



Enabling Technologies for People with Dementia

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National report on results from Lithuania

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ABBREVIATIONS USED

AT	Assistive Technology
DQoI	Brod Dementia Quality of Life Scale
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
ICD-10	International Disease Classification, 10 th version
MMSE	Mini Mental Status Examination
PADL	Primary Activities of Daily Living
PWD	Person with dementia
WP	Work package
WRC	Work Research Centre (Ireland)

1. Introduction

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.

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, Ireland, Finland, Norway and Lithuania**, with the overall objective of 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.

Lithuania joined ENABLE project later, in March of 2003.

This report is based on the results from the Lithuanian assessment trial, which took place from end of March 2003 and will last till August 2004. Data are collected from 12 persons with dementia and 12 family carers. Persons with dementia, living in their own home, tested each one of the ENABLE products for up till one year.

In a national level our aim was to test each one of the three ENABLE products and to find out how motivated people with dementia and their carers were to try and to use stand alone products which could support their every day life, and whether the motivation and usefulness were associated to the aim of the design of the product.

The Lithuanian Bioethics Committee has approved the trial. Recruitment of the patients had been conducted through Primary Mental Health Care Centres in Kaunas city and a consultation office on Memory impairment in Kaunas 2nd Clinical Hospital. One researcher has been involved in doing interviews and collection of data.

Lithuanian medicosocial context of ENABLE

Lithuania has a small population of 3.5 millions. At the beginning of 2002 Lithuania counted over 494 000 **elderly people** (65 years and older), who made up 14.2% of the total population of the Republic. People older than 75 years old make up 5.2% of the total population. According to projections reaching to 2020 made by the Department of Statistics the number of older people will increase, and the population will age quickly. Retirement age gradually will be reached to be 60 for women and 62, 5 for men. Average life expectancy (based on 1996 data) is 76, 1 for women and 65 for men.

The prevalence of **dementia** is estimated to 4, 5% in the age group 65 - 79 years old, and 20% in the age group 80 years and older. This means that there are about 33.500 people suffering from dementia in Lithuania today (Ott et al., The Rotterdam study)

Care for the elderly at the primary level includes GP's and community nurses. Domiciliary support includes home help to small percentage of the elderly. Non-governmental organizations provide some home help and run few day centres. At the secondary level, general medicine, surgery, general psychiatry and other medical care is available to all older people. Tertiary level (2 hospitals in the country) provides highly specialized care (e.g. neurosurgery, cardio surgery etc).

There is a recognized dearth in Lithuania **dementia services**. Few services exist that are dedicated specifically to the care of people with dementia. Diagnosis and assessment of people with dementia are performed by the specialists (neurologists, psychiatrists, geriatricians) at the "secondary" or "tertiary" services from the referrals by general practitioners or other specialists. When diagnosis of dementia is confirmed, specific treatment is available. If the patients are followed-up by psychiatrist in a Primary Mental Health Care Centre which exist in every district patients are able to get support by team consisting of psychiatric district nurse, social worker and psychiatrist. Mainly (~95%) demented persons are cared for at home by their relatives. Home-based social services are very limited for the elderly. Respite care and institutional care is provided by the Nursing Hospitals. Those who are alone and need permanent social and medical care are accommodated in psycho neurological houses, which are populated with all groups of age. The elderly makes up approximately 20% from total number of residents in care institutions for mentally disabled. There are no exact data how many of them are with acquired cognitive impairment. Care institutions for disabled are institutions of social services where disabled people can live for a longer time or permanently when they need constant care, nursing and medical service and are not able to live at home independently.

There are five self-support groups of relatives whose family members suffer from dementia in the country, but they lack formal support, information, education on dementia. There are no day-care centres for demented people, neither a Memory Clinic.

Other important feature that services are more limited to the families living in rural areas.

At present, **technology-related services** for people with dementia are not well developed. Housing adaptation for private houses might be done by private family' initiative. In general, the focus of housing adaptation has been on structural adjustments, such as ramps, accessible bathrooms, extensions and so on rather than on the installation of assistive technology. Assistive technologies usually mean technical aids to help with mobility problems, re-education of balance and handling and transfer.

An 'AT service' per se does not exist in Lithuania. Assistive technology tends not to be used in practice with people with dementia in the community. More common technical aids are walking aids and aids for daily living, such as bathroom aids. To obtain AT, typically carers or relatives contact their GP or social worker.

2. Aim of the project

The **overall objective** of ENABLE is to investigate whether it is possible to facilitate independent living of people with dementia and to promote their well-being through access to enabling technological systems and products.

Key scientific and technological objectives are to:

- Develop prototypes and provide a test series of products that aim to enable the person to keep him/herself occupied with activities which give pleasure, support memory or facilitate communication, and to adapt and validate products that are commercially available
- Develop a methodology for assessment and analysis of effects of products aimed to enable people with dementia living in their own home.
- Develop an approach towards cost/benefit analysis and make preliminary estimations based on the experience of users and carers.
- Examine whether such products can enable people with dementia and support their well-being by giving positive experiences, reducing worries and unrest, and reducing the burden on carers.
- Disseminate knowledge to people with dementia, their carers and organizations as well as to health and social care service systems and industry about the potential of enabling products.
- Make an overview of the problems and needs which each of the products aim to solve or reduce, both for the person with dementia, for their carers and for the society.

The expected achievements of the project include:

- Test series of new technological products with documented effects and commercial possibilities
- New insight about how to involve users with dementia and their carers in product development and assessment, in line with ethical principles to maintain their dignity and respect.
- New knowledge about effects on users and carers of specific technologies that aim to further enable people with dementia. This includes knowledge about factors, which facilitate and promote positive effects, as well as the opposite.
- New knowledge of costs and benefits of enabling technologies for people with dementia both at micro and macro level based on empirical evidence.
- Raised awareness among different actors in the society about dementia and the potential of enabling technology
- Commercial possibilities created for products developed which are found to be useful and cost/effective.

The explicit **aims** for work package 4 (WP4) were as follows:

- To examine whether the products provided can mitigate or solve certain practical problems in carrying out daily tasks for persons with dementia living in their own home
- To examine whether the mitigation or solving of these practical problems may have further impact on supporting independent living on the well-being of the persons, and reduce the burden on their carers.
- To examine whether the products provided yield socio-economic costs and benefits.

3. Enable

Dementia such as Alzheimer's disease is a type of brain disorder characterized 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). 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 emphasize 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.

Products in the project

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 Lithuania it was decided to test two of the newly developed products:

- **A locator for lost objects** (keys, purse etc);
- **An electronic “Night and Day” calendar** to enable time orientation.

The product that was developed in the project was:

- **A gas cooker monitor** to prevent incidents due to forgotten pans.

An automatic night lamp, multimedia “Do-it-yourself” Picture Gramophone, bath water level control and remote day planner were not assessed in Lithuania.

A multimedia “Do-it-yourself” Picture Gramophone was not selected for the assessment due to lack of the day centres for people with dementia in the country. An automatic Night lamp to prevent falls at night, a medicine reminder “Careousel”, which gives a sound when it is time for medication, and 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 were not selected for assessment due to lack of resources and possible recruitment problems. Also the bath water level control device would require plumbing, and water pipes of a different standard than the Lithuanian. This could mean that the implementation would take time and cost more money than budgeted.

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). 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. 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. 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 daytime or nighttime 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 nursing 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 turn 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

ENABLE Lithuanian report on assessment trial

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 Lithuania

Night and day calendar

Basic functioning

Disorientation for time is common among people with dementia. Also, some people mistake night for day and *vice versa*. The aim of the Night-and-Day calendar is to:

- Enable people with dementia to find out whether it is day or night;
- Reduce the risk that the people with dementia go out in the middle of the night and get lost;
- Avoid that people with dementia call family members or others in the middle of the night and wake them up - unless they need help;
- Help people with dementia with time orientation.

