the suggestion of being able to zoom in to a section of the chart was also made by this group of users.

Professional staff tended to be looking back over a week or several weeks worth of data as they considered the care package, and 2 suggested being able to see a week at a view, or an alternative way of navigating through the data.

### **5. Intrusiveness/acceptability**

Because there is sometimes concern about monitoring systems and intrusiveness, the transcripts were analysed for comments related to this.

#### **People in whose home the system was installed**

Two of the installations were in the homes of people who could answer questions about whether they found the systems intrusive. One was the pilot, an elderly man who does not have dementia. The second was a woman in the early stages of dementia. Both users said they did not find the system intrusive.

*I don't even know it is there. Matter of fact I was surprised when I went to the front door, one day this week I think, to see there was one up there . I never look at them (the sensors).*

Service user with no dementia

The woman with early stage dementia revealed how she had come to terms with the sensors:

*No they weren't bothering me it's just, sometimes I used to think oh.., I'd better make sure there's not one in the toilet (laughing), but then I thought don't be so stupid, you know, well it can't.. it can only it's only a . (movement detector).*

These comments were made before she had seen the charts of her own activity. Being shown the charts seemed to further her understanding of the system, and its acceptability. This user and her family have chosen to keep the system in, in preparation for the future.

The other 4 people in whose homes the system was installed had moderate dementia. At the time the system was installed a simplified explanation of the system was given. Reactions to the system were very much tied in to whether the system was visible.

In two other cases (plus the long term installation from outside the county), the system was installed discreetly. A simplified explanation was given at the time of installation, and the system controller was hidden out of view. None of these three systems were interfered with, and family carers reported that they thought that the person with dementia was unaware of the system.

In two cases, it was difficult to hide the system controller, which plugs in to the telephone socket and power supply. One service user initially switched off the system several times (which she was convinced was a lamp); this system was eventually moved out of sight and was no longer tampered with. The second was distressed by the system. The sensors upset her (her carer remarked on how good her eyesight was!) and the controller was using up her electricity. She sought the caretaker's help to remove the system. The system was taken out after two weeks. Nevertheless, the care manager found the two weeks data of value.

The lessons we have learned about installation are discussed at the end of the results section.

### **Family Carers**

Family carers took the view that it was better if the system was out of sight out of mind, and that their relative's lack of insight would make it difficult for them to understand and accept the system. It would be more intrusive if the person was aware of the system.

*Knowing it was there would have caused him more upset, and I think if carers and family are aware of the system, know what it does and why it's there, I don't see any reason why it shouldn't go in. Daughter*

Installing the system covertly was not seen as intrusive as it underpinned the caring role which was trying to maintain independence.

*The system allows (my mother) to follow her routine without intruding or encroaching on her independence and daily life. Son*

## **Professional Staff**

One of the four care managers voiced concern about whether service users would notice the sensors.

*It is something you've put in the room, all be it quite small and unobtrusive, it is something that's there and people will note and comment on. In my case the person was able to understand . but I can imagine that in another case somebody might be quite concerned about what is on the wall.*  
Care manager

Other care managers, however, compared possible intrusiveness with the intrusiveness of other devices or other interventions.

*I don't think the system is too intrusive to be honest. We were talking yesterday at a team meeting about tagging, people wearing watches, but it needs to be taken off with two hands and they can't take it off themselves. I think that could be quite distressing. (Just Checking) doesn't impinge on their lives really. It can make it better.* Care manager

*For Mrs xx, in having the system there, she doesn't need to have that higher intrusion of a greater care package.* Care manager

## **6. Improvements and Rolling Out Use of the Just Checking system**

The final group of comments related to improvements that could be made to the system, and views on how such a service could be rolled out to carers and professional staff.

### **Improvements**

User feedback on the system is very useful in its further development. Suggested improvements were:

- Latest data update time (implemented)
- Making it clearer when the person with dementia has left the house (implemented)
- Showing when an exit door is left ajar (implemented)
- A zoom facility so that parts of the activity chart can be scrutinised
- A quicker way of navigating through past charts (eg a week or month at a time)
- A week at a view to be able to see trends

### **Rolling out use of the system**

#### **Family Carers**

The majority of family carers were pleased to have tried the Just Checking system and thought it would benefit other family carers. The system was seen as a sound way of supporting carers in their caring role. Families of three out of five of the installations with people with dementia (plus the long term installation) wanted to

keep the Just Checking system, and have arranged to do so, even with though this required a financial contribution from them.

One family carer suggested that social services should consider organising a local response service for carers like himself who live some distance away, which he could ask to call at his mother s home if the data from the system gave him cause for concern. The family carer thought that he would be happy to pay for such a service, probably along the lines of a call out charge.

### **Professional Staff**

The professional staff who used the system were unanimous in seeing a value in using the system for assessment for people with moderate dementia. There were different views on whether the system should be used routinely as part of the assessment process; care managers recognised the importance of having some knowledge of the person and household to be able to interpret the data, (a knowledge of any weekly routine, regular visitors to the house, etc) and this might not yet be the case if the system was used at an initial assessment.

The care managers were not particularly keen to learn to install the system themselves. They would prefer to be able to arrange for the system to be installed while they/and or the family carer was there to talk with the person with dementia.

