



Enabling Technologies for People with Dementia

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Report of the assessment study in ENGLAND

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Executive Summary

The European Commission has funded Enable, a three year longitudinal study involving five countries to examine the feasibility of devices, and to assess the socio economic costs of providing technology to enhance the quality of life of people with dementia and their carers.

This report is based on the findings of the UK assessment trial of Enable. Both quantitative and qualitative data has been collected from 32 people with dementia and their carers who were asked to try out one device per household for up to one year. The findings suggest that people with dementia and their carers have a great deal to benefit from devices that can facilitate independent living at home, and at the same time presents recommendations and challenges for developing technology for use with people with dementia in the future.

Dementia Voice would like to express their gratitude to the participants, their families, friends, carers, and professional carers from the Community Mental Health Teams in the south and southwest of England. who provided valuable information and insight into the lived life of a person experiencing dementia, and who provided the time, patience and effort in allowing the assessment trial in England to take place. A special thanks to Pat Lysaght, Nurse Manager, and Karen Hayes, Researcher at the Peggy Dodd Centre – the site for the Picture Gramophone.

Bristol, UK, January 2004.

Kerry Jones, Research Officer

Principal Investigator for the assessment trial in England

1 Introduction

Enable is an exploratory and descriptive study, with the overall aim being to determine whether it is possible to facilitate independent living of people with dementia, and to promote their well being by facilitating access to enabling technological systems and devices. Between March 2001 and June 2004, the Enable methodology was guided by the ethical considerations and the needs of people with dementia in research from five European countries – **England, Lithuania, Ireland, Finland, and Norway**, with the overall objective for the study being to:

1. Define the feasibility of the devices
2. To assess the effects of providing assistive devices to people with dementia
3. Provide a comparative analysis of the devices tested by European countries.

A methodological approach was developed by Enable to assess the benefits of enabling technology, and to ascertain the socio – economic costs associated with using assistive devices to facilitate independent living for people with dementia.

The protocol was developed and defined for use with research for people with dementia in their homes. The protocol submitted for ethical approval was guided by adhering to the sensitive ethical conditions required within a study in which people with dementia provide informed consent.

Observation to the sensitivity and ethical conditions of conducting research for Enable was submitted to four Ethical Committees across the south west of England, between October 2001 – December 2001. Consent was obtained from various committees between March 2002 – September 2002. Applications to several committees across the south west was necessitated by the fact that access to respondent's was obtained through several community mental health teams across the regions, given the dearth of available respondent's in the Bristol area. Often research participant's entering the memory clinics in the region are recruited onto independent research trials, and therefore do not meet the inclusion criteria for the Enable project.

2. Technology and People with Dementia

To date, very few studies have sought to include people with dementia in their research. However, in the last five years, researchers have increasingly appreciated the value of obtaining user led information through the use of data collection tools, which are designed for use with people with dementia. Part of the dilemma of defining the assessment tools for Enable was to meet the need of the person with dementia sensitively and appropriately to that of the tools available. The multi disciplined nature of the team revealed the complexity of issues that can prevail - including concerns about hearing the voice of the person with dementia. The majority of partners asserted that it was vital for the person to be heard to provide a meaningful insight into technology and its use in the home of a person experiencing dementia.

The trial of the Picture gramophone was conducted in a day centre for persons with dementia in Bath. The study with results will be presented at a later juncture.

3. Enabling Devices

Dementia such as Alzheimer's disease is a type of brain disorder characterised by a progressive loss of cognitive functioning, reduced memory and ability to learn and reason (ICD-10). Dementia implies heavy burdens for the person affected and their carers, and imposes an enormous economic burden on society in general. In the US, Alzheimer's disease alone is the third most costly disease (Wimo *et al*, 1997; Lillevold, 1999). This is especially significant, considering a doubling of the number of people with dementia is expected during the next 50 years as a result of the ageing population (ETAN, 1999, European Commission, 1997). Current social policy aims to provide support so that the person with dementia can live in their own home as long as possible (Warner *et al*, 1998), and many affected people want to live at home and manage daily tasks themselves. However, their ability to maintain relationships or to handle different tasks and activities deteriorates progressively and reduces their quality of life. Even people with mild to moderate dementia experience frequent failures. The complexity of the technology around them plays a role in the loss of abilities, and carers emphasise the disabling role of contemporary technology (Sweep, 1998). Taken together, this can lead to worries and depression, and in turn to poorer functioning than otherwise could be possible. Thus, many of the challenges for people with dementia and their family carers are of a very practical nature (TED, ASTRID). Some examples are given below.

3.1 Time orientation

Confusion about day and date is a common problem for people with dementia. Not knowing what day it is may have severe consequences for a person since it is a basis for structuring one's life, and making plans for the days to come. Disorientation of time was rated as a big and burdening problem by formal as well as family carers (Sweep, 1998, Haugen, 1985, Zarit, 1996). Many people with dementia ask what day it is over and over again, some times at very short intervals. Carers are often stressed by frequent questions, and these can create irritation and thus affect the relations between the person with dementia and the carer in a negative way. Different assistive devices are available to facilitate time orientation. Case reports have shown that some persons increase their time orientation as a result of using an assistive device, and that their feeling of coping was supported (Holthe *et al*. 1999, Johansson and Nygård, 1999). Also, the carers experience fewer questions, since the person with dementia was able to find out day and date him/herself. The case reports illustrate how problems with time orientation are manifested in daily life for different people. The interviewees living alone and who otherwise were able to manage daily tasks felt that time orientation was a big problem for them (Johansson and Nygård, 1999). The authors emphasise the importance of identifying the problems as early as possible and to offer appropriate assistive aids. They expect that a person with mild dementia can get used to the device and be able to make use of it for a longer period. Johansson and Nygaard also emphasise that the use and acceptance of the assistive device seem to be dependent upon the individual; his/her (pre-morbid) personality, insight into own situation as well as motivation and ability to try something new. The study of Holthe *et al*. concluded that the individual's personality seemed to be important for the person's acceptance of the assistive aid provided (Holthe *et al*. 1999).

3.2 Day-time/night-time confusion

Whether it is day-time or night-time is a problem for some people with dementia. Examples of unintended consequences of this are:

- Waking up family carers at night by telephone calls
- Going out of the house at night, for instance at 5 a.m., instead of 5 p.m. to wait for the taxi to pick them up to the family dinner. The persons may feel embarrassed and be depressed by not being able to cope. There are also many examples of incidents and accidents if they are not able to find their way back home.
- Digital watches which differentiate between day-time and night-time are difficult to use for people with dementia, since they are not able to interpret the information, e.g. "19.45" to "a quarter to eight". In some nursery homes in Norway the carers have put up a placard on the patients' door, and written DAY on the one side, and NIGHT on the other side. Turning the placard twice during the day has reduced wandering at night. Such wandering had previously disturbed the other patients since the wanderers often do not find the way back to their own door (Gunn Helene Larsen, pers. commun.). An automatic NIGHT/DAY display would have facilitated the work for the carers, but this has so far not been installed.

3.3 Prevent falls at night

Falls at night is a well-known incident when old people get up at night, e.g. to go to the toilet.

Turning on the light may reduce the number of falls. In a care home for 8 people with dementia, no falls were registered during a 2-year period after installation of an automatic bedroom lamp that was activated when the person got out of bed (Bjørneby, 1996). In a care home of similar size, 4-5 falls were registered during one year, and in a care home for 12 people, 10 falls were registered during one year. No falls were registered in a care home where the light was kept on during the whole night (Bjørneby, *pers. communication*)

3.4 Cooker alarm

To forget to turn off the cooker may cause burning of food and pans, and in some cases, fire. Cooker alarms which turns off the electricity in case of over-heating, are commercially available for electric, but not for gas cookers. Damage due to forgotten cookers is a big problem. Smoke, burning or fire damage constituted 15% of all insurance costs in Norway in 1995, and people > 67 years were particularly vulnerable (Bjørneby, 1996). Bjørneby's study demonstrates that cooker alarms may prevent damage since no fires occurred in a care home for people with dementia equipped with cooker alarms. The care home was equipped with smart house installations, which also included smoke detectors, door alarms and other safety sensors. The cooker alarm was released most frequently of all the alarms. However, fires were prevented since the incident was detected quickly, and actions were taken immediately.

The examples above illustrate that assistive technological aids can support some people with dementia. However, few assistive devices are available for people with dementia. We also need more knowledge about the feasibility of different assistive aids for these patients and how to assess the usefulness of the products, both for the patient, the carer as well as the costs and benefits for the society.

In the ENABLE project, six new assistive technological products have been developed for people with dementia who will use them to find out whether these products can further enable them in their daily tasks. All the products address well-known needs of people with dementia and have been developed in collaboration with users, carers and experts. The design and functionality have been based on specific user requirements developed as part of the project. The products are listed below.

Item	Usage	Expected effect
Automatic Night and day calendar (Forget-me-not™ adaptation)	As a calendar. Day and date is always correctly displayed, together with time of the day (Morning, Afternoon, Evening or Night)	Facilitate time orientation, prevent people from going out and make phone calls at night
Locator for lost objects	Pressing picture button causes lost item to bleep. Stops when picked up	Finding frequently lost items, such as keys and purse. Reduce worries and time spent for seeking lost objects
Automatic bedroom lamp	Turns on the light when the person gets out of bed	Prevent falls at night, reduce anxiety
Gas cooker monitor	A cooker which the user can operate as usual, but which are fitted with sensors which detect pan overheating. The cooker is turned off in a manner which enables the user to subsequently carry on using the cooker without outside help being necessary.	Prevent fire or food being burnt due to overheating because the user has forgot to turn off the cooker. Reduce worries.
:		
Remote day planner	A screen which displays tasks and activities for the day. The information is provided by the carer through the internet	Reduce worries of not knowing the appointments and events every day

3.5 Enable Devices assessed in England

Products

Products aiming to support memory facilitate communication, or to provide pleasure and comfort had been identified prior to the start of the project. Prototypes and test series of seven new products was developed during the first year of the project.

In England it was originally decided to test six of the newly developed products:

- A locator for lost objects (keys, purse etc)
- A gas cooker monitor to prevent fires
- An automatic night lamp to prevent falls at night
- An electronic “Night and Day” calendar to enable time orientation
- A multimedia “Do-it-yourself” Picture Gramophone for entertainment and enjoyment of favourite music
- A picture telephone “Picture Phone,” with big buttons, which can be pre-programmed and show names or pictures of the persons one would like to call.

Respondents did not receive the picture telephone since the majority already had similar style phones in their own homes. Therefore data exists for five products tested in England.

Other products that were developed in the project were.

- A remote day planner to remember appointments and events, for example birthdays and anniversaries.

This was not assessed in England, as the supplier on the technology went bankrupt and the technology was not available from other companies, and the product was never ready to be implemented. Additionally, another existing product was not selected for testing:

- A medicine reminder “Carousel”, which gives a sound when it is time for medication

4. Methodology

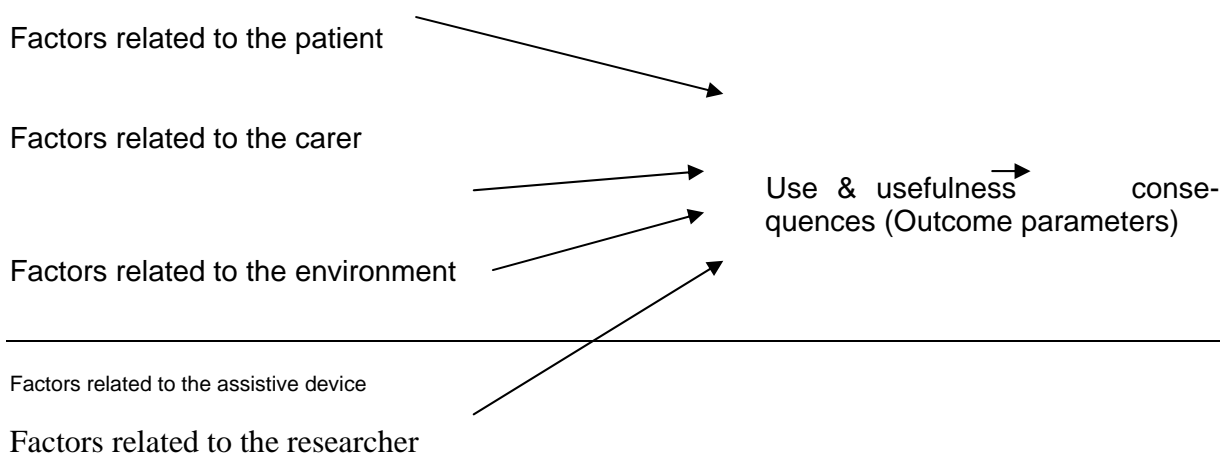
4.1 Outcome Measures

A methodology for the assessment of effects, including cost-benefit analysis has been developed (theoretically) as part of the ENABLE project. The methodology will be tested out in practice in a pilot study among users in Ireland, England, Norway and Finland. The ICIDH model (now called ICF – International Classification of Functioning, disability and health) has been used as the general framework for the methodology development. ICF was developed by WHO to classify the functions and disability associated with various health conditions (WHO, 2000). The ICF model encompasses different aspects, as follows

- The individuals health condition: dementia comprises different diseases which affect the brain in different ways and which may give rise to symptoms of different character and progression rate. Co-existing medical conditions can also be important.
- The individuals body function and structure: dementia diseases are progressive and effects are often dependent on the phase of the disease.
- Personal factors: each person is unique and effects may be dependent on factors such as gender, personality, attitudes, education and profession.
- Environmental factors: these include home environment, availability of family and professional care services etc., which may promote or reduce the impact of enabling products.