The Night-and-Day calendar consists of an LCD display, which shows day, date and “Morning” (“Rytas” in Lithuanian), “Afternoon” (“Diena” in Lithuanian), “Evening” (“Vakaras” in Lithuanian) or “Night” (“Naktis” in Lithuanian), as appropriate. At midnight, day and date shifts automatically, and similarly, the time of the day shifts from Night to Morning at 7 a.m., to Afternoon at 12 noon, to Evening at 6 p.m. and to Night at 11 p.m. It is connected to the mains. The text will disappear in case of power failure, but will reappear when the current is turned on.

Technical details

Development of the Night and Day calendar is based on the software of the Forget-me-not™ calendar, which has been on the market since 1998. A new microprocessor (PIC16 627) has been used, and the software modified according to the new functions specified. A revised circuit card has been designed. Day, date and time of the day are shown in the respective (in our project – Lithuanian) language on a LCD display of 4x20 characters, according to the specifications given by the leaders of the WP4.1-4.4. The Night and Day calendar prototypes were fit into a commercially available picture frame, except for the use of a specially constructed encapsulation on the backside. It can be placed on the wall, on a table etc. where it easily attracts the user's attention. A picture, personal or other can be put into the frame.



Picture 1. Night and day calendar adapted for Lithuanian language

Locator for lost objects

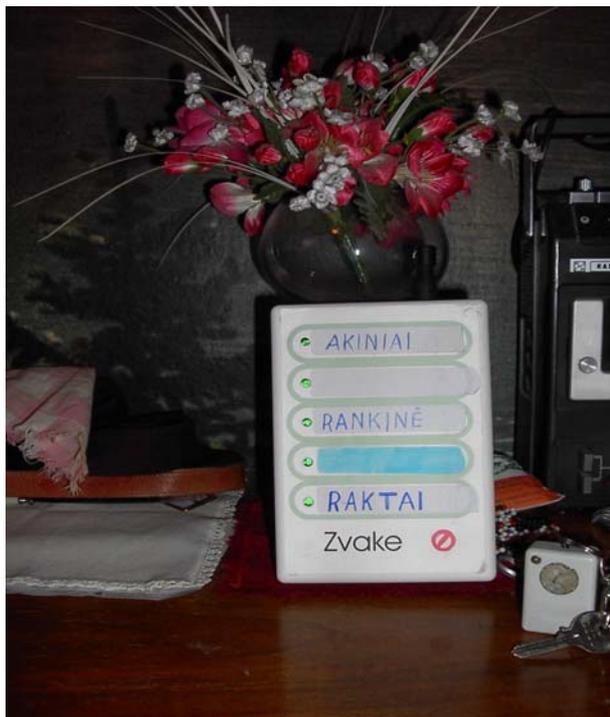
Basic functioning

The locator device is aimed at enabling people who have mislaid objects in their homes to locate them. It also enables carers to locate objects that have been mislaid by the person they are caring for. The device has a series of touch panels on the front onto which can be stuck pictures of objects to be located. When the user touches the picture they initiate a noise from tags attached to the lost object so that it can be found. The device is not yet commercially available but it is hoped it will be by early 2003.

Technical details

The device can be placed on a horizontal surface or be wall-mounted, and requires plugging into the mains. It has space for five objects to be pictured on the front panel together with a cancel button. The touch panels simply need to be touched by the user to initiate a search, and a light appears within the panel to indicate that it is signalling. Each object to be found has a tag connected to it or inserted in it. The tag detects that it is being called by the panel unit and initiates the sound. If it is picked up it will stop. Users can cancel the sound on the panel if they wish by touching the cancel sign, and it will stop anyway after 5 minutes. The unit generates a coded radio signal that is picked up by the tags. The tags check every two seconds to see if they are being called but go into sleep mode in between to conserve their batteries. The unit has a range that is suitable for a domestic dwelling. Battery life is about 5 months. The tags can be mounted on key rings, pension books etc, or put inside purses, glasses cases etc. The sound has been developed to be two-toned. A pure tone is provided at the

resonant frequency of the sounder to maximize output. In addition a brief burst of pseudo white noise is provided as this has been shown by other workers to be easier to locate.



Picture 2. Locator for lost items adapted for Lithuanian language

Gas cooker monitor

To forget to turn off the cooker may cause burning of food and pans, and in some cases, fire. Cooker alarms which turn 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.

Basic functioning

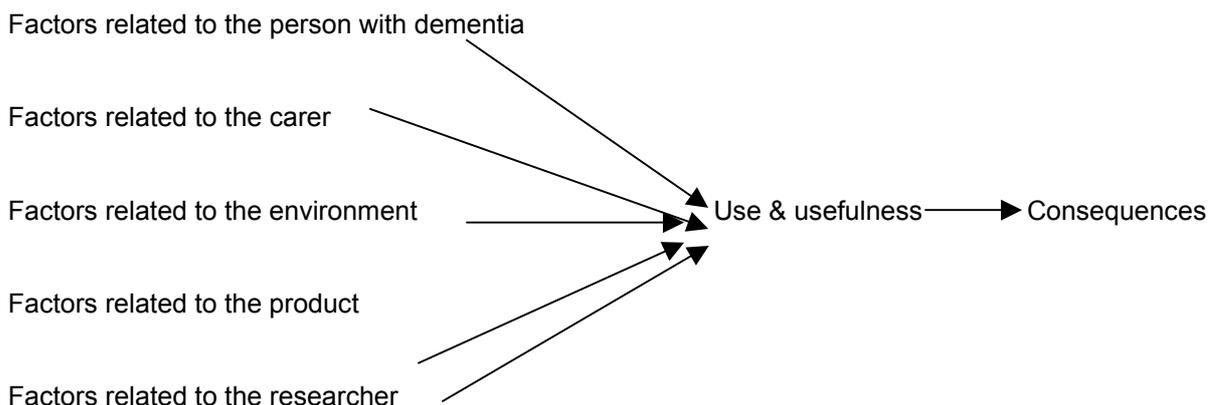
A cooker, which the user can operate as usual, is fitted with sensors, which detect pan overheating. The cooker is turned off in a manner, which enables the user to subsequently carry on using the cooker without outside help being necessary. Expected effect is to prevent fire or food being burnt due to overheating because the user has forgot to turn off the cooker. Reduce worries.

4. Methodology

4.1. Hypothesis and 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.

Figure 1: Factors related to use and usefulness



Factors related to the patient include the stage of the disease, cognitive functioning, nature of and degree of the problems, duration, ethnicity, personality/attitudes, and 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

4.2. Ethical procedures: applying to committee

In Lithuania, an application with all required documents (ENABLE protocol, the questionnaires, time schedule, information letter, informed consent forms, form for the ethical assessment of biomedical, CVs if investigators, pictures of the products etc., in English as well where available and requested) was delivered to the Regional Biomedical Research Ethics Committee in Kaunas. The Lithuanian Bioethics Committee mandated to issue approval to the Regional Biomedical Research Ethics Committee. Project coordinator participated in the meeting of Regional Biomedical Research Ethics Committee in Kaunas.

4.3. Recruitment

The ethical approval for the field study was received from Lithuanian Ethical Committee in the end of March 2003. The recruitment was started immediately after that. People were recruited in one town – Kaunas, through Primary Mental Health Care Centres in Kaunas and through the Consultation Office on Memory Impairment in Kaunas 2nd Clinical Hospital. The staffs at these institutions were asked to identify potential subjects satisfying the project's entrance criteria. The aim was to enrol twelve persons and twelve carers in the ENABLE project. The researcher called to make an appointment for the user need analysis and for the first home visit (T0). The same researcher followed the respondents through the whole interview process. Interview guides for the four interviews (T0, T2, T3 and T4) made for the whole project and translated into Lithuanian, were used. A standard letter was given to potential participants giving information about the project and asking them to indicate to the research team their interest in being involved. The consent procedure developed as part of the study protocol was followed. Family caregivers were also asked for consent and they were interviewed according to the same time schedule about their impression of the feasibility on the person with dementia as well as effects on their own situation.

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.

