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Platform for self-assessment and efficient management for informal caregivers

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- **Draft (D)**: describes planned contents and main structure of the different sections. Document is between 0% - 50% completed.
- **Intermediate (I)**: document is approximately between 50% - 100% completed. It is the previous step before it could be released.
- **Released (R)**: document is 100% completed, reviewed and authorized for release by the partner responsible of the deliverable or the WP leader.

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Executive summary

BREATHE project is an Ambient Assisted Living (AAL) project cofounded by the AAL Joint Programme (Call 5, 2012) and the National Authorities and local R&D Programmes in Spain, United Kingdom, Ireland and Italy. BREATHE project has for goal to provide an ICT-based solution to alleviate the challenges experiences by carers and improve the quality of life of both the carer and the person cared-for. It is expected that a successful project outcome will impact at three different levels:

- Personal, by increasing quality of life and care.
- Local and regional, by providing a tool usable by different stakeholders to effectively manage the reality of the informal care as well as by opening opportunities of new business models and employment.
- European, by reducing health system costs as a consequence of an effective management of the informal care.

The aim of the work package (WP1) was to gain insight into the needs of formal and informal carers and achieve an understanding of the type(s) of technological support that would benefit the carers and the person cared-for. Specifically the objectives were to:

- To determine what causes family and informal carers most concern in their caring role.
- To ascertain what would help family and informal carers in their caring roles.
- To explore the views of family and informal carers about their current use of technology.
- To determine if they would be willing to accept technology as an aid to caring.

As BREATHE is proposing ICT-based solutions, the deliverable sought **to determine the attitude of the carers as well as the person cared for towards technological solutions**.

The BREATHE project began, in WP1, by eliciting the needs and requirements from stakeholders; namely carers, formal and informal, as well as healthcare professionals. Information was gathered through interviews and focus group held in 3 countries; Spain, Ireland, and U.K. Deliverable D1.1 reports on the findings of the interviews and focus groups. The methodology for data collection were normalised across the 3 countries and the survey material translated where needed. Participants were recruited and the interviews and focus group discussions conducted in the 3 countries in the language of the country. The data were aggregated and analysed.

Analysis of the profile of the informal carer participants was in line with current accepted findings. The profiles in all 3 countries who participated in this WP study, fit the common profile according to the EUROFAMCARE project (2011) i.e. a woman (76%), aged around 55, quite often the child or child-in-law of the assisted person, less

than a half of them are employed, dedicating approximately 46 hours/week, for 5 years in total. The BREATHE WP1 findings confirm finding by Bass et al. (2012) and Malhotra et. al. (2012), who identify the aid and/or support for carers and health and social care professionals when caring for a person with a long term condition include psychosocial support, financial support and access to help for practical e.g. aids, and specialist support e.g. advice.

In support of work by Rowan and Mynatt (2005) and Consolvo et al. (2005), the informal carers felt positive that the proposed BREATHE technology would support them as carers so that they would be able to go about their life with peace of mind. They felt that the technologies should be marketed towards the family and friends of older people rather than the older person themselves.

In accordance with work by the likes of Nehmer (2006), Olivier et al. (2009) and Vergados (2010) the informal carers across the 3 countries were interested in the technical capability of home monitoring systems as a means to reliably and automatically detect activities and routines of the person with a long term condition, that is to gain knowledge of daily routine, risky situation, location and/or activity in home, and social activity.

The thematic analysis highlighted a few themes relevant to each group of respondents. Recurrent themes across all groups of respondents (formal, informal, professional, and cared-for) was **the usefulness of the technology, invasion of privacy, issues around consent (carers) and autonomy (cared-for)**. The consistency in themes is evidence of pertinence and relevance.

1 About this document

1.1 Structure of this document

This document has been structured in 8 main sections described below:

- Section 1 described the document structure.
- Section 2 introduces the project and discusses the aims and objectives.
- Section 3 discusses the methodology.
- Section 4 describes the characteristics of study participants.
- Section 5 discusses the findings.
- Section 6 provides a qualitative analysis of the data.
- Section 7 ends the document with a discussion of findings.
- Section 8 BREATHE high level requirements.

References are listed followed by appendices containing the consent forms, materials used for focus groups and interviews as well as the information leaflets distributed to participants.

2 Introduction

Today, informal caregivers i.e. family carers, unpaid carers, face a number of challenges, including poor understanding of the local health and social care systems, lack of experience and/or formal education in care resulting in poor quality of care and in emotional dissonance, limited societal support, lack of specific tools to manage the whole care cycle (lack of knowledge about the physical and/or psychosocial and/or emotional difficulties of the cared for person and the longer term implications, skills deficits to support the cared for with activities of daily living, lack of technical support with respect to caring aids), problems with coordinating care affecting mainly women (lack of support and advice, work and/or family commitments) with other 'care' employment and psychological issues such as stress, anxiety and/or depression (Bass et. al. 2012, Malhotra et. al. 2012). Family care breakdown can lead to financial burden and/or institutionalisation.

Family carers provide 80% of long-term care to dependent older people in Europe (EUROFAMCARE project, 2011). It is widely recognized that the World's population is now ageing at an unprecedented rate (WHO, 2014). As the demography across Europe changes inevitably there will be increasing numbers of older people who want to live independently in their own homes for as long as possible but with age may need some support and/or assistance. This results in escalating demands on statutory services and informal caring arrangements as well as 'human' cost to the cared for and carers. As a means of offsetting this pressure, there has been a focus in recent years to support the independent living of people in their homes for longer rather than entering residential care facilities. Most of this work fits under the banner of 'telecare'—technologies that support the remote care of people who wish to live as independently as possible in their own homes (Vines, 2013).

Prior research has highlighted how remote home monitoring technologies can support peace of mind of concerned distant carers (Rowan and Mynatt, 2005), or focused on ways to provide quality of life information to carers living nearby (Consolvo et. al. 2005). There has also been a vast amount of work focused on the technical capability of home monitoring systems to reliably and automatically infer activities and routines from such data (e.g. Nehmer. 2006, Olivier et al. 2009, Vergados, 2010). It has been suggested that many older people are concerned that such technologies may have a negative impact on such relationships (Beach et. al. 2009). However, in a recent study of remote monitoring technologies, Huber et al. (2013) noted that there was no significant impact upon existing communications and relationships between older adults and their caregivers. Research in this area is growing and it is a subject becoming more important as such technologies mature from being research experiments and projects into consumer products that can be purchased from large retailers. While recent research has focused on reciprocal monitoring systems (Caine et. al. 2011, Huber et. al. 2013, Shankar et. al. 2012), consumer variants are moving towards one-way monitoring systems that provide reassurance to caregivers' e.g. Family link, 2013, or raise alarms in

case of emergencies (O^2 health, 2014). These technologies are often marketed towards the family and friends of older people rather than the older person themselves.