4.1.2 Primary and secondary outcome measures

Our hypothesis is that whether the person with dementia uses the product or not can be explained by factors related to the person with dementia, the carer, the environment, the product or the researcher, as illustrated below.



- Factors related to the patient include the stage of the disease, cognitive functioning, nature of and degree of the problems, duration, ethnicity, personality/attitudes, social life;
- Factors related to the carer include family relation to the patient, co-habiting or not, frequency and character of caring, working status, attitudes towards the person with dementia, feeling of burden/general health;
- Environmental factors comprise both services from the social or health care system as well as the patient's home environment;
- Factors related to the devices include the design, function and reliability;
- Factors related to the researcher include motivation and attitudes to the project, the devices, the patients and the carers.

Use & usefulness are the primary outcome measures. Use of the devices may have further consequences for the patient, the carer and the community. These will depend on the character of the problem (falls at night, forget to turn off cooker, time orientation), the importance of the problem for the patient, the carer and the society and how it affects them, respectively. These are secondary outcome parameters. Outcome parameters marked with * are used as outcome parameter categories also for the primary carer.

Categories of secondary outcome measures (consequences) are:

- Support independence
- Support feeling of coping
- *Create pleasure, activity
- *Reduce general emotional burden due to worries, anxiety, stress or irritation
- *Prevent unwanted incidents or accidents
- Support memory
- *Prevent situations creating unwanted negative feelings between the patient and the carer due to stress in connection with e.g. not finding lost objects, repeated questions, passivity

An approach to cost-benefit analysis will be made both on micro and macro level.

A unified instrument is constructed based on selection of recommended guidelines and validated scales comprising the following aspects:

4.2 Ethical Procedures

The final ethical approval for all field study sites in England was approved by September 2002. The process had taken some considerable time with consent sought by application to four different committees between October – December 2001. Ethical procedures presented several dilemmas to the England assessment trial, one of which was the potential impact upon recruitment. Each of the four ethical committees operated according to different guidelines, with review of applications for some operating on a monthly, bi monthly or tri monthly basis. In addition, guidelines differed according to the time length commit-

tees were enabled to review the application, and to then inform principal investigators of outcome. In one instance the ethical committee panel of fourteen people in one area, asked for an interview with the UK principal investigator (KJ) to ask questions about the study.

One of the main questions raised by committees pertained to the scientific validity of the study, since ethical panels were used to receiving applications for randomised control trials taking place in the hospital site itself, and were in the majority of cases unfamiliar with the idea of including people with dementia in face to face style research. This presented a dilemma as consent forms and letters to participants used by the principal investigator often omitted the word dementia, since in the experience of Dementia Voice people with dementia have often stated a preference for 'memory problem'. After lengthy justification, the England team were permitted to use original consent forms.

From application to outcome the entire ethical process took 11 months, which served to impact upon recruitment. In the initial phases considerable time was spent in promoting Enable to various teams and organisations, with consent not yet permitted, people who were ready to be recruited to the project could not participate and were eventually lost to the project due to eventual cognitive decline, or loss of interest.

4.3 Recruitment

Recruitment took place via staff in community mental health teams, social services, and voluntary organisations, who were familiar with the work of Dementia voice, and who would be willing to be involved in research, which could be of some use to their patient's and clients. Recruitment via memory clinics was not sought since patients attending the clinic were often asked to participate in research trials, for drug companies for the large teaching hospitals in Bristol, and would therefore be excluded from the Enable recruitment criteria as defined below:

Inclusion and Exclusion criteria

The inclusion criteria were:

- People who live in their own home with a diagnosis of mild or moderate dementia according to ICD-10, preferably Alzheimer's disease, vascular dementia or mixed Alzheimer's/vascular types. Patients with sub-cortical dementia may be included, but must be described carefully.
- Age > 50
- MMSE score > 12
- Reasonably good nutritional status and general health; i.e. able to move on their own both within the house and outside
- A primary caregiver who is able and willing to participate. A primary caregiver is defined as that persons or persons who have responsibility for the day to day care needs of a cognitively impaired person. The definition does not exclude carers living apart from their dependent, or those who have additional care/work responsibilities (Stone et al 1987)
- The primary caregiver can either live with the person with dementia or have frequent contact with him/her. Frequent contact means telephone call or visit at least once a week.
- Informed consent given

- Living in a reasonable distance from the researchers

The exclusion criteria were:

- People participating in other intervention studies
- Any major psychiatric disorder
- Active malignancy
- People with fronto-temporal dementia
- Patients without a reliable caregiver
- Nursing home patients
- People on a waiting list for nursing home

Recruitment consumed a significant proportion of time in the assessment trial in England. Health care professionals acted as the ‘ gatekeepers’ to recruiting people with dementia and their carers. The initial referrals illustrated the enthusiasm of professionals who having read the literature about the devices and had viewed the “ Tomorrow’s World” programme about the devices in the Gloucester Smart House on UK national television had high expectations of the devices and what they could achieve for their client’s. Either through carer’s and dementia support groups (showing the Tomorrow’s World video) or through home visits, health professionals introduced Enable and distributed literature to people with dementia and their carer’s about the potential benefits. (this would later have a direct impact upon the expectations versus outcomes of the use and usefulness of devices.)

Participants were recruited at various sites across the south and west of England. This meant that for some locations travel to participants comprised a journey of 90 miles. Participants were recruited from through a voluntary organisations; community mental health teams, and social services.

Carer’s and professionals in health and social care who had received the inclusion and exclusion criteria would recommend participants for recruitment. However, participants were not as keen as carers or the health professional’s himself or herself. The main reason was that the person with dementia did not wish to be reminded that they had a memory problem, and for some this meant totally denying a memory problem.

Other problems were experienced in recruitment due to the lack in the availability of products, in particular products that required more testing on site prior to implementation in people’s homes. This meant that the devices that people had chosen and for which they were enthused about, were not installed at the planned T0. Due to the prolonged wait for a fully functioning device the person expecting the device had either lost interest, experienced significant cognitive decline or had gone beyond recruitment deadline (June 30, 2003) This was a situation mainly experienced by participants awaiting cooker monitors.

Technical problems in the devices in particular the locator, and cooker monitor not only led to a loss in original recruitment but also several drop – out’s prior to T1. Of 10 locators with tags, which were received by the UK, five were returned after several tests revealed numerous faults with the tags and with the locator panel.

In England fifty-six people were referred and received home visits. Of these, 39 were successfully recruited, and provided consent to participate in Enable, 33 of which received devices. Three participants who consented to cooker monitor installation did not

enter T0 as no heat sensors were available, (ethical approval was sought from committees to install monitors without heat sensors) and in one case installation took place three months post recruitment deadline. A faulty locator meant that negativity was created between carer and participant, and as such T0 never took place. A night and day calendar was installed and consent achieved, and the installation achieved. However, the participant later in the interview stated that they were unsure about the installation and needed time to think about it. No consent for interview was given and therefore did not take place. The device has not been returned.

Thirty three participants for which data has been collected, received the following devices (1)

- 19 Night and day calendars
- 5 Locators
- 5 Night lights
- 3 Cooker monitors

Participants were recruited from the following

Of all 32 respondent's, 12 lived with their carer's, with the remaining respondent's lived alone, and with regular contact with their carer's. This is a familiar situation in the UK. A great many people who are defined as elderly often live alone with sons, daughter's and other family members living either a short distance away where they can visit each day, or live a significant distance where regular contact by phone and long weekend visits in which the primary care giving role can be employed. Carer's report feeling supported to some extent if their mother or father reside in warden-controlled flats, since it means that the day-to-day well being of their relative can be reported.

Note 1. Respondent UKB007 not included in the final data set, as they did not meet the criteria for ' carer' but ad been included in Enable with information provided by CPN at T0 that they had a carer.

4.4 Entry to and from the Project (Drop out)

Of the 32 participants who entered T0, 13 participants withdrew by T1. Reasons for drop – out included faulty device (n = 4); unplugging the night and day calendar device as it wasted electricity (n =3); non motivation (n = 3); entered long term institutional care (n = 2) and passed away (n =1)

Of the remaining 21, thirteen achieved T3 status. The number of drop – outs between T2 and T3 (n = 7) illustrates to some extent the difficulty in utilising technology at the proto-type stage in research. Five of the dropouts occurred as a direct result of faulty devices, with three comprising the cooker monitor, and waiting for the appropriate parts to arrive.

The remaining participants who withdrew did not use the devices (night and day calendars) as they found the text too small compared to other devices they had in the home, whilst another participant entered residential care.

Table 1 Participant drop out by sex, MMSE score; device; research status; reason for drop out, and return of device.

Participant ID	Age	Sex	MMSE	Product	Status	Reason for drop out
UKBOO1	95	M	24	NDC	T1	UNPLUG DEVICE
UKB002	86	F	21	NDC	T1	NON USE
UKB003	87	M	15	NDC	T1	NON USE
UKB004	86	F	16	NDC	T1	LONG TERM CARE
UKB005	86	F	19	NDC	T4	NON USE
UKB006	83	F	22	NDC	T5	COMPLETE
UKB007	62	F	23	NDC	T4	NO CARER
UKB008	71	M	23	NDC	T5	COMPLETE
UKGOO9	77	F	20	NDC	T4	HOSPITALISATION
UKP010	82	M	19	CM	T2	RESIDENTIAL
UKP011	82	M	18	NDC	T1	UNPLUG DEVICE
UKP012	83	F	19	NL	T5	COMPLETE
UKF014	79	F	15	NL	T1	RIP
UKPO16	88	F	18	CM	T2	/RESIDENTIAL
UKPO17	79	F	21	CM	X	NO HEAT SENSOR
UKPO18	77	F	21	CM	T2	BEYOND DEADLINE
UKPO19		F	19	CM	X	NO HEAT SENSOR
UKPO20		F	21	NDC	T5	COMPLETE
UKPO23		F	20	NDC	T1	HOSPITALISATION
UKP024		F	26	CM	X	NO HEAT SENSOR
UKP025		M	17	NDC	T1	UNPLUG DEVICE
UKM026		F	18	NDC	T1	NO RESPONSE
UKY027		F	19	NDC	T5	COMPLETE
UKY028		M	21	L	T4	

UKF029		F	18	NDC	T3	HOSPITALISATION
UKY030		F	18	NDC	T5	COMPLETE
UKF033		M	87	NDC	X	NO RESPONSE
UKF034		M	79	NDC	T2	NON - USE
UKF035		M	81	NDC	T4	
UKY036		F	88	CM	X	BEYOND DEADLINE
UKD038		F	81	NDC	T2	RESIDENTIAL

4.4.1 Technical Problems

A number of technical problems are attributable to the significant level of drop – out. All respondents in receipt of the night-lights reported faults at T1. The lights would either not operate or would come on but not switch off. As a result only one lamp was left in a respondent's home because they felt that a lamp that at least came on automatically would reduce carer anxiety regarding safety at night, even if it meant the lamp would be left on all night or the carer needed to get up and switch it off. No further people were recruited for the lights since health professionals lost faith in the ability of the light to deliver what the original information sheet, *Tomorrow's World* televised programme and BIME video about the devices had stated what it was able to do. This raised ethical concerns among social and health care teams as to the provision of faulty devices to people with dementia in their homes. Another concern of carers of respondent's was the time length in responding to reports of faulty devices, with two participant's waiting three months for a device to be repaired.