Additionally to criteria for inclusion and exclusion there were made inclusion and exclusion criteria for each of the products to be tested. For example a person who wanted to test the night and day calendar must have the need for time of day orientation, not only day and date! It was imperative in the user needs analysis to identify the most important need. Often a person might need several devices, however, only one ENABLE product was provided per person.

The recruitment happened much slower than expected. It turned out to be difficult to recruit participants, more difficult than expected. Probable problem for involving the patients is lack of services for persons with dementia, thus possibility to spread information about the study, involve staff and get feedback by recruiting the patients was limited. One research assistant had access to files and meetings.

During the recruitment approximately 30 families were contacted to answer if they were interested in participation the project. In Lithuania twelve persons with dementia and twelve carers were recruited to the assessment trial:

- 5 tested Night and Day Calendars;
- 5 tested Locators;
- 2 tested Gas Cooker monitors.

4.4. Data collection

4.4.1. Scales used and T stages followed

The first home visit (T0) took place with both respondent and family carer present. The enable product was demonstrated and implemented by the person with dementia. Fieldwork involved the following: the first follow-up visit will be made after one week, and thereafter after one month, and then at three monthly intervals for up to one year to assess the continued usefulness of the product.

The frequency of interviews/contacts can be summarized as follow:

T0	Baseline interview and implementation of product
T1	Telephone call to carer 1 week post implementation
T2	Home visit and interview with patient and carer 3 weeks post implementation
T3	Home visit and interview with patient and carer 3 months post implementation
T4	Home visit and interview with patient and carer 6 months post implementation
T5	Telephone call to carer 12 months post implementation

Developing of methodology had been done before Lithuania joining the project, thus Lithuania accepted the methodology agreed upon earlier and presented here below.

Reviews were made of methods and tools addressing each of the aspects presented below. The work comprised desk research, literature studies and consultation with researchers and experts in dementia care.

- Processes to secure compliance with ethical principles
- Diagnosis of dementia and severity of dementia
- Functional abilities
- Quality of life
- Burden of care/Quality of life of carers/carer stress

A unified methodology for assessing impacts of enabling products for persons with dementia was developed, based on these reviews and the user requirements. The methodology developed served as basis for designing the protocol for the assessment study. A single instrument to gather quantitative and qualitative data was constructed which incorporates factors pertinent to effects on functional abilities, well-being and socio-economic parameters. Some questionnaires on use and usefulness

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were created in the project, in order to be able to measure the outcomes of use and usefulness, which were the dependent variables.

The work with selecting and putting together scales for the questionnaires was characterized by thorough discussions and some of the scales had to be interpreted into Lithuanian.

To develop a new methodology has been time consuming, and the presented selection of scales has provided us with new knowledge on the topic – dementia and technology. Scales used at the different stages of ENABLE assessment study - an overview.

TABLE I A: SCALES FOR INTERVIEWING PATIENTS (time 1 –1and1/2 hours maximum)

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

TABLE I B. SCALES FOR INTERVIEWING THE PRIMARY CARER (carer may fill out some forms by themselves)

<i>Scales</i>	<i>T0</i> <i>Baseline</i>	<i>T1</i> <i>Post 1 week</i>	<i>T2</i> <i>Post 3 weeks</i>	<i>T3</i> <i>Post 3 months</i>	<i>T4</i> <i>Post 6 months</i>	<i>T5</i> <i>Post 12 months</i>
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

Method

The three products selected for assessment were provided to the respondents depending upon the identified individual user need and inclusion criteria. The use need analysis usually took place during the first telephone conversation with the family carer.

Examples of parameters, which were registered, include:

- Aspects connected to the use of the device, including the need for follow-up by family or professional caregivers
- Whether use of the device can mitigate the problems it is aimed to reduce
- Reactions to having a new device in one's home
- Concerns about the device and opinion about its advantages and disadvantages
- Whether the device should be removed

Experienced researchers and care workers were involved to ensure sensitivity to the ways in which people with dementia express their needs and views.

4.5. Data analysis

4.5.1.1. Data collection

The persons with dementia were visited four times during six months; by implementation and first interview, three weeks after implementation, three months after implementation and lastly six months after implementation. Additionally we called them one week after implementation to check that the product functioned as I should, and one year after implementation to hear if the still used the product and wanted to keep it. All respondents could keep the product as long as they benefited from it, without being charged.

The frequency of interviews/contacts can be summarized as follow:

T0	Baseline interview and implementation of product
T1	Telephone call to carer 1 week post implementation
T2	Home visit and interview with patient and carer 3 weeks post implementation
T3	Home visit and interview with patient and carer 3 months post implementation
T4	Home visit and interview with patient and carer 6 months post implementation
T5	Telephone call to carer 12 months post implementation

4.5.2. Quantitative data

All the questionnaire data was put in SPSS file according to the codebook and analysed by SPSS. One single template was made for this purpose, in order to make it simple for the partner who would do the cross-country analysis (Dementia Voice, UK). The SPSS-files are easy to merge, so the data can be pooled for further analysis. Additionally, all answers regarding the cost-benefit questionnaires were punched into a separate file, because these data were to be analysed by another partner (WRC, Ireland).

All data from all T stages are put into the SPSS file. This makes it possible to analyse and investigate possible changes within the period of the participation. Will the patient adapt to the ENABLE product after a period of time, or will they benefit from the product in the start, but not after a certain time, because of the deterioration of the disease?

All respondents will be their own control. That means they will be compared with themselves over the T stages.

The results from the Lithuanian trial are mainly descriptive, as the number of respondents is low, and the number of persons testing each product is even smaller, so no representative ness will be possible in this small selection.

4.5.3. Qualitative data

Qualitative data were comments from the patient and the carer collected during the interview with the questionnaires. Three questions on quality of life seek to explore the voice of the person with dementia, exploring what they are thinking of for the time being, whether they have any worries and what make them happy or make them feel well. There are also qualitative data collected on the questions about use and usefulness of the products, particularly on suggestions for improvements.

Also, the researcher's comments after conducting the interview are of interest, but will not be included in the analysis of the qualitative data from patient and carer. The qualitative data are divided into a file for longitudinal data (all T steps), and one file on product specific questions to patient and to carer. The partners used colour-coding to sort the data, i.e. colour-coding was used to highlight positive and negative experiences with the products. The longitudinal file was analysed to identify categories and themes, and the product specific files were analysed to gain knowledge upon the use, usability and acceptance of the specific product. The emerging themes were of interest in order to picture the "voice of the person with dementia". After doing line-by-line coding of the longitudinal qualitative data, the words and themes identified were categorized. One theme, i.e. family could represent both positive and negative aspects. These were counted in order to identify a tendency on the current emerging themes in Lithuania.

5. Results I

Lithuanian assessment trial will last till August 2004. T4 (interview after 6 months) is completed for all ten respondents at the moment. The last interview will be performed in August 2004 (stage T5). There is two drop-outs (one after T0 and second after T2). The following table illustrates the progress of ENABLE Lithuanian trial till March 2004.

TABLE II. THE PRODUCTS AND PROGRESS OF ENABLE FIELD TRIAL IN LITHUANIA (as for 12 March 2004)

	T0 (N=12)	T2 (N=11)	T3 (N=10)	T4(N=10)	T5
CALENDAR (LIT 901)					
CALENDAR (LIT902)					
CALENDAR (LIT903)					
CALENDAR (LIT904)					
CALENDAR (LIT905)					
GAS COOKER (LIT 906)		Drop out			
GAS COOKER (LIT907)					
LOCATOR (LIT908)					
LOCATOR (LIT 909)					
LOCATOR (LIT910)					
LOCATOR (LIT911)			Drop out		
LOCATOR (LIT912)					

5.1. Description of the characteristics of the participants with dementia

In total 12 persons were recruited and they all finished T0 baseline interview. We had a wide variety in age among the participants: the youngest participant with dementia was born in 1949 and she was 54 when the assessment was started. The oldest participant with dementia was 82. This means that the average age is high, even for persons with dementia living at home. Of the twelve participants with dementia nine were woman and three were man. The selection of gender is as expected and reflects the normal appearance of gender in this age group in the Lithuanian society.