The role played by family and informal carers is integral to the overall quality of life (QoL) experienced by the cared for person (Hellström and Hallberg, 2001). A paradigm shift is slowly taking place as the focus is changing to caring for the elderly in enabling quality of life rather than just providing basic care till death. People are living longer and the expectations of old age are much different than 20-30 years ago. They are no longer willing to settle for having only their physical needs met, but require a more holistic approach to maintain physical activity, independence and social interaction (HubPages, 2014). Consequently, it is of paramount importance that carers receive the best support there is available. Caregiving has been shown in different studies to affect quality of life among informal caregivers. Despite the difficulties experienced by family and informal carers the majority report their role as mainly satisfying (especially part-time carers in comparison to full-time carers (Broe et. al. 1999)) but one that could be improved with greater access to social and professional support (Carers UK, 2012). Currently, there are a number of assessment tools available to determine carer satisfaction, burden and/or management e.g. The Barthel Index (Mahoney and Barthel, 1965, Caregiver Burden Scale (Zarit et al. 1980), but not infrequently the outcomes of these assessments fall short of any substantial meaningful interventions to support care giving; they remain only an assessment of burden.

3 Methodology

3.1 Aim and objectives

The aim of this deliverable is to gain an insight into the needs of family and informal carers and what would help support their caring role. Also it needed to explore what the cared for persons believed would help them and their carers and if a technological intervention would be acceptable to everyone. The BREATHE platform will provide an ICT-based solution for the caregiver and the elderly in order to mitigate these problems and impact at three different levels:

- Personal, by increasing quality of life and care.
- Local and regional, by providing a tool usable by different stakeholders to effectively manage the reality of the informal care as well as by opening opportunities of new business models and employment.
- European, by reducing health system costs as a consequence of an effective management of the informal care.

The BREATHE solution is based on a system that maintains updated models of both caregiver and assisted person and offers strategic support and customized guidance for the informal caregiver during the whole long-term care process. Overall the BREATHE Project aims to provide a rich platform for improving the quality of life of informal caregivers at all levels. In order to achieve a plausible scenario in which family caregivers can find useful services and resources to an adequately support of domiciliary care, it is necessary to involve them in the development process from the initial stages. This system is fed by three independent information sources:

- Ambient Assisted Living (AAL) system that gathers information about daily life activities of the elderly at home.
- Structured information that both caregiver and assisted person provide (e.g. through questionnaires).
- Non-structured sources of information such as a diary, notes and posts on social networks.

The carer will be able to interact with the BREATHE platform in any of three ways. The first is a Web application designed to be used even by informal caregivers with limited Information and Communications Technology (ICT) skills and with special emphasis in making it appealing and friendly as well as being unobtrusive and not inhibiting into their daily activities. The second is a smart phone application that allows the informal caregiver to have ubiquitous access to the BREATHE service. Last is the AAL system at home. BREATHE assumes that informal caregivers need to have “eyes” in the home or premises where the elderly or the assisted person requires care. Although vision is the most basic cognitive process used for recognising a person, an event, or an action; fusion of video data and information acquired by other sensors can facilitate

activity analysis. Appropriate measures will be taken to preserve dignity and maintain privacy and confidentiality.

With regard to the outputs of the system, the BREATHE platform will provide status reports that informal caregivers can share with doctors, smart progressive learning support that provides guidance when needed avoiding overloading with unusable information, connection to social networks in order to avoid isolation, support for self-assessment about depression and stress levels, customized pieces of advice for both the caregiver and the assisted person depending on their actual status and support for the participation of social care professional working behind the scene.

Overall objective of WP1:

To collect a complete list of needs and requirements of AAL and ICT solutions from the different end-users involved in the value chain, to identify those technical specifications of each individual subsystem as well as the overall integrated solution and to deal with of legal and ethical constraints to inform the informal long-term care of elderly people.

Measurable objectives of WP1:

- To determine what causes family and informal carers most concern in their caring role.
- To ascertain what would help family and informal carers in their caring roles.
- To explore the views of family and informal carers about their current use of technology.
- To determine if they would be willing to accept technology as an aid to caring.

3.2 Participants

To gain the understanding required it was necessary to include a range of care givers and people receiving care for example:

- Informal carers (family carers who may or may not live with the cared for person) and who care for a person with at least one Long Term Condition (LTC).
- Formal carers (officially employed as paid carers) who care for a person with at least one Long Term Condition (LTC).
- Health and social care professionals: any other type of healthcare professional with some knowledge of the care process, e.g. GP, community nurse, physiotherapist, Occupational Therapist etc.
- People with Long Term Conditions (LTCs) who may or may not live with their main carer.

Participants were recruited in three countries in Europe; Spain, Ireland, and U.K. The table below shows the target recruitment numbers for the different types of users for individual interviews and group sessions:

Site	Face to face interviews of 50-60 minutes each	Group sessions of 80 minutes each
UK	• 6-10 with informal caregivers • 4-6 with formal caregivers • 3-6 people with LTCs • Optional extra: 2-4 with community health professionals who assist caregivers, e.g. GPs, social care professionals, community nurses (optional) • (15 – 26 interviews in total)	• 1-2 groups of 6-10 informal caregivers • 1-2 groups of 6-10 formal caregivers
Spain	• 6-10 with informal caregivers • 4-6 with formal caregivers • 4-6 with people with LTCs • Optional extra: 2-4 with community health professionals who assist caregivers, e.g. GPs, social care professionals, community nurses (optional)	• 1-2 groups of 6-10 informal caregivers • 1-2 groups of 6-10 formal carers
Ireland	• 6-10 with Informal caregivers • 4-6 with formal caregivers • 3-6 people with LTCs • Optional extra: 2-4 with community health professionals who assist caregivers, e.g. GPs, social care professionals, community nurses (optional) (15 – 26 interviews in total)	• 1-2 groups of 6-10 informal caregivers • 1-2 groups of 6-10 formal caregivers

Table 1 - Target recruitment desired numbers for individual interviews and focus groups

Information and deciding whether to participate**:**
All potential participants, when contacted, should be given a copy of the information sheet (See Appendix 3 - Information sheet). They must have **at least 24 hours** to decide whether to participate. In practice this is likely to be longer, as a mutually convenient focus group or interview time must be arranged.

3.3 Inclusion and exclusion criteria for the different participating groups

The table below lists the inclusion and exclusion criteria employed to recruit participants.