### Summary of installations with people with dementia, users and use of the system

Service user profile	Reason for Installation	Service user reaction	Carer log-ins	Did the Carer Keep the JC System?	Professional staff log-ins	Outcome
Moderate dementia	Family carer concern about going out	Ignored	Daughter every day & son most days	Kept	Non involved	Carer reassured
Moderate dementia	Concern about night time, and possible effect of clock change	Ignored	Every day several times a day	Kept	Twice during assessment period	Care package changed
Moderate dementia	Concern about lack of eating, question about nights	Switched off system initially, then ignored once moved	Twice during trial	Not kept	Care manager & CPN twice during assessment period	Care package changed
Mild/moderate dementia	Concern about going out, was this happening at night.	Disturbed by system. Removed after 2 weeks	Every day, sometimes twice a day	Not kept	Carer manager 3 times, CPN once during assessment period	Confirmed no need for care package
Early stages of dementia	Family member concern about going out. Interested to try the system for the future.	Positive	Two members of family each logged on approx. once a week	Kept	Care manager 5 times during assessment period	Confirmed no need for care package
Moderate dementia (long term installation)	Reassurance about daily routines	Ignored	Every day, twice a day	In place for 9 months	Out of county	Carer reassured. Move to residential care postponed

Case studies of each of the installations is in appendix 1.

## **WHAT ELSE WE LEARNED**

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Practical issues which arose during the trial, and the best way to tackle them were:

- Consent and Ethics
- Installation

### **Consent and Ethics**

At the start of the trial staff were given an information sheet about the trial, and a series of questions which the care manager would use to satisfy themselves that there was a sound reason for installing the Just Checking equipment. Warwickshire County Council's own guidance and procedures on the following were to be used if required:

- How to act in the best interests of someone lacking capacity to consent
- How do you know if someone lacks capacity to give consent?

The trial confirmed that the Just Checking system is of most value to family carers and professionals who are looking after the interests of a person with moderate dementia. It can be difficult to obtain reliable information from a person with this stage of dementia, and there may be causes for concern because the person no longer has the insight to judge risks, and may have difficulty with orientation in time and social norms. The Just Checking system can provide valuable additional and objective information about what is going on, so that appropriate care and support is provided. It is most likely to be the case therefore, that the system will be installed in the home of a person who lacks the capacity to consent.

The trial clarified that current Warwickshire County Council guidance and procedures were sufficient to cover the ethical issues in using this type of telecare equipment for people with dementia.

### **Installation**

Whatever the situation with consent, there is still the practical issue of installing the Just Checking system in the home of a person with dementia. The choices of how to tackle installation are:

- Fully inform the person with dementia about the system, then install
- Simplify the explanation, then install
- Install covertly

The experience from the trial is:

- For someone with moderate dementia, the system is difficult to grasp in concept, particularly if the person has limited understanding of movement sensors and internet technology, Where a full explanation was used with a

person with moderate dementia she appeared to understand and be happy that the system went in, but later had forgotten the explanation and was distressed by the sensors and the controller (which was not hidden).

- A successful approach was to simplify the explanation (this is an extra security system so that we can help you to stay safely in your own home), and then install the system in a low profile way, with the controller hidden if possible. On the whole, candidates did not seem to notice the sensors if they were put in discreetly.
- A further approach would be to install the system without the person's knowledge, perhaps when they were out, or diverted. This was the approach that had been taken by the long-standing installation.

# **COST BENEFIT ANALYSIS**

Although this trial is small, the themes that emerged from interviews with carers and professional staff were common themes. In other words we heard the same comments from our all our users, so we can have confidence in them. Looking at how the themes relate to each other there are two clear benefits to social services of using Just Checking, on which we can look at the potential costs and benefits.

## **1. ASSESSMENT TOOL FOR PLANNING CARE PACKAGES**

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The Just Checking system proved a useful assessment tool which provides significantly more information about the daily activities of a person with dementia. It allows professional staff to make more informed decisions about care needs, and use a wider range of responses, reducing the reliance on home care. Home care is a finite resource, in which there is an acute staff shortage. Releasing home care which is not required, or not building it in to a care package in the first place, enables it to be allocated elsewhere, where it is essential.

### **Assessment needs in Warwickshire**

There are an estimated 6000 older people with dementia in Warwickshire. If we assume that Warwickshire social services comes in to contact and makes an assessment of 10% of these each year, there would be 600 assessments.

If it was deemed appropriate to use Just Checking for assessment in 25% of these cases = 150 assessments.

Each assessment would last 3-4 weeks. One system can be used for 12 assessments a year

150 assessments would need 12 Just Checking systems.

### **Costs**

Annual cost of buying and running Just Checking = £300

(based on volume discounts for 10+ systems, and writing off the capital costs over 3 years)

Annual cost of 12 systems = £3600

### **Benefits**

If the information from 10% of assessments using the Just Checking system showed that home care could **on average be 1 hour a day less than would have been the case without using the system**

= 15 x 3.5 hours x £13.60 (national average hourly home care)

= £714 per week

x 52 = £37,128 per annum (or 2730 hours of homecare)  
less annual cost of 12 systems (needed to carry out 150 assessments) = £3600  
**Net annual savings = £33,528, or 2730 hours of home care**

2730 hours of home care is 1.7 full time equivalent home carers

Another way of looking at this is the cost of using the Just Checking system for a month s assessment is £25.