The respondents MMSE score was ranging from 14 to 24. Their diagnosis was divided into two categories: nine had Alzheimer disease and three had vascular dementia. Other dementing disorders (as Lewy Body dementia) did not reveal due to small sample. According to the MMSE score, five had dementia in a mild stage, and the rest had dementia in a moderate stage. Remarkable is that all the participants were prescribed with the specific drugs for dementia treatment.

All participants did not need help in primary activities of daily living (PADL) or needed only very little. In instrumental activities in daily living (IADL) nine participants needed some help. This help was received from family members.

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As we can see in Table III, the majority of respondents in Lithuanian selection were white-collar workers (N=7), three of them were blue collar workers (tailors, driver).

Four respondents in Lithuanian selection were living alone and the rest of respondents were living with someone else (spouse or child).

TABLE III. CHARACTERISTICS OF THE PARTICIPANTS IN THE BEGINNING OF THE ASSESSMENT (T0)

	Included, N = 12
Age in years	
Mean (Min-max)	75 (54-82)
Median	78
Gender	
Male	3
Female	9
Socio-economic status	
White collar	7
Blue collar	3
Other	2
Housing	
Living with someone else	8
Living alone	4
Diagnosis	
Alzheimer disease	9
Vascular dementia	3
MMSE Score	
Min-max	14-24
Mean	18
Median	18
Severity of dementia	
Mild dementia	5
Moderate dementia	6
No info	1
Medication for dementing illness	
Yes	12
No	0
Goes out alone	
Yes	9
No	3

5.2. Description of the characteristics of the carers

Of the twelve family carers nine were woman and three were man. Their age rated from 38 to 78. Four of the family carers were spouses, six were children and two had another relation (neighbour, friend). Seven of the twelve family carers were working (having paid work). In this group six were children and one was the neighbour, which was working half day. Five were not working, this because of retirement. Six of the carers lived in the same house as the respondent. Two lived within a distance of 1 kilometre, two lived in a distance of 1-9.99 kilometres and two lived in a distance of more than 10 kilometres away from a respondent. Very important that no one from carers do not get none care allowance (Table IV).

TABLE IV. CHARACTERISTICS OF THE LITHUANIAN CARERS IN THE BEGINNING OF THE ASSESSMENT (T0)

	Included, N = 12
Age in years	
Mean (Min-max)	58 (38-78)
Median	52
Gender	
Male	3
Female	9
Relationships	
Spouse	4
Child	6
Other	2
Currently taking medication	
Yes	2
No	10
Currently working for pay	
Working	7
Not working	5
Receive care allowance	
Yes	0
No	12
Distance from pwd	
0	6
< 1 km	2
1-9.99 km	2
>10 km	2

5.3. Expectations and motivation of participants to test the products

In Table V we can see expectations and motivation of the participants and their carers in the beginning of the study (at stage T0). The problem, which is tried to be solved, was very important for five persons with dementia (41.7%), for four persons with dementia the problem was important (33.3%) and for three persons with dementia the problem was somewhat important (25%). For the majority of carers (N=8) the problem was important (66.7%) and for the rest of carers the problem was very important (N=4, 33.3%).

The respondents in Lithuanian selection were divided in two equal parts when they answered about usefulness of the device. Six of them (50%) thought that the device is useful and other part (50%) thought that the device is very useful. Nine carers (75%) thought that the device will be useful for the pwd and 3 carers (25%) thought that the device would be very useful for pwd.

Talking about the motivation, all 12 respondents and their carers were motivated for the using of the device.

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TABLE V. EXPECTATIONS AND MOTIVATION OF PARTICIPANTS IN THE BEGINNING OF THE STUDY (T0)

	<i>Not important</i>	<i>Somewhat important</i>	<i>Important</i>	<i>Very important</i>	<i>Missing</i>
<u>How important is the problem which is tried to be solved by the device for the person with dementia (own report)</u>	0	3 (25%)	4(33.3%)	5 (41.7%)	-
<u>How important is the problem which is tried to be solved by the device for the carer</u>	0	0	8 (66.7%)	4 (33.3%)	-
	<i>Not useful</i>	<i>Somewhat useful</i>	<i>Useful</i>	<i>Very useful</i>	<i>Missing</i>
<u>How useful the device is expected to be for the person with dementia (own report)</u>	0	0	6 (50%)	6 (50%)	-
<u>How useful the device is expected to be for the carer</u>	0	0	9 (75%)	3 (25%)	-
	<i>Yes</i>	<i>No</i>	<i>Missing</i>		
<u>Is person with dementia motivated to try the product (own opinion)</u>	12 (100%)	0	-		
<u>Is person with dementia motivated to try the product (carer's opinion)</u>	12 (100%)	0	-		

TABLE VI. WHO ELSE IS TAKING CARE OF THE PERSON WITH DEMENTIA BESIDES THE PRIMARY CARER AS REPORTED IN T0

	Included, N = 12
Family members	6
Relatives	0
Neighbours	0
Friends	0
No other help	6

Table VI illustrates that besides the primary carer only for six carers other family members could help in taking care of pwd. Other six carers do not get any help from others. No formal care reflects limited number of services for people with dementia, especially for those living at home with informal carer. This was one of the main reasons for bigger carer's stress.

Case story: Daiva (pseudonym)

Carer of 76-years old man is daughter who lives some kilometres away from her father. She visits her father every day or is in phone contact with him. They were hoping that Locator will for some part increase father's independence and will reduce his anger when his things are lost in the house.

Daughter is experiencing quite big stress because father's behaviour is worsening. He was angry when he could not find his things; he became aggressive in point of his grandchildren. Daughter feels many negative feelings because of worsening father's mental condition. She understands that she should be patient for him, but every day worry exhaust very much and stress level is increasing.

6. Drop outs

In Lithuania two out of twelve persons with dementia dropped out of the assessment trial before three months (T3). Actually one of them dropped out very shortly after T1 and other definitely before one month (T2). The persons who dropped out were two women, age - between 77 and 78. One of the respondents lived alone, one with spouse. One of the respondents was provided with gas cooker monitor, one with item locator.

TABLE VII. CHARACTERISTICS OF THE DROP-OUTS (N=2)

	Case 1	Case 2
Gender	Female	Female
Age	78	77
Marital status	Living alone	Living with spouse
Product	Gas cooker monitor	Locator

The reasons for dropping out were:

- Found the device not useful
- Refused to continue/wish from patient to withdraw
- Technical problems with the device.

Case story: Adele (pseudonym)

A 78-years old woman lives alone. Carer – friend, which lives near to the pwd. The son of pwd lives very far away from his mother that's why he cannot care of his mother. Pwd has problems with burnt food, forgets to turn off the gas cooker. It was real danger to break fire in the kitchen. The son and the carer were very anxious about safety of pwd. Son even contemplated mother's living with him, but mother was much resisted to changes like that.

Pwd was disgruntled when installation process was prolonged. Day after installation pwd and carer called to the researcher and said that something with the system is wrong and that pwd can not prepare the food because the knobs are turning off after 3 minutes when they are on. Researcher tried to overload the system few times and consulted with installers by telephone. This process lasted few hours. It was a big discomfort for pwd because she baked the pie for guests who should come to visit her soon. This situation for researcher was very unpleasant, the researcher felt very guilty for situation like this. But at the end we succeed to solve these technical problems.

Every day researcher called to pwd asking about gas cooker monitor. Only few days' system worked without failures, but after five days the same problems started. The knobs turned off very often. Installers from UK promised to come in Lithuania as soon as possible. Pwd and carer agreed to wait for engineers on condition that gas cooker monitor would be uninstalled straight off when any problems will arise.

After repairing the system by engineer from UK, carer called to the researcher (after 5 days) telling again about the same problems. The gas cooker monitor was uninstalled on the following day.