Type of user	Inclusion/Exclusion criteria
Informal carers	Include only people from 18 to 90 years old, inclusive Include only people who can give written, informed consent Include informal carers who have been in an informal care role for at least six months (full time or part time) for a person with LTC(s) Include people who have some experience of caring for someone in one or more of these categories: • Stroke survivors • Frail older people • People with musculo-skeletal disease, or mobility problems Exclude anyone who is not a native speaker of the primary language of the trial site country

Formal carers	Include only people from 18 to 90 years old, inclusive Include formal (paid) carers who have been formal carers for at least six months for people with LTCs in a domestic setting Include only people who can give written, informed consent Exclude anyone who is not a native speaker of the primary language of the trial site country Include people who have some experience of caring for people in one or more of these categories: • Stroke survivors • Frail older people • People with musculo-skeletal disease, or mobility problems
Professional	Include only people from 18 to 65 years old, inclusive Include people currently working in a healthcare field relating to the care of people at home, with at least 6 months' experience in that role Include only people who can give written, informed consent Exclude anyone who is not a native speaker of the primary language of the trial site country Exclude anyone who is not a native speaker of the primary language of the trial site country Include people who have some knowledge of the care of people in one or more of these categories: • Stroke survivors • Frail older people • People with musculo-skeletal disease, or mobility problems
People with LTCs	Include only people from 18 to 90 years old, inclusive Include only people who can give written, informed consent Exclude people who have had their LTC(s) for less than six months Exclude people with temporary or permanent cognitive impairments or current mental health concerns Exclude anyone who is not a native speaker of the primary language of the trial site country Include people who have LTCs requiring care, in one or more of these categories: • Stroke survivors • Frail older people • People with musculo-skeletal disease, or mobility problems

Table 2 - Inclusion and exclusion criteria for user´s interviews

3.4 Methods of data collection

As it was necessary to explore in detail these views and ideas a qualitative approach was preferable. Individual interviews and focus groups were chosen as the methods of data collection offering the opportunity for peer support, exchange of ideas and sharing of common values (Nachmais and Nachmais, 2008, Savin-Baden and Major, 2013).

3.4.1 Individuals interviews

This method required all answers are to be provided verbally, and not in writing. The interviews were expected to last for around 60 minutes and were conducted according to the template described here:

1. The participant arrives and is welcomed by the researcher.

2. The participant is offered refreshments and shown to the interview room.
3. The participant is given the opportunity to ask questions about the study.
4. The consent form is signed if the participant is willing to participate.
5. The audio recorder is switched on.
6. The interview begins and the researcher follows the agreed running order of questions.
7. The interview ends and the audio recorder is switched off.
8. The participant is thanked and is free to leave.

The following sections present the templates followed by the interviewer to collect information from:

- Formal carers of people with LTCs.
- Informal carers of people with LTCs.
- People with LTCs.
- Professionals with a view on caring to people with LTCs.

3.4.1.1 Questionnaire for formal carers of people with LTCs

Thank you for agreeing to take part in this study. Your involvement will help us to understand what people think about the proposed BREATHE technology, and will help us to make the technology as useful as possible for carers of people who have Long Term Conditions (LTCs). We will be asking informal carers and people who have Long Term Conditions what they think too, but this is an opportunity to tell us what you think from your point of view as a formal carer. Do feel free to ask any questions during the session – the interviewer will be happy to provide you with any more information about the work or to explain the questions in more detail.

Section A – About your circumstances

Firstly, we would like to ask you some questions about you and about your circumstances. This will help us to understand your views, and will help us to make the best use of the answers that you provide. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. *What types of Long Term Conditions have you experienced when caring for people in their homes?*
2. *How long have you been a formal carer for people with Long Term Conditions in their homes?*

Now we have a few questions about using technology:

3. *Do you use a smartphone?*
4. *Do you use a tablet computer (e.g. an iPad)?*

5. *Do you use the internet at all?*
6. *If yes, what device do you use for this? (PC, laptop, tablet, smartphone…)*
7. *How often do you use the internet?*
8. *Do you provide care for people who already use any assistive technology (for example any technology which helps with practical or medical needs)?*

Section B – Your experience of informal carers

As you know, this project is about designing some technology that might help to support informal carers. So, we would like to ask you about some of your experiences of people who provide informal care, to help us to understand what you think the real needs are for this kind of technology. So, since your role involves being in the homes of people with Long Term Conditions, and their informal carers.

9. *What are the 3 things that you think cause informal carers to worry the most about people with Long Term Conditions? [if needed, some examples are: time pressure, carers' own health and wellbeing, carers' knowledge of X's LTC, their social life, how to seek support, how to cope with current or future situations]*
10. *What do you think might help with the things that you have mentioned [ask about each one in turn]?*
11. *What are the top 3 concerns that you think informal carers have in relation to their caregiving role? [if needed, some examples are: what financial/practical support they receive, any emergency when the person with a LTC is alone at home, the quality of care provided to X, how to deal with acute episodes relating to the LTCs, what to do if a person's LTC gets worse]*
12. *What do you think might help with these things [ask about each one in turn]?*

Section C – The BREATHE system and monitoring

Now we are going to talk about the new technology that we are planning to design. You might have mentioned some of these already, which is fine, but please consider each of these different possibilities:

13. *Would it be useful to informal carers to be given information about the following things, in order to be reassured about the wellbeing of people with Long Term Conditions?*
    a) *Would they like to know about X's daily routine? [for example, sleeping, eating, drinking, going out]*
    b) *What about risky situations? [for example having a fall, leaving appliances switched on, going out at night]*
    c) *What about location within the home and how active the person is? [for example whether they are moving between rooms or staying in one place]*
    d) *Would they want to know about any social activity? [for example going out, talking on the telephone, having visitors]*
    e) *Are there any other specific activities you think they would like to know about?*

Here is a separate sheet which describes the possible ways that the BREATHE system might monitor people in their homes, in order to provide support to carers. [Give time for the participants to look at the sheet – Appendix 2]

14. *If there was an emergency relating to the person with a Long Term Condition, do you think it would be useful for the informal carer to be able to look at X at home in a way that is described on the sheet?*
15. *If yes, which way(s) would be the most useful to the informal carers?*
16. *Do you think they also want to be able to see what X is doing in some way, in some non-emergency situations?*
17. *If yes, which way(s) would be the most useful?*

As well as visual information, the BREATHE system could send information reports to the informal carer's smartphone, for example "X is fine today", or "X has not been to the bathroom since yesterday". This information could be based on specific information that has been chosen in advance.