This is less than the cost of 2 hours of home care.

The trial sample, although very small, produced savings in home care costs that more than covered the costs of the trial

## **2. SUPPORTING CARERS AND KEEPING PEOPLE AT HOME**

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Providing carers with the Just Checking system reassures them that the person they care for is managing when they are not there. It alleviates some of the worry and provides objective information about what is going on. In this small study, all of the people with dementia were managing better than was expected by the family carers, and carers could see that the information from the system might help them to keep their relative at home for longer.

### **Costs**

Annual cost of buying and running Just Checking = £300  
(based on volume discounts for 10+ systems, and writing off the capital costs over 3 years)

Average hourly cost of home care in England = £13.60 (Source: Social Services Performance Assessment Framework Indicators 2004-2005)

Average cost of residential care in England = £405 a week (Source: Social Services Performance Assessment Framework Indicators 2004-2005)

If a person with dementia was supported at home with Just Checking and an intensive home care package of 3 visits a day.

Cost of home care would be 10.5 hours @ £13.60 = £142.80 a week

Cost of residential care minus cost of home care  
= £405 - £142.50 = £262.50 net saving per week.

**The system pays for itself if residential care is postponed for 8 days.**

Family carers can rent the Just Checking system for £9.50 a week (plus £100 deposit).

# CONCLUSIONS

Returning to the original objectives of the trial:

## **1. Value to the family carers**

The trial provided strong evidence that family carers found the system of value. They find the information it provides reassuring, and supportive in their caring role. They want to continue using it and are willing to pay for it. Supporting carers is a key factor in keeping older people at home and independent for longer.

## **2. Promotion of independence and remaining in the community**

Information from the Just Checking system gave a greater insight to carers and professionals about the daily activities of a person with dementia. In most cases the person with dementia had a pattern of activity that was better and more consistent than expected. The trial demonstrated that this telecare system has a role in allowing people to remain independent and more in control of their own lives without too many intrusive visits from health and social care. It supports their wish to remain in the community.

## **3. Collaborative working**

In the trial cases there was already a good collaborative relationship between professionals and family carers. Nevertheless, the objective data from the Just Checking system provided more information to be shared and discussed, which underpinned the collaboration between care professionals and family carers.

## **4. Assessment of need, care planning and review**

Just Checking proved a valuable tool for assessment of people with dementia. It provided objective information which allowed professional staff, with family carers, to see daily patterns, and to make more evidence based decisions about care needs. In particular, it influenced decisions to both reduce home care support and increase home care visits.

The extra information provided by the Just Checking system creates an opportunity to meet needs with a wider range of responses. It offers the potential of reducing the reliance on home care, in which there is a shortage of staff.

The Department of Health circular which sets out arrangements for the Preventative Technology Grant (Dept of Health 2006b) stresses that adoption and application of telecare should be included in care planning and delivery.

## **5. Risk Assessment Process**

The Just Checking system provides information about daytime and night-time activity and has a role in risk assessment. In the trial the Just Checking system

was often installed because there was a particular concern, related to a perceived risk, in particular going out and for how long.

The system was able to show how often something was happening. It provides an objective measurement on which to assess risk.

#### **6. Preventing or delaying admission to residential care**

The majority of family carers and professionals who took part in the trial thought that Just Checking had a role in helping someone to remain in the community. In one case, where the Just Checking system had been in place for 9 months, the family carer was emphatic that the system had postponed a move to residential care. This fits the ethos and criteria for the Preventative Technology Grant.

# GLOSSARY

**Assistive Technology** A product or service designed to enable independence for disabled and older people

**Dementia** is a group of progressive diseases of the brain that slowly affect all functions of the mind and lead to a deterioration in a person's ability to concentrate, remember and reason.

**Telecare** Care provided at a distance using information and communication technology. Telecare is the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living.

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# APPENDIX 1 CASE STUDIES

## MRS Y

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Mrs Y is 85 and lives alone in her own house. She has had a formal diagnosis of vascular dementia, but is physically fit and active. Her daughter lives approximately 15 minutes drive away.

Home carers call 3 times a day to prompt meal preparation. Mrs Y's daughter spends each Wednesday with her mother at her house, taking her out shopping or to the library or hairdresser. On Friday Mrs Y is picked up for a luncheon club, and returns home mid afternoon. The daughter and her husband go to Mrs Y's on a Saturday afternoon and help with maintenance of the house and garden. On Sunday morning the daughter picks up her mother and takes her back to her own house for the day.

Mrs Y's family was willing to trial the system because they wanted to establish if she was going out by herself. On a couple of occasions in the past year Mrs Y has gone out for a walk and forgotten how to get home. Passers by have helped her back. On the second occasion the person who had helped her home knocked on a neighbour's door to check that he was bringing Mrs Y back to the right house. The neighbour phoned the daughter to say what had happened and was rather upset and unreasonable that this had occurred and asked what was the daughter going to do about it. On another occasion the home carer found Mrs Bailey at the house with her coat on as if she has been out, but when questioned gently, Mrs Bailey described a walk in a town where she lived many years ago; it wasn't clear if she had been out at all.