7. Results II

7.1. Device specific results

7.1.1. Use and usefulness rated by the persons with dementia and their carers

Nine of the persons with dementia, who completed the trial, stated that they used the product and nine of the carers said that the person with dementia used the device. Eight of the ten persons with dementia rated the product they tried to be useful to them at T3, and two said the product was not useful. Eight of the family carers maintained the product was useful to their relative, and two assessed the device not to be useful. The use and usefulness at stage T3 is presented in table VIII.

TABLE VIII. USE AND USEFULNESS RATED BY THE PERSONS WITH DEMENTIA AND THEIR CARERS (T3)

	Use				Usefulness				Tech. probl. ¹	
	pwd ²		carer		pwd ²		carer		Yes	no
	Yes	No	Yes	No	Yes	No	Yes	No		
Calendar	5	0	5	0	5	0	5	0	0	5
Locator	3	1	3	1	2	2	2	2	4	0
Gas cooker monitor	1	0	1	0	1	0	1	0	1	0

¹ tech. probl. – technical problems, ² pwd – person with dementia.

How often each product was used at T2 and T3 stages is presented in Table IX. The biggest part (60%. N=3) of respondents in the Lithuanian selection were used the calendar more seldom than once a day, and other two respondents used the calendar every day (at T2 and at T3). Four carers answered (80%) that at stage T2 the calendar was used by pwd every day and only one carer (20%) said that calendar was used by pwd more seldom than once a day. At stage T3 the situation changed – even four carers noted that pwd is using the calendar more seldom than once a day.

At stage T2 the locator was used by pwd once a week (N=3; 60%) or more seldom than once a week (N=2) and at stage T3 one part (50 %) of respondents said that they used the locator once a week and other part (50%) used the locator more seldom than once a week. The same noticed the carers.

Gas cooker monitor was used by respondent and their carer (N=1) more than once a day.

TABLE IX. HOW OFTEN THE PRODUCT HAD BEEN USED BY THE PERSON WITH DEMENTIA AT STAGES T2 AND T3

Calendar	Own reporting	T2 (N=5)	T3 (N=5)
	Every day	2 (40%)	2 (40%)
	More seldom than once a day	3 (60%)	3 (60%)
	Carer's reporting	T2 (N=5)	T3 (N=5)
	Every day	4 (80%)	1 (20%)
	More seldom than once a day	1 (20%)	4 (80%)
Locator	Own reporting	T2 (N=5)	T3 (N=4)
	Once a week	3 (60%)	2 (50%)
	More seldom than once a week	2 (40%)	2 (50%)
	Carer's reporting	T2 (N=5)	T3 (N=4)
	Once a week	3 (60%)	2 (50%)
	More seldom than once a week	2 (40%)	2 (50%)
Gas cooker monitor	Own reporting	T2 (N=1)	T3 (N=1)
	More than once a day	1 (100%)	1 (100%)
	Carer's reporting	T2 (N=1)	T3 (N=1)
	More than once a day	1 (100%)	1 (100%)

7.1.2. Night and day calendar

TABLE X. THE USERS OF THE NIGHT AND DAY CALENDAR BY AGE, GENDER, MINI MENTAL STATUS EXAMINATION AND LIVING STATUS

Participant ID	Age	Gender	MMSE	Living	Status
LIT 901	76	Female	18	Children	T4
LIT 902	79	Female	21	Alone	T4
LIT 903	80	Male	16	Spouse	T4
LIT 904	82	Female	14	Children	T4
LIT 905	79	Female	17	Spouse	T4

The Night and day calendar was the most popular product in Lithuania. 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 carer s becoming increasingly frustrated. For those living alone, this meant a great deal of anxiety, and phone calls to 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.

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All five participants find the calendar useful; carer's opinion was the same. When reasons for the **usefulness** of the calendar were asked **people with dementia** responded (T3):

- "Calendar helps me in everyday life. I do not feel my illness so much".*
- "It is very good thing for people like me, because we have big memory problems, and this product helps us to solve this problems".*
- "Useful because I forget sometimes what month and week day it is. I can look at this calendar and I do not need to ask about this".*
- "Very useful, because it is half of my brain. I could not live now without calendar".*
- "Helps to orient in day and night time".*

The **carer's** responses about usefulness were very similar and it is summarized below:

- "His and my life became much easier".*
- "My wife is in a good temper often, she do not asking about time, she do not get up at night".*
- "Mother always can look at the calendar and remember what day is it. She is in the habit of using the calendar".*
- "The main problem was solved with installation of this product. Mother is much more self-confident, calmer, our relationships are better".*
- "Useful because she can feel more confident and more safe".*

TABLE XI. SUGGESTIONS FOR IMPROVEMENT FOR NIGHT AND DAY CALENDARS (5 CASES)

Comments from pwd	Comments from carer
Everything is fine, I am satisfied the way it is. I habituate to this calendar very much and I think that it is quite convenient.	Could be useful to include a clock. The frame is too big and the text is too small.
Screen letters could be bolder and bigger. The frame is not stable.	It is difficult to read in daylight. It could show day and nighttime.
The letters could be bigger; the contrast could be better, because I must put glasses when I want to see the text.	The brightness could be better and letters - bigger. The frame is not standing very keel.
The display could be bigger; the contrast could be better, because I cannot see the text when it is sunny day.	Contrast could be improved and the display could be bigger.
Everything is fine.	No suggestions. I think everything is fine at the moment.

When **participants with dementia** were asked about any **positive experiences** about the use of the calendar, all participants answered the question:

- "Green light in the night time creates cosines in my bedroom".*
- "I feel safe and calm because I know that I have my calendar when I need".*
- "It is great that I can try product like this. It really helps me to orient in time and I do not have to ask about it. My husband is thankful for it particularly".*
- "My life became easier with this product, I feel much better".*
- "My relationships with my family became much better. I am not so officious for them".*

When **carers** were asked about any **positive things** about the pwd use of the calendar, they answered:

- "Positive thing is that her independence is supporting every day".*
- "Mother is not so angry, she cries not so often".*
- "He became calmer and he is not so nervous like earlier".*
- "She asking about day time very rarely and her sleeping became much better".*
- "Positive thing is that we are not at odds with my wife. I am not so angry".*

Only one **negative** issue mentioned person with dementia and one carer. Person with dementia said, that she worries about expenditure of electricity because her pension is not very big. Carer said, that

mother complain often about using the electricity without necessity.

Case story: Monika (pseudonym)

Referral: A 78 years old woman lived alone and her caretaker was neighbour, who lived in the same landing. Old woman had a son who died 7 years ago. The granddaughter lives in abroad and pays for the neighbour for caring. Woman with dementia was often awaked in the nights or early in the morning and came to the carer to ask what time is it. In the day-time she sat by the window and asked passers – by after what the time was (even in winter time). The neighbour and neighbour's family were tired of being disturbed at nighttimes and it was unsafe for pwd health.

The calendar was demonstrated at the first home visit (T0) and together with the woman and her carer; we agreed to put the calendar in her kitchen, where pwd is spending most of her time.

Result: At first the calendar was disconnected very often by the pwd because the electricity was economized. Only after one week pwd saw usefulness of the product. When the day and night calendar was installed, interruptions at nighttimes decreased. Despite some small misunderstandings when old woman did not know where from this new thing is, the product is very useful for the pwd and for her carer because if pwd woke up at night, she used to look at the calendar. Old woman can orient in week and month days without asking about it her carer. Pwd became calmer and not so suspicious. Earlier pwd felt not secure because she was unconscious of time and now she is safer and is not so out of conceit with her memory.

Case story: Aloyzas (pseudonym)

Referral: An 80 years old man lives with his first wife (overall had three wives). Man with dementia had orientation problems in day and night time, in week and month days. Carer talked about his wandering at night, reading the newspapers, listening to the radio during the nights.

The calendar was placed in the bedroom on the table. Beside this table pwd loves to sit and look through the window, listen to the radio, or read the newspapers. Initially pwd did not put much value upon the calendar, but did not mind for installation. He said that his problems with the memory are not so big, but he can try the calendar. Carer told for the researcher that pwd started more and more often look at the calendar. After 3 weeks he said that the calendar is very good thing and that it really helps him.