18. *If information could be sent to the informal carer about the person they care for, do you think it would be better for the information to be:*
    a. *Sent to the smartphone automatically (like a text message)*
    b. *Available for the informal carer to look at whenever they chose (like looking at a webpage in their own time)?*
    c. *Neither*
    d. *Both*
19. *Do you think health professionals should be able to see any of the monitored data about X, for example data about activity levels or a record of any emergencies?*
20. *If yes, what kinds of information would be useful to send to a health professional?*

Section D – The BREATHE system giving guidance and support

As we have described already, the BREATHE system could provide with monitoring information about the person with a Long Term Condition. However, BREATHE could also potentially provide guidance and support to informal carers.

21. *Do you think it would be useful if the system could provide information about the person's long term condition? (e.g. how to deal with particular aspects of their care, or what to do in an emergency)*
22. *If yes, what kinds of information do you think could be useful to informal carers?*
23. *Would you want the system to provide support to the person with a Long Term Condition if their informal carer were not available?*

Some informal carers find that caring for someone with a Long Term Condition can affect their health and wellbeing.

24. *Do you think it could be useful if the BREATHE system could monitor the health and wellbeing of informal carers in relation to their caring role? For example, the*

system could regularly ask the carer about their health and wellbeing and provide some relevant resources to help them based on their answers.

25. *Do you think that it would be useful if the system could help informal carers to get in touch with other informal carers for peer support?*

Section E – Obtaining and using the BREATHE system

This final part is about how the technology might be provided, and how people might be involved in using it.

26. *If an informal carer were using the BREATHE system, and it asked them to spend a few minutes to complete on-screen questionnaires as part of the system, do you think they would be prepared to do this?*
27. *Similarly, if the system worked in a way that meant they had to complete on-screen brief on-screen diaries, would they be prepared to do this?*
28. *Who do you imagine might provide and pay for the BREATHE system? [examples if needed: carers themselves; a private company; government healthcare; private healthcare cover]*
29. *Finally, if an informal carer was interested in using this system, do you think they would you be happy to install it themselves in the home of the person they provided care for, if they were given enough training?*

Thank you. That is the end of our questions.

30. *Is there anything else you would like to ask, or anything else you would like to tell us?*

Thank you very much for taking part in this research, we value your views and will respect your privacy by keeping your answers anonymous. We will only use this information in relation to the BREATHE project.

3.4.1.2 Questionnaire for informal carers of people with LTCs

Thank you for agreeing to take part in this study. Your involvement will help us to understand what potential users of the BREATHE technology think about it, and will indicate how to make the technology as useful as possible for carers of people who have Long Term Conditions (LTCs). We will be asking people who have Long Term Conditions what they think too, but this is an opportunity to tell us what you think from your point of view as a carer. Do feel free to ask any questions during the session – the interviewer will be happy to provide you with any more information about the work or to explain the questions in more detail.

Section A – About your circumstances

Firstly, we would like to ask you some questions about you and about your circumstances. This will help us to understand your views, and will help us to make the best use of the answers that you provide. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. *Who is the person you care for, i.e. their relationship to you?*
2. *I understand X has at least one Long Term Condition. May I ask what type of condition(s) X has?*
3. *Do you live with [X =the person you care for*]? *Researcher: refer to this person as e.g. "your father", or by name, from now on*
4. *If you do not live with X, how far away do you live?*
5. *If you do not live with X, does X live alone?*
6. *How often do you contact X by phone?*
7. *May I ask your age?*
8. *Where do you live? (Place, rather than address)*
9. *What is your current or previous profession?*

Now we have a few questions about using technology:

10. *Do you use a smartphone?*
11. *Do you use a tablet computer (e.g. an iPad)?*
12. *Do you use the internet at all?*
13. *If yes, what device do you use for this? (PC, laptop, tablet, smartphone…)*
14. *How often do you use the internet?*
15. *Do you or X already use any assistive technology (for example any technology which helps with practical or medical needs)?*

Section B – Your role as a carer

As you know, this project is about designing some technology that might help to support carers. So, we would like to ask you about some of your experiences as a carer, to help us to understand what you think the real needs are for this kind of technology. So, thinking about your role as a carer.

16. *How many hours a week do you think you spend caring for X?*
17. *What are the 3 things that cause you the most worry about X? [if needed, some examples are: time pressure, your own health and wellbeing, your knowledge of X's LTC, your social life, how to seek support, how to cope with current or future situations]*
18. *What do you think might help with the things that you have mentioned [ask about each one in turn]?*
19. *What are your top 3 concerns you have in relation to your role as a caregiver?[if needed, some examples are: what financial/practical support you receive, any emergency when X is alone at home, the quality of care that others provide to X, how to deal with acute episodes relating to X's LTC, what to do if X's condition gets worse]*
20. *What do you think might help with these things [ask about each one in turn]?*

Section C – The BREATHE system and monitoring

Now we are going to talk about the new technology that we are planning to design. You might have mentioned some of these already, which is fine, but please consider each of these different possibilities:

21. *Would it be useful to you to find out about X in any of the following ways, in order to be reassured about X's wellbeing?*
    a) *Would you like to know about X's daily routine? [for example, sleeping, eating, drinking, going out]*
    b) *What about risky situations? [for example having a fall, leaving appliances switched on, going out at night]*
    c) *What about location within the home and how active they are? [for example whether they are moving between rooms or staying in one place]*
    d) *Would you like to know about any social activity?[for example going out, talking on the telephone, having visitors]*
    e) *Are there any other specific activities you would like to know about?*

Here is a separate sheet which describes the possible ways that the BREATHE system might monitor people in their homes, in order to provide support to carers. [Give time for the participants to look at the sheet – Appendix 2]

22. *If there was an emergency relating to X, do you think it would be useful to be able to look at X at home in a way that is described on the sheet?*
23. *If yes, which way(s) would be the most useful to you?*
24. *Would you also like to be able to see what X is doing in some way, in some non-emergency situations?*
25. *If yes, which way(s) would be the most useful to you?*

As well as visual information, the BREATHE system could send you information reports to a smartphone, for example "X is fine today", or "X has not been to the bathroom since yesterday". This information could be based on specific information that you have chosen in advance.

26. *If information could be sent to you about X, would you prefer the information to be:*
    e. *Sent to your smartphone automatically (like a text message)*
    f. *Available for you to look at whenever you like (like looking at a webpage in your own time)?*
    g. *Neither*
    h. *Both*
27. *Would you want health professionals to see any of the monitored data about X, for example data about activity levels or a record of any emergencies?*
28. *If yes, what kinds of information would be useful to send to a health professional?*

Section D – The BREATHE system giving guidance and support

As we have described already, the BREATHE system could provide you with monitoring information about X. However, BREATHE could also potentially provide you with guidance and support as a carer.