The daughter carries a heavy caring role and worries about her mother. The daughter and her husband did not have a computer and internet access at home but the husband had access at work, so he printed off the chart each day to bring it home. Mrs Y's son lives in New Zealand, and he logged on each day too.

During the trial Mrs Y went out on her own occasionally and each time she returned within half an hour. The daughter was surprised at how active her mother was during the day, how early she went to bed and how consistent her day and night time patterns were. During the trial period, the daughter and her husband went abroad on holiday for two weeks, and logged on to the system each day while away. The daughter said she was very reassured to be able to see that the home care visits, and lunch club visits took place as planned.

## **Outcomes**

- Daughter and her brother have kept the Just Checking system; the daughter has now bought a computer to be able to log on at home.
- The daughter feels that her brother is more able to share in the care, and possibly in any decisions that might have to be made in the future.
- System has been in for 7 months (April 2006), and will help the daughter and son see any deterioration and plan accordingly.

Mrs X is in her 80s and lives alone in her own home where she has lived for 20 years. The house is set in a large garden which Mrs X loves. Her son lives an hour and a half s drive away. He and his wife usually visit every 7-10 days. They organise shopping, maintenance and repairs, cleaning etc.

Home carers call 3 times a day to prompt meal preparation. Social services suggested installing the system to establish if Mrs X was going to bed and following some sort of routine. The previous year Mrs X appeared to the home care team have been disorientated by the change from British Summer Time to GMT. The system was installed 2 weeks before the clock change.

Mrs X s son uses a computer for much of the day, and was interested to try the system. He asked for the data to be uploaded every hour during the day.

The system was installed while Mrs X was present, although a simplified explanation of the system was given and the system controller was hidden out of view. Mrs X does not appear to remember that the system is in.

The system showed that Mrs X had a clear daytime/night-time pattern. She was more active and more consistent than her family thought. She often leaves open the side door which leads from the kitchen in to the garden. Sometimes she was leaving it open at night. The care manager offered to put in place a further short homecare visit in the evening to ensure that the door is closed. This appears to have cured the problem.

The change in time did not disrupt Mrs X. Over the following few days she made a gradual adjustment to her getting up time.

The son is reassured that his mother is managing well enough at this time and able to stay in the house which she loves. As the trial period was extended, the son noted a disturbed night in which his mother did not go to bed, but commented that he could see that subsequent nights had settled down again so there was nothing to worry about yet.

During the trial there was one incident in which the son looked at the system late in the evening and could not see any recent activity. At the time, the system did not display the latest update time and the son misunderstood the data, thinking it was more up to date than it was. He feared the worst, that his mother might have fallen and by lying inactive on the floor. It was too late to ring neighbours. The son called the police who agreed to make a social call. They found Mrs X asleep in bed. The system now clearly displays the latest update time. However, the incident also serves to demonstrate that there may be a need for a local response service which family carers could call on.

## **Outcomes**

- Son and social services reassured that Mrs X is managing at the moment.
- Additional daily 15 minute home care call added to care package, at a cost of £3.40 (assuming national average homecare hourly rate of £13.60).
- Son has kept the Just Checking system and pays for it.

Mrs W has dementia but is keen to continue living in her own flat. Physically, she can manage most daily tasks such as getting up and dressed, and using the kitchen, but she is unable to tell her daughter what she has done in the day.

She has two home care visits a day, at breakfast and teatime. Her daughter, lives some 10 miles away, and calls in during her lunch break twice a week. The daughter does the shopping, and organises cleaning and maintenance of her mother's home. A hairdresser calls once a week.

Mrs W does not like people going in and often asks home care staff to leave as soon as they arrive. Her daughter says that she never sought much social contact.

There was concern that Mrs W might not be eating much. The home carers reported that she often refused to eat during their visits in the morning and early evening, and it wasn't clear if she was eating any lunch. The care manager was considering a further home care visit at lunchtime. The daughter often found her mother asleep in the chair and thought she spent much of the day asleep. She wondered if her mother was up a lot in the night.

Installation was tricky. Mrs W thought that a lamp was being installed (because the installation was in the same position as previously she had had a lamp.) She kept switching off the system. Eventually, the son in law helped to move the system controller into the spare bedroom so that it was hidden. From then on Mrs W did not tamper with the system and did not seem to be aware of the sensors.

The Just Checking system showed that Mrs W usually gets up at around 8am, and spends time in the kitchen preparing breakfast. By the time the home care team visits, Mrs W has had breakfast and doesn't wish to eat again. She visits the kitchen just after 12 noon, to make lunch. If the evening home care visit is earlier than 5pm, Mrs W does not wish to eat then, but goes in to the kitchen later to prepare a meal. Regular visits to the bathroom indicate that she is eating and drinking.

There are periods of quiet and periods of activity. Mrs W was more active than her family thought. She goes to bed at around 9pm. There are night visits to the bathroom, but she returns to bed. Over the weeks Mrs W's daily living pattern was much the same.