Result: The carer reported a lot of good and positive changes in their every day life. These changes were in their communication and in pwd's everyday feelings. Pwd is very satisfied now with the product, he is happy that decided to try it. He makes boast about the calendar for all his guests. Pwd does not get up at night so often, he knows, that he can rely on this calendar in day and in night time. Carer is not interrupted so often in the night.

7.1.3. Locator for lost items

TABLE XII. THE USERS OF THE LOCATOR BY AGE, GENDER, MINI MENTAL STATUS EXAMINATION AND LIVING STATUS

Participant ID	Age	Gender	MMSE	Living	Status
LIT 908	76	Male	23	Spouse	T4
LIT 909	63	Female	22	Alone	T4
LIT 910	79	Female	15	Child	T4
LIT 911	77	Female	21	Spouse	Drop out
LIT 912	74	Male	24	Spouse	T4

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.

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Only two **respondents with dementia** find that Locators are **useful** for them:

"Useful, but very rarely, because locator do not work well. I try to find my things without this product".

"I can find my walking stick and keys".

Other two find it **not very useful**:

"For me is not very useful, because I do not have patience to play with this thing. For my wife it is useful sometimes".

"Not very useful, because I do not use the locator for three weeks".

Two **carers'** response about the **usefulness** positive:

"Mother says that it is useful for her sometimes. She told about the locator and said that it helped to find things".

"Useful in some situations. Father feels competent when he should to change elements. He is happy that his opinion is important".

Other two carers find locator **not very useful**:

"She has not used it for month because she had a feeling that the locator can not help her. She tried to find her things without locator".

"It is more useful for me than for him. He uses locator very rarely".

TABLE XIII. SUGGESTIONS FOR IMPROVEMENT FOR THE ITEM LOCATOR (5 CASES)

Comments from pwd	Comments from carer
I do not like sensors, which are very big. It is very uncomfortable to use and to fix these sensors.	I think the product is quite acceptable. We see only one problem - sensors are very big and bleeping not always.
The sensors could be lesser and their fixing could be improved. Locator should work properly and it must be reliable.	The sensors should be very small, bleeping louder. Good technical working must be secured, because we can not use it.
The sensors should be very small, because now I could not fix them to all things I planned (documents, glasses etc.).	The sound could be louder, the sensors are too big, and it is hard to fix them to wanted things (glasses). It is hard to press the press-buttons on the control box sometimes.
All technical problems should be solved and the sensors should be smaller. Sometimes it is hard to press the panel, sound should be louder.	The sound could be not so silent, because sometimes it is hard to hear. The elements work very short time; we changed elements two times at this moment.
The sound could be not so silent. Two sensors have got broken, though the size of the sensors has limited the benefits. The sensors are too big.	This product can be improved because now it is like a toy, it is not working like we all hoped - the sensors are very big and we cold not fix them where we wanted.

Two families talked about **positive things**:

"I found my keys couple of times. It is fun for my grandchildren".

"Sometimes it is very fun to look for things with my grandchildren".

"Locator really helped to find keys several times more quickly".

"We could found father's keys several times and avoided negative feelings".

The **negative feelings** reported by all families show the technical failure of the product:

Person with dementia:

"I am frustrated sometimes, because I could not find my things even with locator. The bleeping sound is very quiet".

"I had a feeling that it is my problem that the locator is not working".

"It seems like toy. When it does not work like I expected, I do not want to use it".

"Since I do not have patience enough, I became nervous and angry when locator does not help me to find lost object".

Carer:

"I worried only about negative feelings of my mother".

"Mother is calling very often and complaining about the locator".

"Since locator does not work technically well we have negative feelings sometimes: irritation, anger".

"Sometimes father is very angry when the sound of sensors could not be heard and we should help him nonetheless".

Case story: Vale (pseudonym)

Referral: A 63-year old woman lived alone. She had vascular dementia after a stroke. Her biggest problem was regular searching for lost things: keys, walking stick, handbag, and wallet. She was very nervous, irritated and disgruntled and called her son who lived nearby. The son and his family had to help her all the time with finding of lost things or their mother became very angry. Carer and his family had consequences for work and family life.

The pwd and her carers seemed very positive and motivated to test the locator. Locator for lost items was placed in the living room. The tags were attached to keys from home, to wallet, to handbag and to walking stick.

Result: In spite of some small technical problems, the locator is still in use and all find it quite useful. Pwd can find things without help do not call for children and is not so angry. She can feel more independent and self-confident when could find lost things. There were small technical problems with batteries but researcher helped to solve these problems as quick as possible. There were problems to attaché the tag to the walking – stick. But after some time the tag was removed from the walking stick because it was very uncomfortable for pwd.

Case story: Jonas (pseudonym)

Referral: A 76-year old man lives with his wife, but main carer is daughter which lives some km from pwd. Old man often forgets where he puts his things, is very angry, bad relationships with other family members.

Locator for lost items was placed in the living-room. The tags were attached to keys from home and from vault, to wallet.

Result: Pwd and his carers expected more from this product, because there were a lot of technical problems with the device. He changed batteries some times, but the sound was very silent anyhow. The tags were too big and he could not attach it to glasses and this was the biggest problem. Granddaughter helped very often with finding lost items at home. Pwd is using the locator, but he try to find his things without the locator, because there were some times when even with locator things were not found. It was very irritating situation for pwd. Because of technical problems with the device pwd and his carers are less motivated for using this product.

7.1.4. Gas cooker monitor

TABLE XIV. THE USERS OF GAS COOKER MONITOR BY AGE, GENDER, MINI MENTAL STATUS EXAMINATION AND LIVING STATUS

Participant ID	Age	Gender	MMSE	Living	Status
LIT 906	78	Female	21	Alone	Drop out
LIT 907	54	Female	17	Spouse	T4

Only one family is testing now the gas cooker monitor, because other participant dropped out after T1. Talking about usefulness, pwd and her carer said that gas cooker monitor is useful for them because *“We both feel safer”*.

Talking about **positive things**, pwd answered that: *“I know that I will avoid accidents with my cooker.”* Her carer said: *“I feel safe when I know that at home everything is fine.”*

Only carer mentioned **negative** experiences: *“Reliability of the product is not as big as in the beginning but I am still happy with gas cooker monitor.”*

Case story: Ilona (pseudonym)

Referral: A 54-years old woman lives with her husband. Son and daughter lives in abroad, there are not many relatives. Pwd has problems with burnt food, forgets to turn off the gas cooker. It was real danger to break fire in the kitchen. Woman felt very unsafe, worried about unturned gas when was not at home.

The installation and correction processes were quite long and raised some discomfort in the house, but very high motivation of pwd and of her carer do not provoked negative feelings.

Result: From the very beginning family had small technical problems with the device: sometimes the knobs turn off when there is no need. Carer noticed that it is related with fridge: when the fridge turns off, the knobs that are on also turns off. Despite these problems family is very satisfied with the device. Pwd and her carer find this device very useful, they are very happy that they can use device like this. Carer feels that there is safe at home and pwd feel much safer too.

Case story: Adele (pseudonym)

Referral: A 78-years old woman lives alone. Carer – friend, which lives near to the pwd. The son of pwd lives very far away from his mother that’s why he can not care of his mother. Pwd has problems with burnt food, forgets to turn off the gas cooker. It was real danger to break fire in the kitchen. The son and the carer were very anxious about safety of pwd. Son even contemplated mother’s living with him, but mother was much resisted to changes like that.

Pwd was disgruntled when installation process was prolonged. Day after installation pwd and carer called to the researcher and said that something with the system is wrong and that pwd can not prepare the food because the knobs are turning off after 3 minutes when they are on. Researcher tried to overload the system few times and consulted with installers by telephone. This process lasted few hours. It was a big discomfort for pwd because she baked the pie for guests who should come to visit her soon. This situation for researcher was very unpleasant, the researcher felt very guilty for situation like this. But at the end we succeed to solve these technical problems.