People testing out the locators experienced technical problems and this has resulted in a significant drop – out by device with all locator participants reporting problems by the T1 stage. One locator remains with a respondent and their carer, and they use it when they want to use it. All participants and their carer have reported the difficulty in using the pads at the front of the locator. Even when pressed with firmness, the locator light did not respond, and when it did respond the tags would either not respond, but would the second time, or would not stop ringing the third time.

The inconsistency of the tags was reflected by a series of 8 tests carried out per tag at dementia Voice when in receipt of the locators.

Respondent's reported how frustrated they felt that the device would not work. It also caused some distress as many thought their 'memory problem' would be to blame, and as a result would not be believed. It was only until carer's or the researcher visited and tested the device was the fault reported, and the device removed. This clearly raised ethical concerns among carers and health and social care professionals who were concerned about devices leading to feelings of ill – being.

It is worth noting that researching technology among people with dementia can prove highly beneficial not least because of the insight gained into a lived life. However, it can also affect final outcome significantly. Research morbidity has resulted in a loss of *seven participants who have entered long term institutional care* out of the original 32, recruited to the study, and a further valuable participant sadly passed away.

In addition, problems occurred with prototypes, which were prone to faults. This has resulted in a total of *9 drop – outs due to faulty devices and in some cases drop out due to the frustration in waiting for the time between reporting the fault*, and the time in receiving a visit to examine the product for possible repair. Three participants reported that this took as much as three months.

This scenario is evident with the *cooker monitors which have resulted in total drop – out* status due to faults reported and the same participants who although have now entered residential care, could have completed T4 had the device been fully operational at implementation. Devices, which are not ready for implementation, illustrate additional consequences for respondent's who have provided consent and provide all the criteria, but who are left out from the research, because a heat sensor does not fit the cooker.

Other issues prevail, and which do not pertain to the device. For example, one participant became frustrated by the device as it created negative relations between carer and user as it reminded the user that they had a memory problem; and it 'wasted electricity'. By T4 the participant had hidden the night and day calendar, and to date it has not been located in the home by the carer.

Participants, carers, and health care professionals report their disappointment when a device does not function, or does not reach the implementation stage, and this is not only a consequence for drop – out but for further recruitment to the research. Many health care professionals, who act as the 'gatekeeper access points' to recruiting people with dementia, have raised questions about the feasibility of a device that is not fully operational and the ethical considerations about its subsequent implementation. As a result continued recruitment has proved difficult after the health care professional has been a witness to a faulty device, and their resulting enthusiasm diminishes along with their hope that it has a benefit for their other client's in the community.

4.5 Data collection

A series of questionnaires comprised to form the final interview schedule. Questions pertaining to quality of life for the carer and the person with dementia, use and usefulness of devices and the socio economic benefits were incorporated to enable analysis of the primary and secondary outcomes defined below:

Scales	T0 Baseline	T1 Post week 1	T2 Post 3 weeks	T3 Post months 3	T4 Post months 6	T5 Post months 12
Socio-demographic data on patient	X		X	X	X	
Form I A (on product)	X					
Form I B (on outcomes on product)				X		
Form II problem/need analysis interview	X					
Form II.i Willingness to pay			X	X	X	
RUD Interview with carer A1.1, A1.2, A1.3	X					
RUD Follow up questionnaire B1.1, B1.2			X	X	X	

Relative's Stress Scale (Greene)	X		X	X		
Experiences on the product			X	X	X	
Telephone-call Is everything OK?		X				
Telephone-call Is product still in use?						X

B: Interviewing person with dementia (time 1 –11/2 hours maximum)

Scales	T0 Baseline	T1 Post 1 week	T2 Post 3 weeks	T3 Post 3 months	T4 Post 6 months	T5 Post 12 months
MMSE (if not available from the memory clinic)	(X)					
Socio-demographic data (if possible)	(X)				(X)	
Quality of life (Brod)	X		X	X		
Experience with product/overall impression			X	X	X	

4.5.1 Description and justification of the scales and T stages followed

Initial phases of the assessment period comprise several visits in a short space of time, this was to ensure that the person with dementia could feel comfortable about using the device, and provided an opportunity for questions to be raised as to the feasibility and suitability of the device after being tried out in the person's home. Many people found this time very useful, and felt reassured by a home visit. Carer's who worked were contacted by phone and interviewed.

Information was gathered from participants about their quality of life and about the use and usefulness of devices. Further information in the form of qualitative data was recorded to ascertain other factors, which may serve to impact upon the use of a device and the quality of life of the participant and their carer.

The principal researcher to ensure consistency, and where MMSE test scores were unavailable or had not been taken in the last six months carried out all interviews; this was also carried out by the member of the community team or the researcher who has experience of performing the test with people with dementia.

4.5.2 Researcher experience of data collection

Interview schedules were designed to answer the questions set out by Enable. However, this often meant a long interview for people with dementia, and consequently difficulty in answering some of the questions. Participants were often prompted by their carers, as to their experience of the device, and this at times caused distress at being reminded of a memory problem in the presence of other people in the household.

The use of the Brod scale in Enable emphasised a conversational style type approach to questions. This could work well if participants were at their optimum sense of well – being on that particular day, and who were able to focus and concentrate on the test. However, many commented that they preferred not to be tested (prerequisite to completing the Brod scale) in some instances since it served to remind them of their memory loss if they were presented with choices and could not remember the way to answer the question. However, the scale enabled themes to be drawn upon in schedule II and expanded upon.

An open format in the form of semi-structured interviews often led to more information imparted by the participant.

4.6 Data Analysis

Quantitative data was recorded onto SPSS sets according to the coding book defined by Enable. The UK qualitative data was placed onto templates which allowed for the categorisation of the data into several themes, mainly the use and usefulness of the device; quality of life of the person with dementia and their carer by research stage, and by device.

4.6.1 Quantitative

All quantitative data from the interviews schedules was placed onto the SPSS and the data sets analysed by the SPSS system. As the report focuses on UK participants, the data is described in a descriptive format, with the utilisation of frequencies and cross tabulations to study the statistical significance by the Fisher exact test In the analyses both cross sectional data sets (T0,T2,T3) and longitudinal data sets (T0 – T3).

Cross sectional. T0 data has been analysed to form a descriptive account of the participant's recruited in England, and T3 data to investigate the outcome of assessment. The data collected between T0 and T5 has been recorded into one data set on order to analyse longitudinal outcome of assessments, with the use of SPSS.

4.6.2 Qualitative

The qualitative data comprises information obtained through open ended questions and in field notes and which have been transferred to word template and with key words placed onto excel coded templates. The analyses comprises colour coding to classify responses, with emphasis upon the use of case studies, and all data analysed using coding analysis.

Cross sectional. The data in the excel files and those held in word documents on Enable vignette templates, will enable an understanding of the reasons for drop out, and lead to a greater appreciation of outcome.

Longitudinal The longitudinal data is available in excel and word template documents and has been analysed utilising colour coding in the first instance and used to highlight the importance of using case studies in the project to highlight important variance.

5. Results I

5.1 Characteristics of the Participants with Dementia

Table 2 Characteristics of the participants experiencing dementia in England for all stages (n= 32)

<i>Age in years</i>	
Min Max	60 - 95
Mean	81.1
Median	81.5
<i>Gender</i>	
Female	22
Male	10
<i>Socio Economic Status ¹</i>	
Blue Collar	10
White Collar	9
Other [House person]	13
<i>Living Situation</i>	
Alone	13
With someone	19
<i>Household Gross Income</i>	
<i>(Euros)</i>	
14,999 or less	23
15,000 – 24,999	2
30,000 – 34,999	1
40,000 or more	6

¹ Socio economic classification based on Office National Statistics Standard Occupational Classification (SOC 2000) <http://www..statistics.gov.uk/methods/soc/structure.asp>

Participants in England comprised of a population of younger people (below the age of 65) experiencing dementia, as well as older persons (85 years and above), with the average age (median) being 81. The youngest participant, provided evidence of a dearth of services for this particular age group, spending much of her week in a day centre with people in the 80 years and above age group. While this particular participant enjoyed many of the activities there (music and singing), she looked forward to the opportunities to spend time with younger members of her family. Or this participant the nearest available service and activity is in another city twenty miles away which is provided by the Alzheimer's Society, which s unable to offer transport.

With ten men in the sample at baseline, women dominate the data in their trial of devices in Enable. This accounts for the relatively high level of 'other' occupations classification, which defined that 13 women were housewives. This is not an unusual socio economic phenomenon for women of this age group given the social history of the early 21st century. Men within the sample were employed in gas and electrical engineering; shoemaking (Cobbler), and a nuclear science occupations.

The majority of respondents received a state pension (n = 23), which accounts for the high number of respondents who receive a household income below 15,000 Euros. Many people in receipt of state pensions, and who receive no other income can expect to receive less than A gross household income category (6,000 Euros or less) would provide a more accurate reflection of household income. This is a situation, which does not differ to those participants who live with someone (n= 19) to those who live alone (n=13) and can expect to receive 6,000 and approximately 5,000 Euros respectively.

Table 3 Characteristics of people with dementia for all stages (n=32)

<i>Diagnosis</i>	
Alzheimer's	13
Vascular	6
Lewy Body	0
F03 Unspecified	13
<i>MMSE</i>	
Min – Max	15. 2
Mean	20.9
Median	21.0
<i>Stage of severity</i>	
Mild	25
Moderate	7
<i>Medication</i>	
None	20
Anti – dementia	6
Anti – depressant	2
Anxiety suppressant	0
Other	4
<i>Person go out alone</i>	
Alone	16
Always with someone	16
<i>Day centre hours</i>	
No attendance	9
1 – 4 hours	3

4– 9	2
10 – 14	6
15 – 19	4
20 +	8

5.1.1 Diagnosis and Medication

Attempting to yield accurate diagnostic information about participants proved complex. In 13 cases, hospital notes were in other departments (occupational health or psychology) to the community team KJ was working with, and as a result diagnosis by type of dementia was unknown by ‘gatekeepers’ other than the knowledge that diagnosis had been received. However, MMSE score was easier to obtain since, ‘gatekeepers’ themselves had carried out these tests, and were able to provide the information efficiently through their own case notes. Six people in the England study were taking anti -dementia medication, while a very small number (n= 2; n= 4) prescribed with anti depressants or anxiety suppressing medication.

5.1.2 Public Help

The entire level of public help is difficult to define accurately. While week by week, people may be assured of the hours of care they may receive by a home help (n=12) or a day centre, (n=18) other services can be infrequent with a fifteen minute call from a social worker or community psychiatric nurse (CPN). Visits to GP’s or hospital appointments are sporadic and are often unrelated to the dementia.

Participants who live alone attend a day centre facility more times than participants who live with someone. The day centre is a valuable resource for people living alone, and often a means used by social workers and CPN’s to ensure that people experiencing dementia can be monitored unobtrusively over time. In addition, professionals can receive up dates from the nursing manager of the day centre and be assured that a hot meal is provided for each day of attendance. Transporting people to and from the day centre also acts as a checking facility to ensure that people attend and are well enough to do so.

Participants who tend to live alone also receive the greater number of hours per home help, with 5 receiving 2 hours and 6 participants receiving 7 hours worth of care. Often this care comprised of simple household chores such as vacuuming, or ensuring medication was taken. For some participants the home help level of care is divided into 15 minute slots to account for the level of assistance required per task. Many carers and health professionals report how this is a system that replaces a previous hourly paid assistance service. This enabled people to carry out chores and to provide a social and personal contact to the person who may otherwise not have any social contact for people who may otherwise not receive any social contact elsewhere for several days. This may in some way support the view that participants have reported feelings of loneliness.