The information showed that there was no need for an additional home care visit, and indeed the current home care calls have little effect on Mrs W's mealtimes; she prepares regular meals anyway. In consultation with the daughter, the care manager decided to change the emphasis of the home care visits. There was little value in the teatime call so it was withdrawn, but the

daughter was keen that the morning call was retained so that someone went in each day. She had noticed that there was rarely much washing (which she did) and her mother was not changing her clothes. The focus of the morning homecare visits was changed to showering at least twice a week and ensuring clothes were changed

The system was left in for a further month to check that the changes to the homecare package did not disrupt Mrs W's routine; for example, the teatime call might have been acting as a cue for the evening and bedtime.

The system also revealed that weekend home care calls were often missed. On some weekends no homecare calls were made at all. The home carer claimed to have made the calls and to have timesheets signed by the client. The Just Checking charts provided objective information about the time and duration of visits to the house in the ensuing discussion between social services and the home care agency. During the month follow up period, no calls were missed.

### **Outcomes**

- Homecare calls reduced by 50%,
  - releasing home care capacity to be utilised elsewhere
  - cost saving of £47.60 per week, (assuming national average hourly homecare cost of £13.60) or £2475 per annum
- Homecare calls changed to concentrate on help with showering rather than meal preparation, which was not needed.
- More tailored home care package, which is better value for money.
- Objective information about time and duration of homecare calls was available in tackling the problem of missed calls.

Mrs V, 83, lives in her own flat where she has lived for many years. She has short term memory loss, which she is aware of. She sometimes tends to dwell on something and become worried about it. Physically she is very active and goes out to local shops or further in to town most days. She has refused homecare to date.

Her niece lives in the same town and visits often. She organises most things for her aunt, including medical appointments, finances etc. The niece has access to the internet at work.

The care manager suggested installing the system to see how much Mrs V was going out, and for how long, whether she was eating and patterns at night.

The system was installed with Mrs V present and with her (and her niece s) agreement. When the system had been in a few days, the caretaker of the flats contacted the niece to say that Mrs V had been seeking his help to take out the box in her lounge. (One of the sensors had been placed on a picture on the wall near Mrs V s favourite chair, and this seemed to be what was bothering her.) The sensor was moved to a less obvious place. After a further week, Mrs V was again voicing concern to the caretaker about the system taking her electricity . The system was plugged in to a socket in the kitchen which was highly visible. The system was therefore removed.

However, the 14 days data that had been collected showed that Mrs V was very active in the day, using all the rooms, and went to bed at night. She usually got up in the night to visit the bathroom, but returned to bed. Most mornings she went out at soon after 9am and returned within an hour and a half. Occasionally she went out again in the afternoon for a few minutes. She did not go out in the evening or night.

There was one night when she hardly slept at all, and was up for much of the night, but the niece thought that her aunt had been worrying about being picked up for a hospital appointment the following morning, and this may have been preying on her mind. There was no other disturbed night during the fortnight that the system was in.

The care manager was satisfied that Mrs V was managing well, that there was no night-time risk to manage at the moment and there was no need for further intervention at this stage.

### **Outcomes**

- No night-time risk to manage
- No need for care package at this stage

Mrs U is in the early stages of dementia. She is aware of her condition and understands the measures she needs to take to remind herself and cope with daily life. She is physically fit and active and lives on her own in a private retirement flat. Her 4 adult children take an active part in helping her. They all live in the same area.

The eldest daughter takes on the greatest caring role. She often worries about her mother's forgetfulness. The care manager suggested trialling the system because the daughter is anxious about Mrs U going out and possibly forgetting how to find her way home, and whether this might become more of a problem in the future. The care manager was also interested to see how the system could help with assessment.

The Just Checking system was installed in Mrs U's home with her permission. Mrs U still has the capacity to make her own decisions. Mrs U was able to provide feedback on having the system in her home.

The system showed a clear daytime and night-time pattern. She sometimes goes out to spend the evening with her neighbour and goes out to stay with members of her family from time to time. The care manager thought data showed Mrs U is functioning well at this stage and that her daughter may not need to be so anxious. There is no need at this stage to provide home care, although some support for the daughter was considered.

Mrs U and her family have elected to keep the system in preparation for the future.

### **Outcomes**

- Mrs U managing perfectly well at the moment
- Mrs U and her family keep the system in preparation for the future

## **MR T**

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Mr T, aged 79, was diagnosed with dementia three years ago. He is physically fit and still goes out each day for a walk. He is adamant that he should stay in his own home. His daughter and her husband live some miles away and are committed to supporting him for as long as possible. They visit or go out with Mr T most weekends. A Just Checking system was installed 9 months ago.

The daughter logs on each morning to see what sort of night her father has had before she rings him at 9am. She logs on again when she is home from work in the late afternoon to check that he has returned home after his daily walk. Her husband logs on at work, or via his mobile phone. The system enabled them to see that he is visiting the kitchen regularly to prepare meals, that the home care team has visited, and to verify what has happened in the day if Mr T is unable to remember.

The daughter says the system provided "peace of mind". She also noted that a change in daily or nightly pattern was often a precursor to a change in health, and she found this information very useful.