Result (drop-out): Every day researcher called to pwd asking about gas cooker monitor. Only few days’ system worked without failures, but after five days the same problems started. The knobs turned off very often. Installers from UK promised to come in Lithuania as soon as possible. Pwd and carer agreed to wait for engineers on condition that gas cooker monitor would be uninstalled straight off when any problems will arise. After repairing the system by engineer from UK, carer called to the researcher (after 5 days) telling again about the same problems. The gas cooker monitor was uninstalled on the following day.

TABLE XV. SUGGESTIONS FOR IMPROVEMENT FOR GAS COOKER MONITOR (1 CASE)

Comments from pwd	Comments from carer
I think the look of the cooker could be improved. I do not like this dark box with black wires on the cupboard. It is hard to dust this box.	Something with the electricity is wrong, because we noticed that the knobs switch off when the fridge is off.

7.2. Other findings

7.2.1. Quality of Life: the person experiencing dementia

The Brod Scale was used to get information about the subjective quality of life of the participants with dementia. The DQoL is a 29-item scale developed on the basis of domains identified as important to people with dementia. These domains are: (i) physical functioning, (ii) daily activities, (iii) discretionary activities, (iv) mobility, (v) social interaction, (vi) interaction capacity, (vii) bodily well being, (viii) sense of well-being, (ix) sense of aesthetics and (x) overall perceptions of quality of life. The results show that in the beginning of the assessment studies even ten persons rate their overall quality of life as fair and other two respondents rate it to be good or bad. Overall, participants across all stages rate their quality of life as being fair or good (Table XVI). All participants answered quite willingly about their quality of life although their assessment of life quality were not enough high.

TABLE XVI. QUALITY OF LIFE OF THE PARTICIPANTS WITH DEMENTIA ACCORDING TO BROD SCALE OVER TIME (T0-T3)

Overall quality of life	Time stage		
	T0 (N=12)	T2 (N=11)	T3 (N=10)
Bad	1	0	0
Fair	10	7	7
Good	1	4	3
Very good	0	0	0
Excellent	0	0	0

The sum score of the different aspects of the quality of life showed similar results after three weeks and three months (Table XVII).

TABLE XVII. ASPECTS OF QUALITY OF LIFE OF THE PARTICIPANTS WITH DEMENTIA ACCORDING TO BROD SCALE OVER TIME (T0-T3)

<i>Aspects from quality of life scale</i>	<i>Score Mean (min-max)</i>	<i>T0 (N=12)</i>	<i>T2 (N=11)</i>	<i>T3 (N=10)</i>
Self esteem				
Min	7	4	8	9
Max	13	11	14	15
Mean		8	11	12
Feeling of belonging				
Min	6	3	7	7
Max	12	9	13	13
Mean		6	10	10
Sense of aesthetics				
Min	9	7	10	9
Max	21	20	24	19
Mean		14	17	14
Positive affect				
Min	9	4	12	12
Max	19	16	21	21
Mean		10	17	17
Negative affect				
Min	20	14	23	24
Max	36	31	39	37
Mean		23	31	31

7.2.1.1. Emerging themes

The Brod scale is a structured interview, many respondents with dementia spoke in depth about certain themes. The three additional questions were included in the questionnaire in order to be able to “hear the voice of the persons with dementia”. The questions were concerning how they assessed their own quality of life, if there were things they worried about and what made them happy and made them feel well. The answers emerging from the Lithuanian selection may be categorized as: their health condition, family life (relationships with spouses or children, children’s life), negative and positive feelings in everyday life.

Mostly raised themes by the user were about user’s illness and about their family’s. In the majority of cases the users worried about their illness and about their future with disease like dementia. Other worried about their family members (children, grandchildren). There were respondents who did not feel that they had any dementia and they did not express any special worry.

Each respondent was happy about different things, but mostly they were happy about their good relationships with family members, that they taking care of them and loving them.

7.2.1.2. Subjective experiences of Quality of Life

Data collection for the Schedule II was organized 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. Many Lithuanian participants were aware of their memory loss problems and worried about their future deterioration (*“I’m disappointed with my abilities and mind”* (Female, 82 years)). Others talked in more general terms about efforts to remain healthy and independent (*“Worrying about the future and afraid of being a burden for family”* (Male, 74 years)). Another emerging theme in relation to negative affect was concern over family and friends, the need for family/social contact and loneliness (*“I often feel lonely since my granddaughter comes rarely and feel sad when I don’t have anyone to talk with”* (Female, 70 years)). Some respondents expressed their frustrations and concerns about the issue of others not understanding what they were experiencing in relation to the dementia and their inability now to carry out independently activities that they could easily do in the past (*“I feel angry when I am not able to do something or forget, angry with myself and sometimes with the people around about when they do not understand my situation”* (Female, 76 years)).

Talking about happy things, for the majority, it was the simple things in life that made them happy. Some of the respondents spoke about being thankful for what they had achieved in life (*“I am happy, that I had a nice life and good husband and children”* (Female, 77 years)).

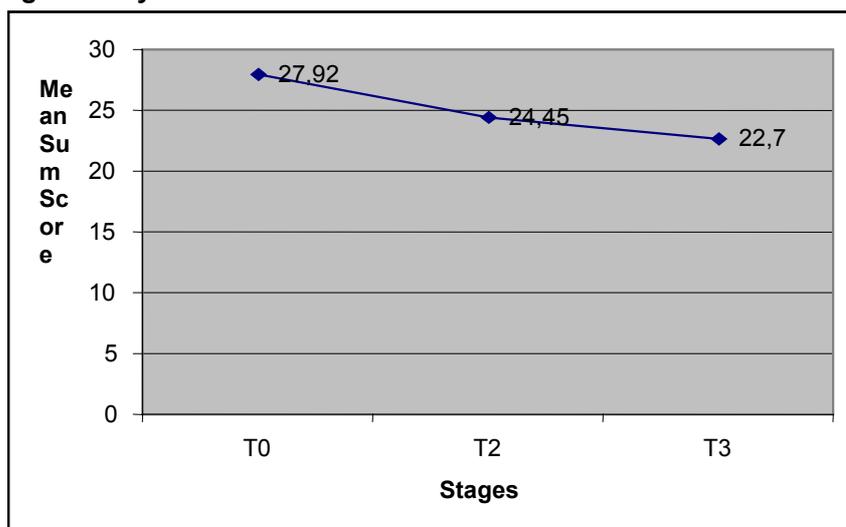
7.2.2. Carer well-being

The Greene caregiver burden scale was used to collect data from primary caregivers at interview stages T0, T2, T3. This 12-item scale allows for a cumulative score to be calculated. Responses to questions asked fall within the range: never, rarely, sometimes, and frequently or all the time. Regarding the Carer’s Stress Scale maximum sum score was 46 and minimum sum score was 15. The sum score was highest for those living with spouse or child and lowest for those living alone. The following table reports raw data on scores and on changes in scores over time. The higher the score the greater the burden is experienced. It is true to say that carer’s sense of well-being has marginally increased over the T0 – T3 stage of Enable. In consideration of the variance of scores for T3, which range from 13 – 31, this decrease could be attributed to decreased level of care required in caring for participants. But either reports of frustration and isolation were clearly felt by carers in trying to locate the appropriate person and subsequent advice proved a lengthy, highly stressful and demoralising process (Table XVIII). Dynamics in decrease of carer’s stress over time is shown in Figure 2.

TABLE XVIII. CARERS EXPERIENCED STRESS DUE CARE RESPONSIBILITIES ACCORDING TO RELATIVE’S STRESS SCALE OVER TIME

Sum Score	Time stage		
	T0 (N=12)	T2 (N=11)	T3 (N=10)
0-10	0 (0)	1 (8.3%)	0 (0)
11-20	4 (33,3 %)	3 (25 %)	4 (33.3%)
21-30	3 (25%)	4 (33.3 %)	5 (41.5%)
31-40	4 (33,3 %)	3 (24.9 %)	1 (8.3%)
41-50	1 (8,3 %)	0 (0)	0 (0)
51-60	0 (0)	0 (0)	0 (0)
Mean	27.92	24.45	22.7
Median	29	24	23
Min	15	10	13
Max	46	38	31

Figure 2: Dynamics in decrease of carers stress over time from T0 to T3



The following table illustrates experienced stress in three stages for each carer. The scores after three weeks and three months demonstrate, that for some carer their stress level decreased quite greatly and only for one carer the stress level increased.