29. *Do you think it would be useful if the system could provide you with information about X's long term condition? (e.g. how to deal with particular aspects of their care, or what to do in an emergency)*
30. *If yes, what kinds of information do you think could be useful?*
31. *Would you want the system to provide support to X if you were not available?*

Some carers find that caring for someone with a Long Term Condition can affect their health and wellbeing.

32. *Do you think it could be useful if the BREATHE system could monitor the health and wellbeing of carers in relation to their caring role? For example, the system could regularly ask the carer about their health and wellbeing and provide some relevant resources to help them based on their answers.*
33. *Do you think that it would be useful if the system could help carers to get in touch with other carers for peer support?*

Section E – Obtaining and using the BREATHE system

This final part is about how the technology might be provided, and how people might be involved in using it.

34. *If you were using the BREATHE system, and it asked you to spend a few minutes to complete on-screen questionnaires as part of the system, would you be prepared to do this?*
35. *Similarly, if the system worked in a way that meant you had to complete on-screen brief on-screen diaries, would you be prepared to do this?*
36. *If you were interested in using this system, who do you imagine might provide it and pay for it? [examples if needed: yourself; a private company; government healthcare; private healthcare cover]*
37. *Finally, if you were interested in using this system, would you be happy to install it in X's home if you were given enough training?*

Thank you. That is the end of our questions.

38. *Is there anything else you would like to ask, or anything else you would like to tell us?*

Thank you very much for taking part in this research, we value your views and will respect your privacy by keeping your answers anonymous. We will only use this information in relation to the BREATHE project.

3.4.1.3 Questionnaire for people with LTCs

Thank you for agreeing to take part in this study. Your involvement will help us to understand what potential users of the BREATHE technology think about it, and will indicate how to make the technology as useful as possible for carers of people who have Long Term Conditions (LTCs). We will be asking carers and professionals what they think too, but this is an opportunity to tell us what you think from your point of view someone who has a Long Term Condition. Do feel free to ask any questions during the session – the interviewer will be happy to provide you with any more information about the work or to explain the questions in more detail.

Section A – About your circumstances

Firstly, we would like to ask you some questions about you and about your circumstances. This will help us to understand your views, and will help us to make the best use of the answers that you provide. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. *Who is the person who cares for you, i.e. their relationship to you?*
2. *I understand that you have at least one Long Term Condition. May I ask what type of condition(s) you have?*
3. *Do you live with [X =the person who provides your care*]? *Researcher: refer to this person as e.g. "your daughter", or by name, from now on*
4. *If you do not live with X, how far away do you live?*
5. *If you do not live with X, do you live alone?*
6. *How often does X contact you by phone?*
7. *May I ask your age?*
8. *Where do you live? (Place, rather than address)*
9. *What is your current or previous profession?*

Now we have a few questions about using technology:

10. *Do you use a smartphone?*
11. *Do you use a tablet computer (e.g. an iPad)?*
12. *Do you use the internet at all?*
13. *If yes, what device do you use for this? (PC, laptop, tablet, smartphone…)*
14. *How often do you use the internet?*
15. *Do you or X already use any assistive technology (for example any technology which helps with practical or medical needs)?*

Section B – Yourself and your carer

As you know, this project is about designing some technology that might help to support carers. So, we would like to ask you about some of your experiences as someone who has some care provided to them, to help us to understand what you think the real needs are for this kind of technology. So, thinking about the care that your informal carer provides.

16. *What do you think causes concern for your carer, in relation to their role as a carer? [if needed, some examples are: time pressure, X's own health and wellbeing, X's knowledge of your LTC, X's social life, how to seek support, how to cope with current or future situations]*
17. *What do you think might help to support your carer in their role?*

Section C – The BREATHE system and monitoring

The idea of the BREATHE system, which is being designed, is to support carers by doing two things: (1) Providing some information to a carer from some monitoring equipment in the home of the person with a Long Term Condition – this would reassure a carer, and let them know if there were any problems or emergencies and (2) providing some information and support to the carer so that they would know how best to provide care to the person with a Long Term Condition. Here is a separate sheet which describes the possible ways that the BREATHE system might monitor people in their homes, in order to provide support to carers. [Give time for the participants to look at the sheet – Appendix 2]:

18. *If there was an emergency relating to your situation at home, do you think it would be useful for X to be able to "see" you at home in a way that is described on the sheet?[e.g. see actual video footage of you, or see your position in a room]*
19. *If yes, in which rooms would you be happy to be monitored in some way?*
20. *Would you be happy for a health professional to see this information?*
21. *Would you also like X to be able to know about what you are doing or how you are, in some non-emergency situations?*
22. *If yes, in which rooms would you be happy to be monitored in some way?*
23. *Would you be happy for a health professional to see this information?*

As well as visual information, the BREATHE system could send information reports to X's smartphone, for example "N is fine today", or "N has not been to the bathroom since yesterday". This information could be based on specific information that you have chosen together in advance.

24. *If information could be sent to X about you, would you prefer the information to be:*
    - *i. Sent to a smartphone automatically (like a text message)*
    - *j. Available for you to look at whenever you like (like looking at a webpage in your own time)?*
    - *k. Neither*
    - *l. Both*
25. *Would you want the system to provide some care support to you if your carer was not available? [for example, the system could help you to contact someone if you needed help]*

Section D – Obtaining and using the BREATHE system

This final part is about how the technology might be provided, and how people might be involved in using it.

26. *If you were using the BREATHE system, and it asked you to spend a few minutes to complete on-screen questionnaires as part of the system, would you be prepared to do this? [For example, the questions might be about whether you had eaten a meal.]*
27. *Similarly, if the system worked in a way that meant you had to complete on-screen brief on-screen diaries, would you be prepared to do this? [For example, the questions might be about how you were feeling or whether you needed any help.]*

Thank you. That is the end of our questions.

28. *Is there anything else you would like to ask, or anything else you would like to tell us?*

Thank you very much for taking part in this research, we value your views and will respect your privacy by keeping your answers anonymous. We will only use this information in relation to the BREATHE project.

3.4.1.4 Questionnaire for professionals with a view on caring to people with LTCs

Thank you for agreeing to take part in this study. Your involvement will help us to understand the potential needs for this type of technology, and will indicate how to make the technology as useful as possible for informal carers of people who have Long Term Conditions (LTCs). We will be asking carers and people who have Long Term Conditions what they think too, but this is an opportunity to tell us what you think from your point of view in your professional role. Do feel free to ask any questions during the session – the interviewer will be happy to provide you with any more information about the work or to explain the questions in more detail.