5.2 Carer Characteristics

Table 5 Description of the carer’s of people experiencing dementia

in England at baseline	
Age in years	
Min – Max	32 - 9
Mean	60
Median	58
Gender	
Female	25
Male	7
Carer relation to person	
Experiencing dementia	
Spouse	8
Child	13
Friend	2
Other	9
Carer KM distance	
Min – max	1 - 160
Mean	21.3
Median	2.5

The majority of individuals acting as carers for the participants experiencing dementia are reflected by the median age group (60 years of age) and that this is indicative of son's and daughter's (mainly daughter's), and wives. The distance in KM is significant with as little as 1 KM distance compared to a daughter who lives 160 KM away, and journeys to care for her Mother every ten days, for a week.

5.2.1 Care provision

Family members comprise the main form of care provision with between 1 and 90 hours per week provided by family; up to 3 hours by neighbours, and 2 by friends. The majority of care is supervisory; with assistance with shopping and daily tasks comprising an average median number of hours of 3.5. However, many carers reported that the number of hours was difficult to define since, tasks were often carried out on an as and when basis. Tasks such as shopping and household chores or finances were carried out at times when the participant was not there or was at the day centre. This meant that carer's spent the majority of their respite time in carrying out household chores and other daily living tasks such as shopping, laundry, finances and general chores. Often what was viewed as respite for the carer by health and social care professionals meant little active rest, since this was seen as an ideal opportunity to complete tasks uninterrupted. It was respite from repeated questions, looking for lost items and concerns over safety which provided the actual break.

Of the carers who worked for pay (n= 15), 14 lived away from the participant experiencing dementia. The hours of work ranged from 15 to 40 hours per week, with the median number of hours given as 37. Very few carers (n= 2) reported that their hours had been affected by their caring role, with 1 reducing the number of hours worked to care for a participant at T3.

Only six carers received payment from the state for providing care to participants. Carers who were not working received payment. Even where carers are living with person experiencing dementia, many are often unaware of what they are entitled to unless their social worker intervenes. In addition, payments from the state are means tested and often comprising a benefit entitled Attendance Allowance in which depending on the severity of a 'disability' a person is entitled to receive funds to purchase care often in the form of home help. It is not aimed at providing a supervisory support.

5.3 Quality of Life: the person experiencing dementia

Table 4 Quality of life sum scores by people with dementia, and by time series stage (T0 – T3)

Overall quality of life	Time Stage.		
	T0 (n=32)	T2 (n=20)	T3 (n=12)
Bad	0	0	0
Fair	10	10	5
Good	6	4	1
Very good	1	0	0
Excellent	1	0	0
Not answered	14	6	6

Participants were asked to provide subjective information about their quality of life with the use of the Brod scale and through open-ended questions in Schedule II of the interview forms. Overall, participants across all stages rate their quality of life as being and good. Several participants (n= 14) did not answer the Brod scale these are for a number

of reasons including feeling anxious, having a bad day, a restless night – these situations are essentially the every day reality of living with and experiencing dementia. The following case stories are taken from field notes as to the experiences of

Case Story I

Carer states relative has had a restless night as concerned about a GP appointment he has this week, and unsure when it is, and does not want to miss it. Appears very tired to carer this morning as KJ arrives and has intimated that this needs to be as short a visit as possible. Consent is sought re: the QOL scale. When KJ and pwd 1: 1 interview style, participant states that he is not up to many questions this morning and wants to try the device instead. Consent is sought to 'chat' to obtain more open-ended information about the subjective experiences of quality of life. Participant is visibly more at ease with this as we discuss the memories that his photographs on the side of the room evoke. Participant laughs as he recounts when a particular photograph was taken, and how this evokes feelings of well – being for him (Qol theme) each time he looks at this particular picture.

Case Story II

The first question on the Brod is attempted and Sue is confused by the question, and states she does not understand the relation between not enjoying a meal to a choice of enjoy meal some, a lot and so forth. She informs me it would be much easier if it were a simple question, with a yes or no answer. We try this with each choice, and Sue is becoming more disorientated. The interview takes place in an open ended format with reference to some of the themes in Brod to try and assess QOL in this way, but this quickly follows to schedule II when she is puzzled by references to birds, and nature. Sue however, goes on to state, what is her main worry. Sue asserts quietly how she fears the 'workhouse', the visualised image of a residential home. She feels frightened at the thought of going into a residential home, of one day having to share a home with others, whom she has never met before, and to remain in a situation over which she feels she will have little say.

Case Story III

Although, Celia is now much more at ease with considerable time spent listening to her fears and concerns, and also repeating consent procedures to provide a sense of security, Celia is very uncomfortable with the scale, and states that she does not like tests. KJ informs Celia that it is OK to stop right away, and that we can just chat if she prefers to allow KJ to record for schedule II. Celia is much happier with this. Schedule II reveals some of the reasons why Celia is sensitive to being tested, with reference to anger and frustration at the self when she is reminded that she has a problem. She states that at times this is in reference to using the device, of being reminded to use it. Celia also reports that she becomes concerned about conversing in public that she may repeat a pre prescribed answer to a question already asked: -

“ looking silly if I am unable to answer a question” and “ I get cross with myself when I can't remember what to say”

5.3.1 Emerging themes: quality of life of people with dementia.

Participants within UK Enable spoke of similar experiences to the cases described. There was often a need to replace the memory of having a problem with one of happy moments experienced in the past. Fears loomed largely in the future, with the knowledge

that they too will one day share their home with others in a residential and nursing establishments to live out their days. There was the need too, to hold onto one's sense of self, of not being tested, and becoming angry with oneself, to be able to answer at will, and from a time and a place that exists

5.4 Subjective Experiences of Quality of Life (open – ended)

Information for the schedule II and from journal notes provided a rich source of qualitative information and insight into the lived life of an individual experiencing dementia - all of which can serve to impact on feelings of well – being and possibly the use of a device. Data collection for the Schedule II was organised into three themes that would enable the participant to impart information in the interview to collect data about the negative, neutral and positive aspects of their life, which may serve to impact upon the level of its quality. and indicate in some cases the successful use of a device or not.

The schedule began with an *open* theme, in which participants were invited to comment on issues identified earlier in the interview with the use of the Brod scale, for example embarrassment or anxiety concerning memory loss. The second phase of data collection of the schedule required data collection about issues pertaining to any *worry* that had been reported by the participant. The final phase of schedule II ended on the *happy* theme to enable participants to end the quality of life phase of the interview in a more positive way thereby aiding the participants towards a sense of well – being.

Two case stories illustrate the emerging themes and their *negative, neutral, or positive* impact: -

Case Story I

Keith's views about his own quality of life centre on dealing with memory loss, and about some of the services that are in place for him at present. He also talks about the social isolation that he often feels even when in a crowd.

i.) Open theme identified

Memory: Worry (negative)

Keith describes how memory loss has implications about his view of himself, particularly his intelligence. As a scientist, Keith has been in demand in his career, and at the forefront of new technology, clearly memory loss has presented a significant impact on him being able to cope to how he and others respond to the memory loss. This is especially the case when he asks for orientation to the date and day whether it is during the day or night. He speaks of waking after a sleep in the chair at night and not knowing whether it is day or night, this can occur too if he wakes suddenly at night. As a very private individual he finds it particularly difficult to receive health and social service intervention.

ii) Worry theme identified

Services: Feeling lost (negative)

Keith talks about how lost he feels in the day centre amongst people whom he states talk about the same things all the time, and by the fact that he prefers his own or one to one company. He is aware that it is a break for his carer, but does not appreciate the intrusion into his personal life, and would prefer his own company in the familiar surroundings of his own home. Keith's carer has informed KJ that Keith has never liked crowds or being amongst large groups of people, and that this in some part explains his reluctance to attend the day centre.

iii) Happy theme identified**Home: Sense of well – being: (positive)**

Having first met Keith in the day centre, and then at home, his presentation and expression differ. He appears more relaxed at home, and more open to being able to provide information, particularly that which provides insight into to his worries and concerns (memory), and how others respond to him. This of course could also be due to the fact that Keith is feeling a bit better on the day he is interviewed at home, to the day he is introduced to Enable at the day centre.

Case Story II**i) Open theme identified****Social isolation: embarrassment (negative)**

While Sarah is very much a private individual, she enjoys the company of close friends, and that of his family. However, Sarah's frustration which she states is due to; -**“not being able to find the right words”** means she does not like to use the phone to speak with friends or family as she is concerned about being able to participate in a conversation, and feels embarrassed when she is unable to, and what other people may think of her as a result. As such, Sarah's way of dealing with this has been to isolate herself in order to cope, and to maintain a sense of dignity of the sense of self.

ii) Worry theme identified**Future (negative)**

Sarah worries about what will happen in the future and is concerned that the T0 is an indication of how well she is coping with memory loss, and whether or not she is to be placed in residential care: **“ You haven't come to test me to see if I have to go into a home have you?”** This is a situation Sarah is keen to avoid, and is often wary of health professional visits to her home or to the GP surgery.

iii) Happy theme identified**Humour (positive)**

Sarah tends to utilise humour to help her cope with living with dementia. This tends to be used more at the day centre where she is among friends, than at home, where relations can become strained by the carer trying to be sensitive, and Sarah's anger at being reminded of memory loss, when he feels contradicted, or she feels she has not been informed about an event when her carer reports that she has.

5.4.2 Subjective experiences of quality life: emerging themes

Participants speak about the sense of loneliness and isolation despite being part of a crowd at a day centre, and of the sense of loss about one's identity, of who they were, who they are now, and how they may be perceived by others as they search for the words, which will provide the perfect answer to a question asked. Loss of word finding ability is often accompanied by other losses that are common to all- the bereavement of a loved one, and of a feeling that things will never be quite the same again. While many feelings lead to sadness, isolation and at times despair for many participants, there are others who also strive to cope. Whether there is a need to be alone, like one has always strived to be, or to feel comfortable and content when surrounded by the security and familiarity of home, or indeed, of using humour among friends to make light of one's memory at the day centre, there is one common theme for all, each individual is unique in how they experience dementia. It is how they have often used their resources to cope with any other situation in their day-to-day lived life.

5.5 Carer well being .

Table 6 Carer well being by time stage (T0 – T3)

Carer well being	Time Stage		
	T0 (n= 32)	T2 (n=21)	T3 (n=12)
Min – max	6 – 32	0 – 35	8 - 41
Mean	17.41	21.95	23.58
Median	17.0	19.01	20.5

Four carers were in receipt of medication, three of which were related to their own health problems (pre dementia care roles) One carer experienced high blood pressure which was raised when stressed in his carer role.

Carer sense of well – being has decreased over the T0 – T3 stage of Enable. In consideration of the variance of scores for T3 which range from 8 – 40, this increase could be attributed to increased level of care required in caring for participants experiencing further cognitive decline, which serves to impact in several ways. Several carer's reported that the level of burden increased in line with attempting to arrange extra care for participants. This occurred for carers who lives with the person experiencing dementia, and for carers who lives away. Reports of frustration and isolation were clearly felt by many carers in trying to locate the appropriate person and subsequent advice proved a lengthy, highly stressful and demoralising process. The following case story highlights the level of stress that can be experienced by carers in attempting to locate assistance:

Case Story I: Carer (daughter)

Riana's carer lives with her husband and children 160 km from Rian (participant), and visits Rian every ten days and stays for a week at a time (at baseline). She is in regular phone contact with Rian to ensure sense of safety and to reduce Rian's anxiety especially at night. They are hoping that the NDC will for some part be able to reduce the level of calls. Rian's carer frequently worries about accidents happening not least because Rian lives alone. As a result, Riana's carer has built a good rapport with the neighbours who make check visits to Rian to ensure all is well. Rian's carer also states that the home help visit each morning and night to administer Aricept. This creates confusion for Rian as she can expect to receive visits from 15 different home help's in a week.

Rian's carer is very concerned about the confusion created by the different home help faces, and her anxieties are also heightened in trying to arrange and negotiate increased care without having to sell Rian's home. Rian's carer also mentions for the first time, that she is also a carer in some respects to Rian's husband who is in a nursing home.

In order to reduce the level of distress experienced by Rian she visits for 10 day stretches at a time, and has needed to reduce her work hours to do this. When her Rian's carer first comes to stay, she states that a great deal of time is trying to find lost items. However, even when these are found she finds it distressing and frustrating herself to realise that she will have to do this all again when she visits in another five days. Time spent away from the family home and work is also adding to the stress of the situation.