Recently, Mr T suffered a bout of pneumonia and spent several weeks in hospital. His mental health deteriorated and a higher level of care was deemed necessary; he has now moved in to residential care. However, his daughter is in no doubt that without using the Just Checking system they would have gone down the residential care route sooner.

### **Outcomes**

- Just Checking in place for 9 months
- Helped reduce the strain on the daughter of caring for her father, who lives 10 miles away
- Delayed the time when Mr T eventually moved into a residential home

# APPENDIX 2

## DISCUSSION GUIDE USED WITH FAMILY CARERS

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How have you found using the system? Did you find it easy to use?

What can you glean from the charts? (Probe for risks/concerns)

Is the system providing a clearer picture of what is going on than you had before? (Confirmation of what you thought, or surprises?)

Have you made any changes as a result of being able to see what is going on when you are not there?

How do you think the system is helpful for you in your role as a carer?

What do you feel about the system?

How are you using it – how often logging on? Change upload times?  
Other members of the family logged on?

Have you referred to the data when discussing things with the social worker?

Would you like to see the system improved in any way?

Do you think the system helps enable your (relative) to stay in their own home?  
In what ways?

Would it be useful to have the system permanently? Why?

The system costs £490 for the equipment, plus £5 a week for the webservice.  
Alternatively, it can be rented for £9.50 a week, with £100 refundable deposit.  
Could you give me your views on these costs.

Buying or rental preferable?

Is this system something you would like to see social services providing for carers? Do you think it is reasonable to be asked for a financial contribution?

## ***DISCUSSION GUIDE USED WITH PROFESSIONAL STAFF***

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How have you found using the system? Did you find it easy to use?

What can you glean from the charts?

Is the system providing a clearer picture of what is going on than you had before? (Probe for risks assessment. Confirm what you thought, or surprises?)

How do you think the system is helpful?

How is the carer using it?

Have you made or considered changes to the care plan as a result of the data from the system?

Have you discussed what the system shows with the family carer, ie has the system been used to consult together? (Probe for any changes in the way professional and family work together)

In what aspects of your work do you see the system most useful?

Do you think the system has a role in enabling someone with dementia to remain in their own home?

Given your experience of the system do you think it is likely to extend (or shorten) the time a person with dementia could remain in their own home?

Do you think the system would be useful for family carers?

What would be an appropriate mechanism for introducing the system to family carers? (How is other support for carers provided or signposted?) How could carers be made aware of the system via Warwickshire CC?

Any improvements you would like to see to the system?

## **PROJECT BOARD:**

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John Whiting	Service Manger for Older Adults
Ed Williams	Senior Social Worker OPCCS, Shipston
Adrian Fry	Senior Social Worker OPCCS, Alcester
Ruth Bell	Senior Social Worker, OPCCS, Leamington
Jenny Barratt	Social Worker appointed as project manager
Jan Roberts	Alzheimer s Society, South Warwickshire Branch
Sue Crowley	South Warwickshire Carers Support Service
Celia Price	Just Checking Ltd

### **Participating WCC Staff**

Ralph Deakin	Care Manager, Shipston
Natalie Wirtz	Care Manager, Alcester
Jo Davy	Care Manager, Leamington
David Skidmore	Care Manger, Leamington
Pam Lucas	CPN, South Warwickshire PCT
Kate Harris	CPN, South Warwickshire PCT

# **APPENDIX 3 CONSENT AND ETHICS**

## **Consent**

Service users and carers who were invited to take part in the study received a verbal explanation, and an information sheet with consent box. Participants were asked to sign two copies, one for the researcher and one to keep.

In some cases the person with dementia was deemed unable to give informed consent that the Just Checking system was installed in their home. This judgement was made by the care manager in consultation with the family carer.

## **Ethical Principles**

In these cases, the care managers worked to the four basic ethical principles outlined below, and Warwickshire County Council's Guidance and Procedures on working with someone lacking in capacity to give consent. The staff who are involved in this study are experienced in working with people with dementia.

Two European projects, Technology, Ethics and Dementia (TED) and ASTRID, produced a guide for professionals (Bjørneby 1999, Marshall 2000) who are considering the use of assistive technology for people with dementia. The guides are based on the ethical principles of non-maleficence, beneficence, autonomy and justice. Copies of the following supporting documents are provided:

- Information sheet provided to service users and family members who took part in the trial
- Ethical considerations in using assistive technology for people with dementia.
- Warwickshire County Council Guidance and Procedures in working with someone lacking in capacity to give consent.



## *TAKING PART IN THE PILOT*

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### **The Just Checking System**

The Just Checking system provides a picture of the daily activity of a person in their own home, by monitoring and logging movement around the house. It can be used to just check that someone is following their normal pattern of life without intruding on them, or undermining their independence. The system has a number of potential uses, including:

- For people who are forgetful, supporting them to live in their own home for as long as possible.
- Reassurance for family members
- Supporting the support given by informal carers and home care services
- Supporting assessments of needs and risk assessments

Warwickshire Social Services, South Warwickshire Carers Support Service and the Alzheimer's Society, are piloting this new system to consider the contribution it can make to supporting people and their carers. We want to make sure that people are getting the help they need when they need it. We are asking a number of volunteers and their family and carers, to try the equipment with us and let us have their views on how useful it was.