Section A – About your circumstances

Firstly, we would like to ask you some questions about you. This will help us to understand your views, and will help us to make the best use of the answers that you provide. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. *What is your current role?*
2. *How long have you been in this role*
3. *What types of Long Term Conditions have you experienced in this role?*

Now we have a few questions about your own use of technology:

4. *Do you use a smartphone?*
5. *Do you use a tablet computer (e.g. an iPad)?*
6. *Do you use the internet at all?*
7. *If yes, what device do you use for this? (PC, laptop, tablet, smartphone…)*

8. *How often do you use the internet?*
9. *In your professional role, do you have experience of informal carers of people with Long Term Conditions using any assistive technology (for example any technology which helps with practical or medical needs)?*

Section B – Your view on the role of informal carers

As you know, this project is about designing some technology that might help to support informal carers. So, we would like to ask you about some of your experiences of informal care, to help us to understand what you think the real needs are for this kind of technology. So, thinking about your role as a carer.

10. *What are the 3 things that you think cause informal carers to worry the most about someone with a Long term Condition? [if needed, some examples are: time pressure, carers' own health and wellbeing, carers' knowledge of the LTC, carers' social life, how to seek support, how to cope with current or future situations]*
11. *What do you think might help with the things that you have mentioned [ask about each one in turn]?*
12. *What are the top 3 concerns you think informal carers have about themselves in relation to their caregiving role? [if needed, some examples are: what financial/practical support they receive, any emergency when X is alone at home, the quality of care that others provide, how to deal with acute episodes relating to the LTC, what to do if the LTC condition gets worse]*
13. *What do you think might help with these things [ask about each one in turn]?*

Section C – The BREATHE system and monitoring

Now we are going to talk about the new technology that we are planning to design. You might have mentioned some of these already, which is fine, but please consider each of these different possibilities:

14. *Would it be useful to you to find out about the person they provide care for, in any of the following ways, in order to be reassured about their wellbeing?*
    a) *Would they like to know about the person's daily routine? [for example, sleeping, eating, drinking, going out]*
    b) *What about risky situations? [for example having a fall, leaving appliances switched on, going out at night]*
    c) *What about location within the home and how active the person is? [for example whether they are moving between rooms or staying in one place]*
    d) *Would they want to know about any social activity? [for example going out, talking on the telephone, having visitors]*
    e) *In your experience, are there any other specific activities they might like to know about?*

Here is a separate sheet which describes the possible ways that the BREATHE system might monitor people in their homes, in order to provide support to informal carers. [Give time for the participants to look at the sheet – Appendix 2]:

15. *If there was an emergency relating to the person with a LTC, do you think it would be useful if the informal carer could look at them at home in a way that is described on the sheet?*
16. *If yes, which way(s) would be the most useful?*
17. *Would they also want to see what they are doing, in some way, in some non-emergency situations?*
18. *If yes, which way(s) would be the most useful?*

As well as visual information, the BREATHE system could send information reports to an informal carer's smartphone, for example "X is fine today", or "X has not been to the bathroom since yesterday". This information could be based on specific information that they have chosen in advance.

19. *If information could be sent to the informal carer, do you think it should be:*
    a. *Sent to the informal carer's smartphone automatically (like a text message)*
    b. *Available to look at whenever they wanted to (like looking at a webpage in your own time)?*
    c. *Neither*
    d. *Both*
20. *Do you think health professionals would want to see any of the monitored data, for example data about activity levels or a record of any emergencies?*
21. *If yes, what kinds of information would be useful to send to a health professional?*

Section D – The BREATHE system giving guidance and support

As we have described already, the BREATHE system could provide monitoring information about a person at home. However, BREATHE could also potentially provide guidance and support for informal carers in their role as a caregiver.

22. *Do you think it would be useful if the system could provide informal carers with information about particular LTCs? (e.g. how to deal with particular aspects of their care, or what to do in an emergency)*
23. *If yes, what kinds of information do you think could be useful?*
24. *Should the system to provide support to the person with the LTC if the informal carer were not available?*

Some informal carers find that caring for someone with a Long Term Condition can affect their health and wellbeing.

25. *Do you think it could be useful if the BREATHE system could monitor the health and wellbeing of informal carers in relation to their caring role? For example, the system could regularly ask the carer about their health and wellbeing and provide some relevant resources to help them based on their answers.*

26. Do you think that it would be useful if the system could help informal carers to get in touch with other informal carers for peer support?

Section E – Obtaining and using the BREATHE system

This final part is about how the technology might be provided, and how people might be involved in using it.

27. If an informal carer were using the BREATHE system, and it asked them to spend a few minutes to complete on-screen questionnaires as part of the system, would they be prepared to do this?
28. Similarly, if the system worked in a way that meant they had to complete on-screen brief on-screen diaries, do you think would they be prepared to do this?
29. If you were interested in using this system, who do you imagine might provide it and pay for it? [examples if needed: a private company; government healthcare; private healthcare cover]
30. Finally, if an informal carer was interested in using this system, do you think they would be happy to install it in the home of the person with the LTC if they were given enough training?

Thank you. That is the end of our questions.

31. Is there anything else you would like to ask, or anything else you would like to tell us?

Thank you very much for taking part in this research, we value your views and will respect your privacy by keeping your answers anonymous. We will only use this information in relation to the BREATHE project.

3.4.2 Focus group sessions

One of the assumptions underpinning the use of focus groups is that the group dynamic can assist participants to express and clarify their views in ways that are less likely to occur in a one-to-one interview. The group environment may offer a sense of 'safety', to those feeling anxious for whatever reason (Harding, 2013). Guidance questions were formulated based upon expert opinion and a literature review. Group size varied from 6 to 11. Participants were required to complete a short socio-demographic questionnaire prior to the commencement of the focus group. A script was used to guide the discussion; the questions are listed below formal carers and informal carers.

All answers were to be provided verbally and not in writing, with the possible exception of the early "About You" information, which could be separated out onto a different sheet. A note taker was available in each focus group. The video recording (optional) made it easier to link all of a person's answers together for analysis. An informal question could be used as an icebreaker, for example go round the room and say where you live:

1. The participants arrive and are welcomed by the researcher.
2. The participants are offered refreshments and shown to the focus group room.
3. The participants are given the opportunity to ask questions about the study.
4. The consent forms are signed if the participants are willing to participate.
5. The audio recorder and video recorder are switched on.
6. The focus group begins and the researcher follows the agreed running order of questions.
7. The interview ends and the audio recorder and video recorder are switched off.
8. The participants are thanked and are free to leave.

Section A – Guideline and script for facilitating focus group discussion (procedures)

The individual interview questionnaires were used as topic guides for the focus groups. The key was flexibility, as the participants may raise issues in a different order, but the interview questions were not necessarily all be covered during the session so that results are comparable between sites.