TABLE XIX. CARERS EXPERIENCED STRESS IN STAGES T0-T3

Carer	Sum score		
	T0 (N=12)	T2 (N=11)	T3 (N=10)
LIT901	37	32	28
LIT902	21	24	19
LIT903	46	28	22
LIT904	19	21	24
LIT905	17	20	17
LIT906	15	Drop out	Drop out
LIT907	33	11	17
LIT908	29	29	26
LIT909	37	38	30
LIT910	29	19	13
LIT911	15	10	Drop out
LIT912	37	37	31

8. Discussions

8.1. Use, usefulness and consequences: factors of importance

8.1.1. User

The main factors of using or no using the device related to the person with dementia are their motivation at first stage, relevance of the problem for the family, stage of dementia (mild or moderate), age of person with dementia. Lower motivation for using the product raised negative reactions to the devices introduced into their home. These negative reactions could lead to drop out. Use and usefulness of product in relation to the person with dementia could depend on their stage of dementia. The researcher noticed that people with mild dementia reacts critical to their memory problem and try to solve it throughout. They feel that their illness have a negative impact for relationships with family and are more motivated to use the device. If a device is implemented as early as possible during the illness process they may be higher levels of use and usefulness recorded, as the person with dementia has the opportunity to get used to the device. The device is more successful for those people who are younger because they do not feel afraid of new technologies and want to try it. Elder people are more afraid of new technologies generally, to broke the device and “do something wrong”. In one case, technical problems with the device increased the feeling of coping with the task for person with dementia. He tried to change the elements of item locators and when he managed, he felt very good about it.

8.1.2. Carer

The families were happy to get a support – enabling technologies. The clear dynamics in decrease of carer stress (Green’s Stress Scale) during the trial shows acceptance of the intervention and positive influence of support.

The main factors of using or no using the device related to the carer are their motivation, willingness to try, living situation (living with person with dementia or not). Carer motivation for using the device is very important, because in some cases carer should help to choose for person with dementia to use the device or not (when pwd can not decide). In some cases carers were more motivated to use the device than users. In those families it required more discussion about this; carers had to relax this situation and to motivate pwd. Those cases, where pwd after these discussions were not motivated, were eliminated, because it was against the ethical rules.

One elderly carer was afraid of using new sophisticated technology (gas cooker monitor and mobile phone).

Reliable and competent carer is a guarantee for ameliorating stress for person with dementia caused by a faulty device. Carers provided good support during implementation process. The frustration of person with dementia could be lowered when carer is living with the person with dementia. He/she could help to solve all technical problems more quickly and without negative feelings. A significant reason for drop out was the frustration of carers created by technical problems of the device, which could not be solved.

8.1.3. Product

The technical problems and failure in the products were the most important factors influencing adequate use and expected usefulness.

Another important variable enhancing adequate and prospective use was a easy-to-use design. Talking about the item locator, the batteries were changed some times, but the sound was very silent anyhow, or the tags were too big and user could not attach it to glasses though this was the biggest problem for the family.

Use of the electricity was mentioned by one user (calendar). The gas cooker monitoring system uses electricity as well. Although, probably due to small number of users (N=2) this was not mentioned by users, but noticed by a local engineer, who helped to install the system, as a possible reason to cancel participation in the project.

8.1.4. Environment

Whether the person with dementia lived alone or not, had an impact on use and usefulness of product only in some cases, because the use of the product in those cases depended on a carer prompting them to use it i.e. night and day calendar. But in other cases, when person with dementia lived alone, this had no impact on use and usefulness the product. Conversely, those who lived alone and have mild dementia, reacts critical to their memory problem and try to solve it throughout. They feel that their illness have a negative impact for relationships with family and are very more motivated to use the device. Also for products that were more commonly used by the carer if they did not live with the person with dementia the device would not have been used as frequently

8.1.5. Researcher

The researcher visited the patient and carer regularly during six moths. In individual cases (when there were technical problems with the device) visits were even more often and telephone calls were also more frequently for those with technical problems with the device. This may influence decision: use or no use the device. The researcher do not troubled those who do not had technical problems with device. For some of pwd the questioning seemed too long and too often. It was quite hard for the researcher to visit families where the devices were not reliable (i.e. locators) and carers were tired from illness of person with dementia. The researcher felt not very good because the devices did not met their expectations.

8.2. Appropriateness of methodology

8.2.1. Experience with the protocol and questionnaires

The questionnaires included many areas of life and the interviews were long. For some people with dementia they were too long: when the Brod Scale was asked at the end of the interview many were too tired to concentrate on the questions. Some questions were confusing; it was hard to understand and difficult to answer some of them for people with dementia. The researcher should re-word some of the "hard" questions that they would be easier to understand. For some respondents this scale was perceived as being silly, other complained about being too detailed. In the beginning of the research (at T0), some users were a little bit suspicious and troubled, but at T2 and T3 they feel more relaxed, definitely less suspicious and pleased that some-one is taking an interest in them, that for some-one his problems are important, that for some-one his health condition is interesting.

The RUD-questionnaires were used to collect data that could be used for a cost-benefit analysis. There were different reactions from the carers answering these questions, but mostly people were polite and answered. Only one respondent was very disgruntled when these questions were asked. Questionnaires on use and usefulness of the enable-product were developed to map the opinions of the persons with dementia and the family carer. The questions were in other words asked to both the respondents with dementia and her/his family carer. In some cases the opinions of user and his carer were different, but they refused to say it when were in the same room.

In the beginning of the trial the follow up period were one week, then two weeks, then two months and a week, then six months and again six months. We found the follow up period good in the beginning and too long when it was more than two weeks. The researcher called more frequently. This caused far more work but it was very useful in understanding the changing situations of the families.

8.2.2. Recommendations for future assessment studies

The more sophisticated products might need more frequent assessment by telephone.

The persons living alone might need more frequent visits or phone call by researcher.

8.3. Ethical considerations

Researcher feels responsible for the well-being of the user and even for positive feelings regarding the products. Disappointments and technical failures in the products led to low motivation to use the products further.

Technical problems may cause feeling of unsafe, thus the prototypes in the trials for people with dementia should be as perfect as possible. Due to technical problems a researcher felt responsibility to call more often than planned by the protocol to secure person, but at the same time a feeling of disturbing persons and interfering with routine daily life accompanied these phone calls.

In some cases, people often felt too embarrassed to report a fault and waited until the researcher discovered the problem.

9. Conclusions

The results from the Lithuanian trial are mainly descriptive, as the numbers of the respondents are low, and the number of respondents testing each product is even smaller, representativeness is not achievable in such small sample as this.

From 12 persons who entered the trial in Lithuania ten have completed and benefited from the tested products.

Enabling products have potential in supporting people with dementia who live at home but this requires high quality products and precisely meeting the criteria for the specific products to be used. In addition, a thorough follow up is needed in figuring out the situation and possible problems of the product.

The decreased burden of carer by Green's Stress Scale showed that intervention (in this case – enabling technologies) in the family might contribute to the well-being carer.

The technology for people with dementia should be elaborated to be secure, safe and comfortable.

Prototype products used in the trials should be more pre-tested before being trailed in the homes of people with dementia.

The carers were sometimes frustrated with the faulty devices. This is very important to remember when further analyses are planned on the quality of life and the use of the products. It is also a clear sign that not only the person with dementia may suffer from failing trials but also the carer can have negative feelings.

The concept of dementia as a disability directs to evaluate missing elements and adapt environment with the help of assistive technologies to be able to compensate the disability of dementia. As the technologies for people with physical disability are provided by social welfare, the assistive technologies for people with dementia should be provided as well.

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