Rian's carer achieves some emotional and physical respite when her brother (Rian's son who lives in France) stays for a few days during school holidays for weeks a time to act as a break to Rian's daughter. Rian's daughter is trying to cope with the situation as best as she can, and has tried to cope by distancing herself, but inevitably feels unable to do this as she becomes concerned for her Mother's welfare.

Rian's carer also describes the 'battle in trying to negotiate extra care for Rian and states: ***"Some days I feel I cannot cope, and it depends how it goes, other days I feel I can get far"*** Much of the frustration at this stage (T3) has stemmed from trying to locate social worker: ***"It's a nightmare trying to get in touch with them. I spend a lot of my time here back phoning them in office hours and they don't phone back, or they tend to phone when I have returned home, even when I have given them my other contact details and my mobile, they keep phoning here (Rian's house) It is so annoying"***

"I have spent a phenomenal amount of time chasing people over the past two and a half years, people say they will get back, but never do" Rian's carer attempted sought assistance with a voluntary organisation to help her locate the most appropriate care, the help never came.

Rian's carer also points out that trying to obtain health services such as those of a dentist and ophthalmologist through a national help line has proved difficult and frustrating since the information provided was inappropriate for Rian. Frustrated and worn down by information seeking processes Rian's carer emphasises how she tries to cope: ***"It makes you (situation) want to go out and find about things and get some knowledge to help you cope with it. I'm finding out all these things (rights and entitlement) to help the situation"***

"I am battling with the authorities at the moment as I have been told we have to sell the house (Rian's) to pay for my Father's nursing home fees. We have already payed so much but we are running out of money, and I know my Mother (Rian) is entitled to services"

"I have now resorted to asking my friend who works in the benefits agency (national state benefit payment system) because I could not find anyone to help me."

You have to know the system it is all experience gained. I would have gone under a long time ago if not”

5.5.2 Carer well-being: emerging theme

Riana carer's story has been chosen since it represents several themes that have been identified by carers within the UK assessments. Often carers report that not only do they have to cope with their own sense of loss at witnessing their loved ones live with dementia, and helping them to cope, but also finding ways in which they can retain a sense of self. For those carers living some distance from the person with dementia often meant experiencing significant stress through concern and worry, and of meeting the demands of caring for one's own family and that of the needs of the person experiencing dementia.

While a host of public services exist, carers felt that they needed to know a system, to know what to ask for, in order to receive it, and of having to draw upon the services of experienced friends and individuals who knew a system far better than they. Even where services were placed, carer's concerns sense of stress was not always reduced. Home helps, often the social contact and the link between the home and services, would often comprise a team of fifteen people whom the person with dementia needed to familiarise themselves with.

As with participants using devices, carers found their own coping mechanisms, often it meant asking other family members to look after the person to achieve some respite. It is at these times that the day centre asks as the respite call for many carers, in enabling them to feel some sense of well being in knowing that their relative was receiving a meal, social contact, and a link with services who could observe the person unobtrusively, and thereby report on their well – being. The more successful schemes of this kind in the UL assessment, was a day centre developed by a voluntary organisation in which activities, were developed by and for the people themselves.

6. Results II

6.1 Devices assessed by England: product selection and rationale

The night and day calendar, the night-light, the cooker monitor, and the locator were identified by focus group members (health and social care professionals) as of being the most use and useful to people with dementia and their carers. Consequently, the most successful devices proved to be the night and day calendar, not least since it required the least interaction by people with dementia compared to the night light; the locator; and the cooker monitor all devices requiring some interaction and intervention by people with dementia due to their design, and to the faults reported per device.

6.1.1 Use of the products

The expectations of the devices were very high in England, (this prompted the high level of motivation by people with dementia who felt motivated to try a device (n= 32) A great deal of time had been spent by the Principal investigator in England in meeting with community mental health teams across the south and west of England, and publicity generated through Dementia voice through the televised *Tomorrow's World* programme about the Gloucester Smart house, had created more enquiries as to the possibility of clients becoming participants of the project. Literature and the BIME video pertaining to the ability of the devices to provide many problem-solving issues for professionals was used to introduce Enable in meetings with health professionals and in carers and dementia groups. Enable was met with a great deal of enthusiasm and hope, especially in relation to devices that could enhance safety in the home and therefore maintain a person in their home for longer.

The recruitment process enabled a filtering down of this enthusiasm to carers in the community, often viewed by CMHT's as being 'at their wits end' and willing to try anything that could help the situation at home. As with the health professionals, carers had the opportunity to peruse the literature and were very impressed. As a result and were keen for all devices to be installed, believing that the devices would provide the solution to some of the frustrations and risks of living with dementia. The people experiencing dementia themselves were keen to try the device, if only to placate the carers, often feeling a 'burden' for the stress experienced by their carer.

Some participants were keen to hide the extent of the problem, and were instead offering to try out the device as they felt their contribution and opinion to research would prove valuable. Other participants were also keen to try out the device, especially when emphasis upon consent was placed, and the option to withdraw at any stage confirmed.

Ascertaining what a device was being used to help with was clear. However, carers expectations of the device was extremely high, and tended to state that the device was being used to help with many of the problems experienced by people in their homes. Carer's in the majority of cases stated that given the literature (and after perusing Enable, BIME, and DV website) they expected the devices to be able to achieve an outcome at all levels. The extent of that outcome varied. While have for some there were some carers who expected a night and day calendar to reduce repetitive questions to a great extent, and to some (italics) extent reduce negative relations. They felt that the night and day calendar had great potential for some things and less in others. The carer's response was often I

One case – had never experienced a positive relationship with their Mother, but they expected to some extent that negative relations would be reduced since it would mean less confusion concerning stage if day and therefore less questions, and feelings of intolerance frustrations for both parties

Often carers made a very vital point in that they had high expectations that the device would work, however it was also difficult to define an outcome given that the device had not been tested for any great length of time by the person. By T2 the situation became much clearer. People had an opportunity to test out the devices, which they often viewed as products at baseline. For those items that were faulty, there was a great deal of frustration felt, since the devices had been viewed as products.

6.2 Night and Day Calendar

Table 9 Night and day calendar participant characteristics by time stage (T0 – T3)

	T0 (n=19)	T2 (n=11)	T3 (n=9)
<u>Gender</u>			
Female	13	8	7
Male	6	3	2
<u>Living situation</u>			
With someone	6	6	6
Alone	13	5	3
<u>MMSE</u>			
15 – 19	9	1	2

20 – 24	10	10	7
25 – 29	0	0	0
Diagnosis			
Alzheimer's	12	7	5
Vascular	2	0	0
F03 Unspecified	7	4	0

The night and day calendar has proved to be the most popular device in UK Enable with 21 respondents receiving a calendar at the consent stage and 19 using and being assessed. This suggests in part that time orientation, particularly to date, day and stage of day was important to the person and the carer, leading to negative relations and increased stress when people wanted to know the date, day and stage and carers becoming increasingly frustrated. For those living alone, this meant a great deal of anxiety, and phone calls to health professionals or carers who may live some distance away, and who were concerned at the distress experienced by the person who is not orientated to time, stage of day.

Almost half the men of the original 22 are accepting calendars at T0. However, by T2 this decreases dramatically (n=3). One of the reasons given for non – use are that the device is being unplugged as it “*wastes electricity*”. In addition, respondents are switching devices off when they retire for the night, and do not remember to switch them on in the morning. In cases where people live alone, health care professionals have reported that respondents are unable to remember where the device has originated from, and are unable to recall its purpose and therefore switch off the device. The next stage has been to wrap the calendar in a bag ready for collection. Literature pertaining to the night and day calendar in addition to Enable and consent information does not necessarily imply that a person will read in full about Enable or about why the device is there and its purpose.

While the night and day calendar has proved very useful for some participants who live alone, the presence of a live in carer suggests that a person can be reminded where the calendar came from (after the researcher has left) and its purpose and also be prompted to use it. Indeed, during introductory - consent and T0 interviews several respondents continued to ask about the purpose of the calendar and its benefits, which is indicated by the presence of dementia. This suggests that a night and day calendar will prove more beneficial to people living with carers, than those living alone, unless a meaningful and sensitive strategy can be employed to remind and encourage use.

6.2.1 Implementation, maintenance, and technical problems

Very few problems were experienced with the night and day calendars, with one drop out reported for a faulty device. In this particular case, three night and day calendars proved faulty. Of these, two were tested and produced symbols upon the display screen; one was left and later unplugged resulting in drop – out. The participant was asked for their response and was clearly frustrated by two calendars that did not work, and was initially reluctant to try a third.

Despite the experience of one participant, the night and day calendars were very simple to implement, and were popular with participants and carers who were relieved that they did not have to press, touch or have to take responsibility for any changes to the calendar. This meant that the calendar could fit in with the environment, and be used unobtrusively without drawing too much attention as to its purpose in the home.

6.2.2 Comments

Many respondents commented upon the calendar's aesthetic properties. Many found it pleasant to look at, and an aesthetic attribute to their home. Despite suggestions about placing familiar photographs in the picture section of the calendar, respondent's commented that they preferred to keep the flowers. The calendar was often used as a means of empowering oneself.

The researcher observed on several occasions, how when asked by a carer what day or date it was as a test, the person using the calendar would appear impatient with the carer, then look to the calendar and state what day and date it was and appear distinctly satisfied with their time orientation achievement.

While the calendar proved to be a popular device, a number of participants and their carers suggested some improvements:

6.2.3 Suggested Improvements

- Bigger text
- Different colour contrast
- Bigger text display area (half the size of calendar)
- More bold in type
- Incorporate a visual clock
- Picture turns to night at night time
- More stages to the day – mid morning; mid afternoon
- Non reflective glass
- Afternoon should be earlier

Respondents tended to cite very similar comments, with the first comment at all stages being the need for bigger text. Many respondents would need to squint at the calendar or pick it up to bring it nearer to them. This also indicated the need for a non reflective glass as commented by many carers. Respondents also commented that the afternoon needed to occur earlier, particularly people in receipt of meals on wheels. One particular participant would receive their meal at 11.30 in the morning and would have finished their dinner by 12.00, and it is this time that represented the beginning of her afternoon.

Both positive comments and suggested improvements highlight the benefits that could be utilised for people with dementia in the future, however, there are some instances where a calendar is not going to prove to have a beneficial outcome, and it is useful to consider case stories in which both negative and positive outcomes prevail:

6.2.4 Case Story I : Mary

Referral

The carer and staff at the day centre have identified Mary as a suitable candidate for the NDC, since she is increasingly disorientating in time and place and is asking repeated questions in the daytime and at night when her carer is trying to relax. Mary lives in a flat/bedsit type accommodation in her daughter's home. Relations between the two have worsened since Mary's cognition has worsened, with the carer trying to provide prompts to Mary who does not wish to openly acknowledge the extent of the disorientation or indeed her memory problem.

Introducing the calendar

Mary was introduced to the calendar at the day centre since the carer and researcher felt it necessary to introduce the calendar to Mary on a one to one basis, so that she is able to decide herself upon its potential benefits. Mary is willing to try out the device, although she is not sure about its potential usefulness as she feels it is difficult to tell without trying it out, but is willing to await events and see.

The calendar is chosen not least because of the problems identified by the carer. In addition, it is the device out of all the devices, which Mary appears to like to try out, and the one, which she can identify, may have a possible use for her.

Carer

The carer is very hopeful that the device can provide a number of solutions, and has answered strongly 'yes, to many of the questions, in particular the negative relations since this is often referred to as a definite consequence, and a hopeful and expected outcome. Mary's carer has responded 'no' to the wander at night questions as Mary has not wandered out of the home, and needed to be brought back, neither is she making repeated calls at night as Mary lives with her daughter. However, she is disorientated, and repeatedly asks questions at night of her carer relating to date, stage of day, which is causing negative relations, especially when the carer needs to remind Mary what the time and stage day is. The carer has identified that Mary does not like to acknowledge as yet the extent to which her memory has deteriorated further, and this is often the root cause of the problem. However, Mary's carer acknowledges that Mary and herself do not always agree, and never have.

Mary

Mary is willing to try the device as she sees it as a quick calendar reference. Her other one is in the kitchen. The device has been placed near Mary, where she is able to see it, and where she is often found resting or watching TV in the evenings. Mary sees her role as someone who is trying out a device and will provide feedback on her thoughts, and states she feels valued if she can do this.