### **What equipment will be installed?**

The system has three components:

1. A small control box, which plugs in to the mains electricity and a telephone socket. You will be able to use your telephone as normal.
2. A door opening sensor which will be attached to your main exit door. The sensor will be attached with double-sided sticky pads, which are removed without trace at the end of the trial.
3. Two or three movement sensors which will be placed in areas of your home which you most use, eg in the kitchen, or near a chair or table where you tend to spend time. The sensors are attached to the wall or paintwork with double-sided sticky pads, and removed without trace at the end of the trial.

There are no cameras and no wiring. The system uses low power radio to communicate between the sensors and the controller.

Several times a day the system automatically makes a 2 minute telephone call to download the data. If you are using the phone at this time the system will realise you are on the phone and will wait until you have finished. There may

be a noise from the system for a few seconds when it tries to pick up the line, but you do not need to hang up. It will stop and try again later.

If you pick up the phone to make a call when the system is using the line you will hear a screeching noise through your phone. Hang up and wait for a couple of minutes and the line will be clear.

### **What will I need to do?**

Nothing if the system is going into your home. Just carry on life as normal. The system works automatically and does not need any input from you.

If you are a carer or relative, you will be given instructions on how to access the system on the internet.

Staff at the organisations involved in the trial will be looking at the charts that your system generates from time to time.

### **How long will the trial last?**

About 3 months.

After the equipment has been installed for a few days we will be in touch to make sure you are happy with the equipment and to answer any questions you may have. When the system has been in for approximately a month we will ask you and your carer about your experience of using the system in a short interview, which we will tape record. Your experiences and views will help us to develop the service further. If you are happy to continue, the trial may be extended for a further 2 months. At the end of the 3-month trial the equipment will be removed.

Of course, you can ask to stop the trial at any time you wish.

### **Any problems or queries**

If you have any queries about the equipment during the trial please ring Celia Price, telephone 01564 741822.

Your contact at Warwickshire Social Services is xxx,  
Telephone xxxx

### **Consent**

Signed \_\_\_\_\_

Date \_\_\_\_\_

Name \_\_\_\_\_

## ***THE ETHICS OF MONITORING PEOPLE WITH DEMENTIA***

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There is often particular concern about the surveillance or monitoring of people. The European project, Technology, Ethics and Dementia (TED), produced a useful guide for care professionals<sup>1</sup>, and this guide has been reflected in more recent technology projects such as ASTRID<sup>2</sup> and the Safe at Home initiative<sup>3</sup> by Northamptonshire Social Services.

Monitoring people with memory problems should be aimed at their safety, prevention of unwelcome situations and reassuring carers. It is useful to bear in mind the ethical principles of non-maleficence, beneficence, autonomy and justice.

### ***ETHICAL PRINCIPLES***

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**Non-maleficence**, means doing no harm. In the case of the Just Checking system, the system is passive and requires no physical interference, nor the wearing of any device.

**Beneficence** means doing what is good for others. It is the basis of western medical ethics. If it is the intention to provide care services that meet the needs of a person, then monitoring to establish those needs, and to check if they change, is beneficent.

**Autonomy** means the right to self-determination and freedom from unnecessary constraints or interference, or loss of privacy. Most older people would prefer to stay in their own home for as long as possible, but sometimes concern by relatives or neighbours about a person's safety or behaviour, means that a person's autonomy and independence is undermined prematurely.

The Just Checking system can enable the person to stay at home, and provide a relative or carer with the reassurance that a loved one is capable of continuing to live in their own home for the time being. It prevents unnecessary visiting or telephoning, which may undermine autonomy, and enables the carer to plan more meaningful visits. Sensors can be sited to log activity without undue invasion of personal privacy, and there are no cameras. Installation of the system may afford greater privacy than carers calling in several times a day.

Permission to install the Just Checking system in a person's home should always be sought. Occasionally the person may not understand sufficiently what the system will do.

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<sup>1</sup> Bjørneby S, Topo P & Holthe T (eds) (1999) *Technology, Ethics and Dementia: a guidebook on how to apply technology in dementia care*. Norwegian Centre for Dementia Research

<sup>2</sup> ASTRID Project (2000) *A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers: A guide to using technology within dementia care*. Hawker Publications, London.

<sup>3</sup> Woolham J, Frisby B, Quinn S, Smart W & Moore A. (2002) *The Safe at Home Project* (Northamptonshire County Council), Hawker Publications, London.

Care professionals face a similar task in trying to explain any proposed care package. For example, it can be difficult to get informed consent that care workers may enter the home to help the person with daily tasks such as getting up and dressed. Nevertheless, care professionals usually decide that the provision of this care meets the ethical principles and should go ahead.

**Justice** is treating people fairly. Fairness includes providing the services that a vulnerable person needs to carry out their daily life. The Just Checking system helps to establish what the person is doing for themselves and when they need care. It enables family carers and care professionals to plan and deliver care when it is most needed rather than undermining independence.

Finally, in considering the ethics of using technology, there is a judgement to be made. In some circumstances, use of this type of technology might not be appropriate, but it is essential to consider the ethics of the alternatives, and to make a considered judgement.