Prior to starting the session, the following explanation was given**:**
The session will be in the form of a discussion, you don't need to wait to be invited to step in but please try not to talk over one another, let the person finish their point before you start yours. There are no right or wrong answers, we just want to hear everyone's point of view, so feel free to disagree with each other.

An icebreaker was used to allow the group to get to know each other, and to help to differentiate between the different participants on the audio recordings. Firstly, we would like to go around the group ask everyone to introduce themselves and give a little background information. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. *Your name.*
2. *What types of Long Term Conditions have you experienced in your role as a carer?*
3. *How long have you been a carer?*

At the end of each Section, the group is asked:

4. *Would anyone like to add anything else on the points raised so far? If no, we'll move on to the next set of questions.*

At the end of the session, the group is asked:

5. *We will just finish off by going round the group and asking everyone if they have any final comments to make or add anything to what we have discussed here.*

Section B – Formal carers (focus group questions)

1. *What are the main things that cause you to worry the most about people who have Long Term Conditions?*
   a. *What do you think might help with these?*
2. *What are the main concerns that you have about yourself in relation to your caregiving role,*
   a. *What do you think might help with these?*
3. *Would it be useful to you to find out about X in any of the following ways, in order to be reassured about the wellbeing of people with Long Term Conditions?*
   a. *Would you like to know about X's daily routine?*
   b. *What about risky situations?*
   c. *What about location within the home and how active the person is?*
   d. *Would you want to know about any social activity?*
   e. *Are there any other specific activities you think you would like to know about?*
4. *If there was an emergency relating to the person with a Long Term Condition, do you think it would be useful for you to be able to look at someone with a Long Term Condition at home in a way that is described on the sheet?*
   a. *If yes, which way(s) would be the most useful to you, and why?*
5. *Do you think you also want to be able to see what they are doing in some way, in some non-emergency situations?*
   a. *If yes, which way(s) would be the most useful, and why?*
6. *Do you think it would be useful if you could be notified of emergency situations from several clients in one centrally-managed way, as part of a service?*
7. *If information could be sent to the you about your clients, do you think it would be better for the information to be (a) Sent to a smartphone automatically (like a text message), (b) Available for you to look at whenever you chose (like looking at a webpage in your own time), (c) Neither, (d) Both?*
8. *Do you think health professionals, for example doctors, should be able to see any of the monitored data about your clients, for example data about activity levels or a record of any emergencies?*
   a. *If yes, what kinds of information would be useful to send to a health professional?*

9. *Do you think it would be useful if the system could provide information about the person's long term condition? (e.g. how to deal with particular aspects of their care, or what to do in an emergency)*
10. *If yes, what kinds of information do you think could be useful to informal carers, and why? What kinds of information would be useful to send to a health professional?*
11. *Do you think it could be useful if the BREATHE system could monitor the health and wellbeing of informal carers in relation to their caring role? For example, the system could regularly ask the carer about their own health and wellbeing and provide some relevant resources to help them based on their answers.*
12. *Do you think that it would be useful if the system could help informal carers to get in touch with other informal carers for peer support?*
13. *If you were using the BREATHE system (having had suitable training), and it asked them to spend a few minutes to complete on-screen questionnaires about your clients or your caring role as part of the system, do you think you would be prepared to do this?*
14. *Similarly, if the system worked in a way that meant you had to complete brief on-screen diaries, would you be prepared to do this?*
15. *Who do you imagine might provide and pay for the BREATHE system?*
16. *31. What do you think would be an acceptable price for the BREATHE system, from the point of view of whoever pays for it?*
17. *Finally, if an informal carer was interested in using this system, do you think they would you be happy to install it themselves in the home of the person they provided care for, if they were given enough training?*
18. *Is there anything else you would like to ask, or anything else you would like to tell us?*

Section C – Informal carers (focus group questions)

1. *What are the main things that cause you the most worry about X?*
2. *What do you think might help with these?*
3. *What are your main concerns you have in relation to yourself as a caregiver?*
4. *What do you think might help with these?*
5. *Would it be useful to you to find out about X in any of the following ways, in order to be reassured about X's wellbeing?*
    a. *Would you like to know about X's daily routine?*
    b. *What about risky situations?*
    c. *What about location within the home and how active they are?*

d. Would you like to know about any social activity?

e. Are there any other specific activities you would like to know about?

6. *If there was an emergency relating to X, do you think it would be useful to be able to look at X at home in a way that is described on the sheet (Appendix 2)?*

   a. If yes, which way(s) would be the most useful to you and why?

7. *Would you also like to be able to see what X is doing in some way, in some non-emergency situations?*

   a. If yes, which way(s) would be the most useful to you and why?

8. *If information could be sent to you about X, would you prefer the information to be (a) sent to your smartphone automatically (like a text message), (b) available for you to look at whenever you like (like looking at a webpage in your own time), (c) neither or (d) both?*

9. *Would you want health professionals to see any of the monitored data about X, for example data about activity levels or a record of any emergencies?*

   a. If yes, what kinds of information would be useful to send to a health professional?

10. *Do you think it would be useful if the system could provide you with information about X's long term condition?*

    a. If yes, what kinds of information do you think could be useful?

11. *Would you want the system to provide support to X if you were not available?*

12. *Do you think it could be useful if the BREATHE system could monitor the health and wellbeing of carers in relation to their caring role? For example, the system could regularly ask the carer about their health and wellbeing and provide some relevant resources to help them based on their answers.*

13. *Do you think that it would be useful if the system could help carers to get in touch with other carers for peer support?*

14. *If you were using the BREATHE system, and it asked you to spend a few minutes to complete on-screen questionnaires as part of the system, would you be prepared to do this?*

15. *Similarly, if the system worked in a way that meant you had to complete brief on-screen diaries, would you be prepared to do this?*

16. *If you were interested in using this system, who do you imagine might provide it and pay for it?*

17. *What do you think would be an acceptable price for the BREATHE system, from the point of view of whoever pays for it?*
18. *Finally, if you were interested in using this system, would you be happy to install it in X's home if you were given enough training?*
19. *Is there anything else you would like to ask, or anything else you would like to tell us?*

3.5 Data analysis

Data analysis was conducted separately using a quantitative method for the demographic data and a qualitative approach for the focus groups and individual interviews. These data were transcribed verbatim and subjected to content analysis using the technique outlined by Elo and Kynga (2008). This methodology involves the distillation through analysis of words, phrases and themes, so the content can be systematically organised into a structured format to relate to categories or themes (Liamputtong and Ezzy, 2005). The extraction process involved highlighting phrases and/or a sentence made by participants from both the focus groups and individual data relating to their views on the acceptance and use of technology in the home to support care giving. The coded data were compared and contrasted for agreement and finally reviewed by an independent researcher for verification. Participant anonymity and confidentiality were maintained at all times with identifiers.