Part of Mary's reluctance to acknowledge a memory problem in a public domain stems from her embarrassment that her daughter has to take care of her needs, and in disagreeing with the amount of help she needs Mary feel she is able to make some decisions, even if they prove to have difficult outcome. Mary is also worried about her memory problem and does not wish to be reminded of it, when her daughter informs her fo the day and date. Mary is clearly sad, unhappy, and angry with her present situation and this is illustrated in the way she expresses herself, and the way she talks about the people who support her. She prefers to be left alone, and has identified " being left alone" as the one thing that makes her happy.

Outcome

Carer has stated that it is difficult to tell whether or not the device has proved useful or even meets potential and listed expectations since there has been disagreement about using the device. On several occasions, Mary has unplugged the calendar as she felt it wasted electricity, however she did not switch it on again in the morning until prompted to do so by the carer. The carer has had to reiterate the purpose of the NDC continually; as such no positive experiences have been reported. Carer has reported that it is " to easy to unplug," and therefore easy to misuse or not use the device.

Carer feels rather stressed, as she needs to spend time in prompting Mary to encourage use. However Mary has remained hopeful and still expects the calendar to have a positive outcome at T3. By T4 the situation had deteriorated to the extent that it required drop – out status. While Mary continued to use the device for some time post T3, negative relations had increased and Mary unplugged the calendar and placed it in a draw on several occasions. Mary has no unplugged the calendar and placed in a location where the carer can no longer find it.

6.2.5 Case Story II: Fran

Referral

A very independent lady, who lives alone, and who tends to her own personal and home care, Fran prefers to live without public and private care assistance, and to carry out many home activities herself to maintain her independence for as long as possible. Fran likes to decide upon her own social activities, in preference of a day centre stating that she is wary of the 'club' type atmosphere, where people sit around in chairs. She would like more social activity in her daily life and reports that she does often feel lonely, although with a good and close relationship with her niece, she feels to some extent that she is supported socially.

More recently, CMHT have observed that Fran has experienced an increase in the amount of times she requires orientation to the stage of day, which has resulted in a number of calls to her niece at night to orientate and to be reminded of the date. Other incidents pertain to lost keys, which were eventually found, and now remain in the door at all times. However, it is the calendar which both Fran and her carer as viewing as being the most potentially useful of all devices to try out.

Fran

Fran openly acknowledges and is able to talk about the use of newspapers to orientate her time which she recognises later are out of date. Fran has agreed to the calendar, as she is concerned about the impact this has upon her niece in the form of frustration, which leads Fran to feel "awful". Fran speaks openly about the effects her memory has on her QOL and she feels others often respond her to negatively as a result: "**Everything I do they say I am doing it wrong, it feels like a put down**" Fran is very keen to assert her independence and is aware that because she experiences memory loss she is reliant on her niece for orientation. Fran views the calendar as a means of enabling her to do that Fran is also very taken with the appearance of the calendar, and her expression is clearly one of delight at the picture.

Carer

The carer states that there has been no incidents she is aware of in which Fran has 'wandered' and fallen or injured herself, although she reports that Fran does visit the bathroom at night and can become disorientated and will make a phone call. There have been no reports where Fran has become disorientated outside the home to the extent she needs assistance by the community or police to bring her home. The carer hopes and expects the calendar to be able to support independence, coping, reduce burden, support memory, and prevent situations with feelings of frustration and hence negative relation. Fran's carer was unsure at the outset whether or not the NDC could in fact reduce the number of calls at night, but hoped it would. In a sense there is some expectation but the strength of the answer does not match that of being able to support memory. Carer hopes that it will improve her own sense of well - being.

Outcome

Fran finds the device very useful, and uses it regularly, she has ensured that it has a place next to her where she sits, and if she needs to go downstairs at night she is orientated towards it, and is able to recognise the stage of day. Fran describes the benefits: “***I wake up and the first thing I do when I go downstairs, is to look at the calendar, and it is then I know what day it is and where I am. I could not tell what day it was before and had to phone my niece all the time, I used to feel awful. I don’t need to ask anyone the date or day anymore, and I have recommended it to friends***”

Fran’s Carer has reported a significant reduction in the number of calls at night related to orientation. Carer is very pleased with the calendar and has asked where she is able to purchase the device (although the amount quoted that she would be willing to pay, is less than at T0). Another outcome is that the carer cites that the level of frustration she usually feels towards her Aunt due to orientation has reduced significantly.

Fran went on to experience significant cognitive decline and was hospitalised with the view to long-term residential care. However, Fran and her carer, for a time at least experienced an increase in their quality of life.

6.2.6 Emerging theme related to the use of the device (hypothesis)

The night and day calendar proves to be a popular device not least since it requires a low level of user participation. It is a device that can be plugged in and left to stand-alone. However, while it provides an opportunity for orientation and enhance the quality of life of the care by reducing calls, it can also be the source of some concern, frustration an even an increase in negative relations. A night and day calendar can mean a device which causes concern, it can ‘waste electricity’. As it is easy to unplug it can be hidden and be unused, and remain of little use as long as one is reminded that the night and day calendar means you have to acknowledge there is a problem in the first instance.

6.3 Locator

Table 10 Characteristics of participants using the locator by time stage (T0 – T3)

	T0 (n= 5)	T2 (n=4)	T3 (n=1)
Gender			
Female	4	3	0
Male	1	1	1
Living situation			
With someone	5	4	1
Alone	0	0	0
MMSE			
15 – 19	1	0	0
20 – 24	3	3	1
25 – 29	1	1	1
Diagnosis			

Alzheimer's	0	0	0
Vascular	2	2	0
F03 unspecified	3	2	1

Six people were identified for locators and provided consent. Participants were referred on the initial frustrations felt by carers in searching for items lost by the person experiencing dementia. Carers reported how they often felt frustrated, anxious in looking for lost items and how this created negative relations in the household.

The locator was seen as the answer to many a wish with the result that expectation were high. Carers reported positively that they expected the locator to reduce a sense of burden, support memory and independence, empower people experiencing dementia so that they would not have to ask for help, thereby aiding a sense of coping with day to day life. Out of an original six, five participants entered into T0 to try out the devices, of these 4 were women, and one male (the male has remained in the study to T3. There is no reported significance between MMSE scores and drop – outs status since all the locators by T2 and T3 had reported faults.

6.3.1 Implementation, maintenance, and technical issues

One participant who provided consent was assigned a drop out status at the T0 interview as the device created negativity between carer and participant, and proved faulty after five minutes of use by the participant, the carer and witnessed by the participant's family, occupational therapist, and researcher.

6.3.2 Comments

All the locator's received at Dementia Voice were tested prior to implementation, with a test involving a testing of each tag over seven times. This test was repeated prior to immediate implementation, with the result that of the 60 tags received 38 were returned for maintenance. The faults were also experienced by participants in the study, in addition to the issues with locator panels; -

Reported faults

- Tag does not emit a sound when the locator panel is pressed
- Tag does not stop ringing after five minutes
- Tag works one time and not the next
- Locator panel does not light up when pressed (even when pressed firmly)
- The tag emitting a sound does not correspond with the number on the locator panel.

6.3.3 Suggested improvements

- Smaller tags to fit on cheque books and glasses
- Louder sound from tags

6.3.4 Case Story I: Sue

Referral

Sue has been referred by her occupational therapist as she is concerned about Sue's sense of frustration and anxiety in losing keys.

Sue

The device is tested, and Sue is willing to try it out. However, she is aware of the sound, but not always sure where it is coming from. In addition, she finds it difficult to press with her thumb on the boxes even when it is quite firm, as the locator does not always emit a sound. The test was not aided by the fact that some tags did not emit a sound even when the corresponding button on the locator was pressed.

After several tries, a sound is emitted from one of the tag, and she tries to search for the missing purse, with prompts from the carer. Sue has become tired and more disinterested after a time, and we agree to rest, and maybe come back to review a week later, after Sue has had time to try the device with the carer and people from the CMHT who call regularly.

Sue's response after being shown how to use the device and try it out has been: "***It is very complex isn't it***".

Carer

Sue's carer is keen to try out the device since a great deal of time is spent assisting her in finding lost items, usually her keys and cheque book. The carer has high expectations that the device will work and be able to facilitate Sue to achieve more independence by reducing reliance on carers when they visit to find items; generate a sense of coping as the memory is supported by orientating the user towards a lost or misplaced item, and in doing so reducing SOME of the emotional stress and worry that the carer feels prior to visiting. Sue's carer identifies the problem as being somewhat important, and the potential of the locator to be somewhat useful. The carer feels it is difficult at this juncture to ascertain with absolute certainty that the locator will be prove as good as she expects and wants it to be, since they have not come across the device before. *To ascertain some answers further without researcher interpretation – carer shown boxes to respond as they wish.*

Outcome

Sue is not pleased with the device at all since it is not working and this has caused anxiety and frustration for Sue and her carer. Sue carer has tried the locator on several occasions and it has failed to operate. Upon testing the locator does not work properly, and it is very hard to press down on the buttons before any sound is emitted.

The button, which is pressed to the tag, which emits a sound, does not correspond. Only one tag is left working out of three, despite new batteries placed immediately prior to installation, and tested on the premises. In addition, the carers have noted that a tag may emit a sound after being pressed firmly on the locator box, but may not do it again, when it is pressed five minutes later.

Sue withdrew at T2.

6.3.5 Case Story II : Larry

Referral

Larry has been referred as a possible candidate for a locator since he is reportedly losing items especially keys. Both Larry and his carer experience a deteriorated health state with eye surgery imminent for Larry, and painful knees and chest from previous events and ill health. Larry's carer experiences some depressive illness – health and is currently undertaking medication for a stress related illness. Both the stress of the illnesses and Larry's memory loss contribute to negative relations, and carer frustration. The locator is being tried as a possible solution to some of the problems experienced by Larry in locating items such as his keys, glasses (never kept in a case) and with the aid of a locator, it is hoped that carer stress will also to some extent be reduced.

Larry

A sociable gentleman, who enjoys company, Larry feels very concerned about his memory loss and worries a great deal about it. He spent the first interview asking many questions about memory loss, and if other people experienced this in society, and if so to what extent? Larry went on to state that he feels isolated in this sense and describes how he feels “*out on a limb*” since his carer does not think he listens, when he has actually forgotten what she has said. This not only causes a great deal of frustration on his carer's part, but also for Larry who at times finds himself defending his position, and trying to convince his carer truly can't remember the immediate past.

Carer

The carer lists all consequences within the schedule as being factors, which pertain to memory loss. She is able to cite incidents where Larry has lost his glasses or keys, and she is often required to intervene and find items. This she states causes her stress, increased irritation, due to the increased time in searching for lost objects, and as a result causes negative relations. There is particular reference to irritation, with recall of conversation that has occurred between Larry and her, and within the interview, with Larry defending his actions, pertaining to memory loss.

The carer has received literature about all the devices, and the locator from the CMHT, and both Larry and his carer are impressed by what they read. The device is tested out with one tag, and the carer feels it is a good idea. In answering to the schedule, she states that she expects to SOME EXTENT that the locator will achieve the outcomes. In the first instance, with initial prompting, the carer expects it to support a feeling of coping by finding lost keys, and therefore reduce the time in locating lost items (supporting memory), support independence since it will reduce the need to ask for assistance, this in turn reduces stress and anxiety, thereby enhancing relations. Particular emphasis is placed upon this sequence of outcome.

Outcome

Larry has been very open to trying the device out, and felt it may be of some use at T0. At T0 Larry did not see much benefit in attaching a tag to his glasses case, since glasses are not often held or found within the case. Larry states that the importance of the problem for him is significant, and that it causes many problems at home, in particular with negative relations. However, the situation is not aided by his carer's ill health, and the stress this places upon their relationship also.

Larry took time to get used to the locator and seemed to react positively towards it. The level of use is limited to once or twice in the space of a few weeks, and usually with the intervention of his carer. His responses state that he has found the space on the pad difficult to press before a sound would emit. Between T3 and T4 Larry has reported using the locator more seldom than once a week, and when this is usually when his carer prompts him. Larry describes his experiences of the locator as frustrating, with a sound emitting from a tag on one occasion, and then not on the next, then sound emitting on the third go. The tags have been changed with the view to BIME having the faulty tags to look at. Larry concluded his experiences of the device: ***“It gives me a headache at times”***

Larry’s carer has used the device more often than Larry, even though they both record more seldom than once a week. Larry is unable to pinpoint the number of times she has used the locator, but states that she uses it more as ***“I don’t see the point in reminding him to use it”*** In addition, the items that is lost more frequently at this juncture are his glasses, and these are never kept with his glasses case.