## How do you know if someone lacks capacity to consent?

People lacking in mental capacity have the same rights under the Act as anyone else. There are effective methods of communicating with people with learning disabilities; the Information Commissioner's guidance (and good practice) requires you to make all reasonable efforts to consult them. Most will be perfectly capable of understanding issues about their privacy and consent. There's no universal definition of mental capacity. The DH describes a person with capacity as someone able to understand, retain, and weigh up information relevant to the decision and its consequences.

Capacity isn't a fixed concept, it's on a spectrum. Different decisions and activities require different levels of capacity. Some mental health problems may cause the individual's capacity to fluctuate over time. For those with dementia, the loss of capacity may be a gradual process so the point at which they are no longer capable of making the decision is difficult to pinpoint. It doesn't follow that someone who makes what is considered the wrong decision is mentally incapable.

Assessing capacity involves the following considerations:

- Presume the person has capacity unless and until that presumption is proved wrong.
- A person with capacity might choose to withhold consent even though the consequences seriously prejudice their health and welfare.
- The more complex the decision, the greater the level of competence necessary.
- Capacity should be considered only in relation to making this particular decision.
- Capacity should be considered based on the person's understanding of the information at the time the information is explained to them.
- Generally, inability to make a decision is when the person can't understand, retain and weigh up information relevant to the decision and its consequences.
- If the person's decision is too outrageous for any sensible person to arrive at, this might indicate a level of incapacity.
- Panic, indecisiveness, confusion, shock, fatigue, pain or drugs might erode capacity, but you must be satisfied that these factors are present to such a degree that the ability to decide is absent.
- Fear might be another factor which can influence capacity to decide, but be aware that fear can also be a perfectly rational reason to withhold consent.

## **A practical approach to assessing capacity:**

Ask yourself the following questions at the time the decision is needed:

1. Does the individual have all or enough information to enable them to make the decision?
2. Could you explain or present the information in a way that is easier for them to understand?
3. Are there particular times of the day when their understanding is better or they feel more at ease?
4. Can anyone else help or support them to express a view?

Once these questions have been addressed, the key issues are:

- Does the individual have a general understanding at this time of what the decision is, and why you're asking for it?
- Do they have a general understanding at this time of the consequences of making, or not making, this decision?
- Are there any other factors present, and if so, to the extent where the capacity to decide is lacking?
- Is the individual just frightened, and if so, is their fear rational?
- Are they able to understand and weigh up the information provided at this time as part of the process of arriving at a decision?

**1<sup>st</sup> November 2004: this guidance was given by Legal Services.**

# How to act “in the best interests” of someone lacking capacity to consent?

“Best interests” is a concept, derived from the common law doctrine of necessity, which held that where there is a necessity to act, professionals are authorised to act “in the best interests” of adults with incapacity i.e. to trust the judgement of caring professionals to “do what is right for the individual”. It is used primarily by medical practitioners but has since been widened in case law to cover not just the individual’s best medical interest but also ‘medical, emotional and all other welfare issues’. It is a vague concept which has not been precisely defined by the courts but which permits a wide ranging discretion tempered by ‘factors’ to be taken into account.

When trying to make your decision as to what is in an individual’s best interests, you should consider:

- What the individual gains if, in this instance, the information is disclosed to other agencies balanced against what they lose of their privacy and confidentiality of information.  
*Tip Draw up a balance sheet of gains and losses to the individual by disclosing the information to determine where the balance lies.*
- The ascertainable past and present wishes and feelings of the person concerned and the factors the person would consider if able to do so.  
*Tip Try to find out the person s own wishes, values and any views they may have had before the lost capacity. These may be contained in an advance in an advance document ( living will ) or expressed informally to relatives, friends or carers. It is important to ensure that these are the person s own wishes and have not been influenced by others.*
- The need to enable the person to participate as fully as possible in any decision affecting them.  
*Tip Try to consult the person and seek their current views. Explain the decision that needs to be made and try to encourage maximum involvement. The individual may have views on what is best for them, even if they are unable to make the decision itself.*
- The views of appropriate others about the person’s wishes and feelings and what would be in their best interests.  
*Tip Consult those close to the individual such as relatives, partners, professional carers or an attorney. However, remember that the individual has a right to confidentiality and may not want certain people involved.*
- Whether the purpose for which the decision is required can be as effectively achieved in any other way.  
*Tip Can the information be compartmentalised with relevant information being disclosed purely on a need to know basis rather than a blanket disclosure?*

- Everything of importance to the person, even if not directly relevant to this particular decision.

Tip *Think about the individual's religion, cultural values, interests, likes or dislikes which may all be important in deciding what may be in their best interests.*

**Practical ways to determine best interests include:**

- Checking the person's case notes to see if a record has been made of any views, likes or dislikes relevant to the proposed decision eg have they agreed to disclosure of personal information to another agency previously? Family members may have useful records.
- Learn the best way to communicate with the person e.g. by involving other professionals who can advise on communication methods and techniques.
- Involve others close to the person or those with expertise on the decision to be made, bearing in mind the individual's right to confidentiality.
- Keep careful records of everything relating to person's care which may be useful to refer to in trying to decide what is in their best interests.

**1<sup>st</sup> November 2004: this guidance was given by Legal Services.**