Larry’s carer has also needed to intervene to test the locator when Larry has indicated it is not working. Larry’s carer informed me of her concerns that they felt awkward and at fault that the device did not work. Not only is this confusing and frustrating for the carer but also for Larry too.

This particular participant has decided to persevere with the locator and decide at T5 whether or not to keep the device. All participants have stated that the locator creates confusion, anxiety, and frustration. Participants have also reported how they have felt embarrassed that they have left the research at a particular stage and would and very much wanted to be a part of the research. In addition, they felt that the locator added to their sense of confusion, and this was distressing.

6. 3.6 Emerging themes: the locator

Clearly, this prompts consideration of the ethical concerns about the implementation of devices in people’s homes that have yet to reach commercial status. Even when devices are introduced as prototypes, the use of literature and carer’s pre Enable experiences of living with dementia means that a carer is hopeful that something or someone can help to alleviate the sense of frustration and helplessness felt with a situation that seems destined to deteriorate further. When literature and prestigious television programmes (Tomorrow’s World) that a locating device can do many things, and provide an answer to several problems, expectations will be high, not only of the locator, but also of the ability of the person with dementia to be able to learn to use and accept the device.

6.4 Lamp

Table 11. Characteristics of participants using the Night Lamp by time stage (T0 – T3)

	T0 (n=5)	T2 (n=2)	T3 (n=3)
Gender			
Female	3	1	1
Male	2	1	1

<i>Living situation</i>			
With someone	2	1	1
Alone	3	1	1
<hr/>			
MMSE			
15 – 19	3	0	0
20 – 24	2	2	2
25 – 29	0	0	0
<hr/>			
Diagnosis			
Alzheimer's	1	0	0
Vascular	2	1	1
F03 unspecified	2	1	1
<hr/>			
-			

Five participants were identified for the night lamp, two of who lived with their carers, and one of which passed away at T1. A further two participants received drop out status by T1 due to faults experienced with the lamps. One participant has remained in the study, to use a night lamp that comes on automatically but does not switch off. Despite this technical difficulty, the carer has found it useful.

6.4.1 Implementation, maintenance, and technical issues

Several technical difficulties were presented with the night lamp, the first of which was that the lamp would not switch off automatically. For participants dropping out by T1 and by T3 this caused some confusion and frustration. A great deal of time had been spent in switching lamps around, and trying to find lamps in the house that would match the night lamp for the other side of the bed. Once the lamp had been installed, the lamps created more problems for people living alone, than the participant living with a full time carer. For particular participant, the lamp was removed because of issues of safety. When one particular participant got up at night to visit the bathroom, the pads attached to the night lamp and which were fitted under the bed, slipped against the carpet, creating movement in the bed, which resulted in a fall. This did discourage the referral of other participants to the study by the occupational therapist for that area.

6.4.2 Comments

These are provided by case study II.

6.4.3 Suggested Improvements

- **The lamp is able to switch off**
- **That the pads (calibrators) do not slide or roll off casters**

While the lamp has not been fully operational in all cases, it has provided both negative and positive outcomes: -

6.4.4 Case Story I: Andy

Andy has been referred with the view to receiving a night lamp as his carer is concerned that he may, in the near future experience injury since he gets up at night to visit the bathroom several times, and the light is not switched on to orientate him to the bathroom.

His carer lives a few miles away, and spends significant time during the day with him, while carrying out her business (from home)

Andy

Andy presents as a quite gentleman who enjoys his independence while being supported by family and support services. An active bell ringer in the local parish, he takes pride in the social aspect of an activity, which gives him a great deal of happiness. Andy is very keen to try the light; ***“if it works it should be OK and help, and save me the bother of having to find the switch. I have twisted around a few times to find the light in the night and don’t know where I am”***

Carer

Carer spends a great deal of time in the day with her Father running her business from his home. Her main concerns pertain to the risk of falling, as she is aware through Andy that he has difficulty switching the light on at night to visit the bathroom. She feels that he does not wander in the sense that he is able to return back to bed, even if it means going to another part of the house to make a cup of tea before returning to bed. The carer does have the expectation after hearing of what the lamp is able to do, that it will be able to support Andy in a number of ways, with particular emphasis upon support in dark environments.

Outcome

Andy finds the night lamp aesthetically pleasing, and is keen to try the lamp at T0. His spirits are dampened somewhat by the fact that the lamp does not operate properly at the first juncture despite attempts by the therapist and researcher. KJ returns another day to install with another lamp. Although this lamp does not switch off, Andy is content to have the lamp since it will light up as he leaves the bed, and is assured an engineer has been notified to visit him and to look at the lamp.

At T2 the lamp comes on but is not able to switch off, Andy is willing to persevere as he is aware the engineer could be with him any day now. The lamp has also meant some sleepless nights, as it has not automatically switched off. Andy would like to persevere, although faith in its ability to meet expectations is waning.

Between T2 and T3 the researcher has contacted and provided reports of Andy’s use of the device to engineers with the view to observing the lamp at some stage in the home for repair. At T3 the engineer is able to visit. After speaking with Andy at length, he would like the device removed as he is fed – up and has had enough.

The engineer explained that the sensors that are being used for the lamps at present are unsuitably calibrated, and there has not been enough time within the project to allow for changes. For Andy even if there were, it could have meant that he would never have the opportunity for a lamp given the deteriorative nature of dementia, and the possibility that he would not have a new lamp until after several months of waiting.

6.4. 5 Case Story II: Rula

Reason for referral

Rula has been referred by the CMHT who forwarded literature on the night lamp and Enable devices to Rula and her carer. Rula had experienced fall a month ago, as she went to the bathroom. Rula's carer noted that she often went to the bathroom at night but that there was no light under the door to indicate that she had switched on the lamp. When asked, Rula stated that she often forgets to switch on the lamp, and is often eager to go to the bathroom more than anything else. Since the fall, Rula's carer has become very concerned at the potential for another fall and is unable to sleep as well as she could since she is listening out for Rula to go to the bathroom, in case she falls again. Rula was also somewhat shocked by the fall, and it limited her ability to be more independent for a while, a situation both Rula and her carer are keen to avoid if possible, knowing how important it is for Rula to be able to feel she can cope without carer intervention or questions about potential need for respite.

Carer

Rula's carer has read the literature and is very impressed by what the night lamp is able to do, she has spoken with Rula about it and they are both very keen to try it out.

The consequences of falling are such that Rula's carer feels that the lamp can meet their needs by providing orientation and reducing falls, and with the lamp switching off at night, Rula's carer expects to achieve more sleep and less anxiety and stress. The carer's expectations are high. Rula's carer has also provided more insight into her expectations with the following quotes: ***" It will help me to feel more settled in my sleep " and I think it is good to be proactive about this than reactive"***

Outcome

Rula reports that the lamp it is useful as she is able to see where she is going at night, and she does not have to worry about switching the lamp on. However Rula feels that it would be useful if it would also switch off as she now wakes up earlier in the morning due to the light from the lamp. Rula's carer provides an account of the situation: ***" Over the past two weeks the night lamp became more and more sensitive to weight and completely stopped working."*** Despite this outcome, Rula's carer is very positive about the lamp: ***"As a health aid I appreciate it and would like to persevere, since as a tool to facilitate independence it's a brilliant innovation."*** The carer's hope that it is fully operational is illustrated by her comment: - ***" If it works its invaluable, the mere fact that I can depend on the light coming on has made me feel a lot easier"***

Between T2 and T3 the engineer was able to visit, and conclude that it would not be possible to obtain the correct parts to ensure that the lamp would switch within the time frame of the Enable project. Rula's carer has both positive and negative comments in relation to the night lamp: ***" The light has been an aid to me, but since my Mum had her TIA it became a burden as I was more anxious and checking if it was working, as it would not switch off. I was worried about her safety and worried that the light would not come on, so I spent time making sure it was working, and I was not confident in the apparatus at all"***

By T4: -

" It is very valuable to us. Mum always switches it off now as it is a visual reminder. However, lately she states in bed as she is sleeping more, so when I get up for the day I can just check" However, Rula's is concerned over some safety issues related to

the lamp without an automatic switch off facility.: - ***“Mam has to stretch and expand her hand to switch it off which is not easy. For safety reasons and because you have to use two hands to reach across it may mean that you will roll off the bed”***

Rula’s carer has provided a variety of positive, negative, and neutral feedback with insight to the potential benefits of the lamp and the times when the lamp itself has proved to be a burden. On occasion the lamp has not worked at all, and Rula’s carer has found it frustrating in waiting between the time in reporting the device and not receiving a call or a visit for several weeks or more. Rula and her carer have consented that they will keep the lamp. Although it does not switch off, they view it as “a sort of trade off” between keeping a device because it is valuable when it works, to that of having to spend the time and some anxiety in ensuring it works, and actually wondering whether it will or not.

6.4. 6 Emerging themes: the lamp

It is difficult to make any generalisations about the lamp since it is a device that has not been fully functioning. As with the locator, the fact that the night lamp is not fully operational means that it is a source of frustration, anxiety, and at times creates extra burden. This highlights ethical concerns in providing prototypes to people with dementia in their homes, with the view that they are expected and are able to cope. It takes the perseverance of a carer for acceptance of a device by household, which has further implications for the distribution of devices to people with dementia by household type.

6.5 Cooker Monitor

Table 12. Characteristics of participants using cooker monitor by time stage (T0 – T2)

	T0 (n= 3)	T2 (n=3)
<i>Gender</i>		
Female	2	3
Male	1	1
<i>Living situation</i>		
With someone	1	1
Alone	2	2
<i>MMSE</i>		
15 – 19	2	2
20 – 24	1	1
25 – 29	0	0
<i>Diagnosis</i>		
Alzheimer’s	1	1
Vascular	2	2
F03 unspecified	0	0

Interest in the cooker monitors stemmed initially from health and social care professionals and the carer's themselves with people experiencing dementia, the lat in the line of people to provide an indication of their interest. Initially, CMHT's referred individuals who tended to live alone and who were increasingly becoming a fire risk, and a case for residential care. Of the three respondents' who lived alone, only one received home help. The two remaining participants, who loved alone, received daily visits and assistance from friends, neighbours, and family and could therefore be observed unobtrusively.

6.5.1 Implementation, maintenance, and technical issues

Of all the devices, the cooker monitors did not achieve T3 status for any participants. Pre T0 there were a significant number of referrals that were not able to receive heat sensors since the cooker was not suitable. This meant that ethical approval through committees had to be sought and this took three months. By this stage, several other problems occurred with the monitors and therefore the three remaining respondents who had provided consent could not participate in the study, until the problem with the monitors was resolved. As the problem could not be resolved beyond recruitment deadline, one participant could not participate in the research. The three remaining participant's each experienced problems with the monitors. Two participants were unable to use the cooker and had to rely on carer's coming in with meals as the monitor was too sensitive and the cooker would shut down. One carer used the cooker stated how they often became frustrated by the sensitivity of the monitor when attempting to cook. After one minute of moderate heat the cooker knob would turn off, which meant that the carer had to hold on to the knob itself when cooking. After reporting the fault, the carer switched the cooker monitor system off.

6.5.2 Comment

It is difficult to determine a positive outcome for the cooker monitor since they knobs failed to work. However, the referral system did highlight a definite need. Where knobs were very sensitive, the cooker monitor was able to shut down, and reduce fire risk, whilst at the same time causing frustration for the person and their carer.

One case story is used here to illustrate an outcome that is reflective of all participants' experiences: -

6.5.3 Case Story: I Lara

Reason for referral

Referred by CMHT with a diagnosis of dementia (F03 unspecified since the notes are with another department, and will come back with a more specific diagnosis if there is one.), Lara was considered a suitable candidate as she regularly cooks the meals for the household including roast dinners, and recently her carer has reported that when he is absent from the home, he has returned to discover on several occasions that the gas has been left on without Lara realising.

Lara

Lara presents as an independent lady who takes a great deal of pride in her abilities to carry out activities within the home, independently. Lara does not welcome being re-

mindful by her a carer that she leaves the gas on, and does challenge his assertions that she does. Lara is uncomfortable with this as we focus on what she is doing and is able to do, as opposed to what she no longer does. Lara informs that she has always kept home has brought up a large family, that have done well for themselves. Lara prides herself on her ability to carry out all home activities without need for outside intervention or assistance. She appreciates her memory is affected in the short term, but is eager to carry out all the activities she is able to prove she is able to cope despite the memory loss. Lara prefers to acknowledge issues of memory loss, which relate to her when referred to in a supportive context which also focuses on her abilities in relation to past and present achievements.

Carer

The carer is very keen to try out the device, and being an engineer himself is shown how it works, where the wiring is and what it is for. He is impressed by the potential use of the monitor and having spoken with the engineers and studied the literature, has high expectations of the cooker. Having seen the device work, he feels that the cooker will be able to alleviate some of the consequences with immediate effect – namely fire, stress, and anxiety, and the need for assistance from himself or a neighbour.

With feelings of worry and more visits by the carer to check that all is well, he feels that the cooker can aid in supporting independence as there will be less ‘interference’ (carer’s words) from him if things switch off, that it will reduce harm, and therefore reduce general emotional burden. All expected outcomes were listed with the same intensity in answer. The carer views the problem as highly significant and has high expectations of the cooker: **“willing to try anything”** This contrasts directly with Lara’s interpretation of usefulness, which is cited as somewhat useful. However, Lara watched the cooker monitor with some interest, but not the same enthusiasm as her carer.

Outcome

At T2 Lara attempted to cook a roast dinner. However, the heat from the oven kept on switching the cooker knobs off which were cooking the vegetables and the gravy. In the end they had to leave the meat and potatoes to cook in the oven, on a very low heat, and try and cook the vegetables in the microwave. Dinner was delayed significantly, and the dinner was not to the standard they usually enjoy. Both Lara and her husband found the experience very frustrating and Lara found it particularly distressing, and switched the cooker monitor off. The engineers have been contacted and will fit a plate guard to try and lessen the impact of the heat from the oven. At present there are wires hanging out above the cooker, and which belong to the cooker monitor. The engineers have been contacted on several occasions to rectify the problem, and have informed Lara’s carer how to disable the cooker monitor.

Lara does not feel it has been useful and is very frustrated by the outcome of the dinner incident, it has reduced her confidence in cooking with the device, and using the cooker normally since it generated negative reactions. Lara feels it is impossible to use the cooker monitor since it is too sensitive when used with an oven or grill. Even when the hobs are used independently of the oven and grill, they still are very sensitive and will switch themselves off.

At this stage, the carer has been instructed to take the wires out of the cooker monitor (by phone) by the engineers. Lara’s carer echoes the same frustration as Lara and that the monitor was also disruptive. He further comments: **“It is so frustrating as it kept being sensitive and would shut down so I shut it all off and used it as normal. There are wires everywhere, I hope it doesn’t stay like that, I have phoned and told them (en-**

gineers) there are wires everywhere, and I hope it doesn't stay like that, we are still waiting"

Several months had passed and the problem had not been rectified, this meant a drop out status due to the time length of a device not being operational and also because it went beyond deadline.

6.5.4 Emerging themes: the cooker monitor

Ethical dilemmas were presented in health and safety was posed for this particular case. With advice given to carers to handle wires. In addition, feelings of frustration have been created (carer information) in waiting for the problem to be rectified by engineers, after having made a phone call. While the carer recognises that the cooker monitor is a device, and is not commercially available he has stayed with the research in order to see an effective outcome. However, this was not a view shared by Lara whose experience has been frustration, distress, and annoyance at a device, which meant extra work, for an activity she is using to prove to others she is a capable individual.

6.6 Emerging themes for all devices

The level of use and usefulness of the devices used by participants who are left in England at T3 is indicative of the problems experienced by devices, and to the level of morbidity attributable to cognitive decline leading to residential care and hospitalization. By T3 there are no cooker monitor respondent's that can be reported upon. Between T2 and T3 the locators and the night lights experienced further drop – outs leaving only one per device. The night and day calendar remains the most popular device, and has sustained with no problems or faults experienced by these participants.

7. Ethical Issues

Of central to concern, to the study in England is the issue raised in providing prototypes to people with dementia and their carers. Expectations and hopes were often high in the beginning with literature and visual aids highlighting positive potential benefits. Health professionals would feel disappointed and reduce the level of referrals, carer's would aim to persevere but at times feel burdened, and people experiencing dementia could at times experience more confusion, frustration which led to increased levels of distress. This is clearly an ethical dilemma. An explanation that the devices are prototypes is insufficient, especially in cases where people live alone, and do not have the same opportunity to voice their concern that device does not work. In some cases, people often felt too embarrassed to report a fault and waited until the researcher discovered the problem. The length of time in waiting for a device to be repaired led to significant drop – out and disappointment in the household. Clear guidelines are recommended about the implementation of prototypes in homes by type (living alone; living with someone).

An increasing challenge to any research with people with dementia in England pertains to application for ethical approval. It is no longer sufficient to act independently as a research organisation, to do so means to exist outside a system that takes a year to obtain ethical approval. This also has an impact on how consent is achieved, given the ethical committee's emphasis upon formal language used in providing pages and pages of literature to people with dementia. For Enable, the process was about involving the person in providing consent of asking their views, listening to and hearing about their needs, and al-

lowing them to decide what is appropriate for them. This could prove difficult if a person felt pressured by a health care professional or their carer, and felt obliged to take the device due to experiences of guilt and carer burden. The approach was to ensure initial consent involved respondents being open to being asked for consent, and to enable them to raise any issues or concerns. The central factor in the English assessment was that consent was ongoing, and not dependent solely upon the views and needs of carer's and health professionals.

8. Discussion: Emerging Themes

8.1.1 User

Assessing the extent of use and usefulness of devices was difficult for several reasons. Firstly, the sample size by T3 was small. This was greatly affected by the type of devices tried by participants. Out of the four types of devices tried in England (night and day calendar, night lamp, locator, and cooker monitor), only one was fully operational. The night lamp and locator have resulted in dropouts to the extent that only participant remains n each to T3. The cooker monitor has resulted in full drop out. This has meant that the number of dropouts as a result of faulty devices is large for this sample. This coincides with the real fact that there exists significant morbidity in dementia research with participants leaving the research due to cognitive decline, hospitalisation, and entry to long-term residential care.

8.1.2 Carer

Comprising the more enthusiastic participants, carers were often more willing to persevere with a device and placed a great deal of faith and expectation in the ability of the device to provide a number of solutions. Where devices did not function accordingly, carers too became frustrated by the three month stage, and would opt out. A significant reason for drop out was the frustration created by waiting for repairs for devices.

8.1.3 Product

The products themselves produced both positive and negative outcomes with participants and carers identifying key issues pertaining to the feasibility for the devices in their homes. Significant factor was the ability of a device to operate as originally intended. Participants, their carers and the health professional who had referred their client to Enable were often disappointed when their expectations of a device as noted in Enable literature failed to produce a satisfactory outcome for the person using the device, because it did not operate appropriately. This occurred for the locator and the cooker monitor, which resulted in full drop – out, and for the night lamp with one remaining participant. This has served to impact upon recruitment, and upon subsequent devices chosen, and a greater demand for the devices that work – the night and day calendar.

8.1.4 Environment

The aesthetic properties of specific devices had an impact upon acceptability to some extent. The night and day calendars were easily acceptable and welcomed not least because the picture of the flower on the front impressed participants. The frame enhanced the calendar and was a device, which could be plugged in and left alone. Participants commented about the ease of the device, and how it fitted in with the environment. The cooker monitor was easily accepted because it tended to match the cooker. However, in

many cases a heat sensor could not be fitted since most people made the most of the space in their kitchens, which meant no space to fit the heat sensor. The night lamps were accepted if they matched the colour of the room, and were approximately the same size as other lights in the room. The locator was an item that often found its place in the kitchen as it was seen as a gadget to be placed alongside other electrical items such as the toaster or the kettle.

8.1.5 Researcher

As part of an organisation whose focus is to inform about person centred care practises, interviews and the way in which tools were utilised focused upon the utilisation of a person centred approach. This meant that the person who is the person with dementia was the central person in the interview. Therefore how they felt that day, at that time guided the research. It was about taking the research to the person with dementia, and not expecting the person to be moulded by the research. Emphasis was placed upon their well – being which meant that in eliciting information, on – going consent was sought and a positive questioning approach was adopted at the end of the interview to ensure participants were left with a sense of well – being. Strains were felt in meeting the needs of Enable and following the format of the questionnaires to that of the researcher's 17 years experience in residential social work, and 8 years research background in the field to that of the needs of the person with dementia. The UK researcher concluded that in order to provide reliable and valid information about the devices for people with dementia, then it is the person who needs to speak, and empowered in a way that allows them to be listened to and truly heard.

8.1.9 Can technology help people with dementia?

England Enable is able to comment on the night and day calendar since it was a device that was fully operational. Other devices did not aid the participant and created anxiety and distress in some cases. The night and day calendar as a technological aid to people with dementia can prove to have a positive outcome. Carer's in many cases have found it valuable in terms of enhancing the quality of life for themselves and their relative experiencing dementia. In this context people not only feel more orientated to the date and the day, but also good since the need to ask carer's about the date and day is reduced. Phone calls and repeated comments are reduced leading to a greater sense of well – being for the carer, and the participant.

8.2.1 Experience with the protocol and questionnaires

Face to face interviews provided a valuable resource for information to be recorded and non-verbal expression and communication to be observed. However, the questionnaire schedules used for the interview were long, in particular the T0, with respondent's concentration diminishing by the time the Brod scale was reached. Not every participant was open to being tested to use the Brod scale for several reasons - a restless night, feelings of ill – being on the day, or nervousness about tests in general. In addition, the respondent's that were not able to answer the test questions often felt disappointed with themselves despite reassurances from the researcher. This highlights the ethical dilemmas posed in developing methodology and defining research tools to suit the person and not the research itself. There were positive outcomes in incorporating the Brod, since it was used to open up discussion and lead to the themes in schedule II. Perhaps other inclusion criteria can be used to assess people's suitability to the Brod scale on the day itself

in the future, since many people were open to discussing many of the themes and felt listened to and heard. The carer's scale proved beneficial and efficient to use, particularly in use in telephone interviews with carers who worked.

The cost benefit questions were difficult to determine an answer for in several cases. Carers were asked and shown expectation variables, and what the device was being used to help with. This could have benefited from a sliding scale of expectations in which the carer can be asked if they expect a device to a **little extent, to some extent, or a great extent** to achieve a particular outcome. Several carers also reported that it was difficult to determine an expectation when a device had not been tested. As such, many carers felt that the literature spoke for itself, and this was the information often used to cite an expectation.

8.2.2 Recommendations for future assessment studies

Devices need to be fully operational if future assessment studies are to elicit information from people with dementia. The research tools themselves need to be more flexible and take into account the changing needs of people experiencing dementia. Other tools could be adopted such as participant observation, and person focused interview styles, which allow the person to speak for himself or herself in an open ended style format.

In England many people who are aged 65 years and above live alone, with no family nearby or who have very little contact with their sons, daughter's or other family members. This meant that the protocol excluded people who may otherwise have benefited from receiving devices. In future home helps and health and social care professionals themselves could act as the 'carer'.

9. Conclusion

9.1 Facilitating Independence and Promoting Well - Being

Enable provides evidence that positive and negative outcomes of the use and usefulness of a device is mainly dependent upon whether or not a device is fully operational. The night-light, the locator, and the cooker monitor have each clearly illustrated how they are not useful. In cases where devices are, it is obvious that the night and day calendar, the only device in the English assessment to be fully operational has evoked numerous positive responses. An increase in the quality of life, the fact that the device is being used, and looked at, and can evoke a sense of empowerment for the individual all serve to lead to a positive outcome.

The fact that the night and day calendar is a device that does not require the active participation of the person with dementia, also has a significant impact on use. The locator, the night lamp, and the cooker monitor required significant involvement of the person and their ability to adapt to new devices in the home.

For all participants, it has been imperative to value their contribution to the English assessment study; in particular those respondent's who felt guilty about returning the devices. B The consent process and the particular approach adopted meant that people could voice an opinion, a need, and be listened to and heard.