3.6 Ethical approval[1]

Due to the nature of the project where individuals were required to volunteer personal information about their caring roles and needs it was necessary to obtain ethical approval. Ethical approval was sought prior to commencement of data collection local ethics committees associated with the three project sites responsible for data collection; namely Spain, Ireland, and U.K. All material pertaining to data collection (protocols, questionnaires, scripts for focus groups, flyers describing project and proposed technologies as well as consent forms) were prepared in line with local procedures and submitted as part of the application. In Ireland, ethics approval was sought from the Faculty of Health Sciences - Faculty Research Ethics Committee (F.R.E.C.) at Trinity College, Dublin. Ethical approval was required for TCD from the Faculty of Health Sciences Research Ethics Committee (REC) at TCD. Applicants had to complete a detailed Ethics Application Form which described the study aims, objectives and methodologies, alongside any supplementary materials (e.g. participant information sheets, questionnaires) for review at an Ethics Committee meeting (usually held monthly).

[1] An intensive review about the ethical approval process followed by all partners in charge of manage the individual interviews and focus groups has been done in the public deliverable D1.3 – Trials strategic plan. This document can be downloaded for free from http://breathe-project.eu/en/publications/

For the BREATHE study, the process was split into two separate applications as these required different methodological approaches and posed different ethical challenges:

1. Application to conduct the interviews and focus groups for user-requirements (WP1).
2. Application to conduct field trials (WP4).

As an SME, CYB do not require ethical approval from an external board. Approval for participation was obtained from the Cybermoor Board for conducting the interviews and focus groups for the user-requirement stage of this research. The BREATHE Ethics Board provided guidance on ethical issue during this project. Similarly, ISI does not require ethical approval from an external board and is therefore not be required to submit an application for data collection for the user-requirements stage or for the conduct of the field trials. At all stages of the study, the BREATHE Ethics Board will provide guidance and support to ISI on any ethical aspects of the project.

4 Characteristics of study participants

The data collection took place at three sites located in three countries; namely Spain, Ireland and U.K. From here on, the three sites will be referred to as ISI in Spain, TCD in the Republic of Ireland and CYB in U.K. Each site recruited and conducted the data collection independently. In this section, the profile of participants is presented, categorized in terms of formal, informal, and healthcare professionals. The types of LTCs are also described.

4.1 Formal carers (interviews)

In general, the formal carers were caring for persons with dementia, incontinence, Parkinson's disease, Lymphedema, diabetes, physical disabilities, problems consequence of stroke(s), Myalgia Encephalopathy (ME), visually impaired, mobility problems, older age related issues, multiple sclerosis (MS), Motor Neurone Disease (MND), heart conditions, bone problems and high blood pressure. The table below shows the participant profile of formal carers at each of the three sites.

Sample characteristic n or %	**Cybermoor Services LTD (CYB), UK**	**Iniciativa Social Integral (ISI), Spain**	**Trinity College Dublin (TCD), Ireland**
n	5	9	No data
Gender			
Female	90	100	
Male	10	0	
Age (in years)			
Mean	47.6	48.9	
Range	40-55	37-56	

Table 3 - Participant profile of the formal carers interviewed per country

The mean length of time as a carer was 9.4 years (range 2 to 19 years) for CYB and 5.3 years (range 1.5 to 12years) based on only 3 participants who answered this question. The health status for CYB ranged from poor to excellent; in general the health status of ISI carers was good. All participants used the Internet; CYB used broadband whereas ISI used broadband and Cable (ADSL). In rank order, the Internet was used in CYB on devices such laptops, desktops and smartphones. In ISI, in rank order, it was used on smartphones, laptops, tablets, desktop or PCs, IPads and internet-connected TVs. The frequency of Internet usage for both CYB and ISI samples ranged from daily use to weekly use. With regard to the use of assisted technology (AT), 60% in CYB used AT and all, 100% in ISI. The types of AT used by CYB carers, in rank order, were care alarms, talking devices (visually and mobility impaired) e.g. clocks, scales, lights, TV, and smoke detectors. The types of AT used in ISI, in rank order, were alarms (specific types not stated).

4.2 Informal carers (interviews)

In general, the informal carers were caring for family members e.g. husband, wife, parents, in laws, close relatives, such as, aunt, uncle, grandfather and in some cases a friend or a neighbour. These carers were caring for persons recovering from cancer, those with problems consequences of pneumonia, visual impairment, problems associated with ageing, Alzheimer, osteoporosis, kidney and heart failure, diabetes, incontinence and catheter, mobility problems C.O.P.D, diverticulitis, peripheral arterial disease, general unsteadiness, mental health problems, respiratory, problems with the heart, COPD, disabilities related to stroke(s), Parkinson's and arthritis. The table below shows the participant profile of informal carers at each of the three sites.

Sample characteristic n or %	Cybermoor Services LTD (CYB), UK	Iniciativa Social Integral (ISI), Spain	Trinity College Dublin (TCD), Ireland
n	7	12	9
Gender			
Female	90	67	67
Male	10	33	33
Age (in years)			
Mean	59.7	50.8	54
Range	50-81	42-65	43-65
Employment status			
Employed	71	6	100
Retired	14	7	0
Other (including unemployed and housewife)	14	0	0
Not known		33	0

Table 4 - Participant profile of the informal carers interviewed per country

The average number of caring hours per week was 49.1 hours (range 10-168 hours) for CYB, 50.8 hours (range 42-65 hours) for ISI and 54 hours (range 43-65 hours) for TCD. The health status for CYB ranged from fair to excellent; fair to good for ISI and poor to good for TCD. In CYB, 29% of the carers lived with the cared for person, 50% in ISI and 89% in TCD. Some of the carers lived next door to the cared for, whilst other lived up to 20 to 100 miles away. Phone contact with cared ranged from 3 times a day to every day in CYB, daily to 3 times a week in ISI and daily (1) in TCD. One person in ISI had a panic button linked to their telephone line. Health and social care support occurred 86% in CYB, 100% in ISI and 33% in TCD. The type of help (in rank order) in CYB was a cleaner, district nurse, other familial support and day-care centre respite. In Spain, all persons with a LTC were assisted by the National Health Public System (NHPS). In Ireland, support came from HSE home help, the Alzheimer Society of Ireland and respite from the carers association. Medical cover was 100% in all cases across all countries (not specified).

All CYB and ISI participants used the Internet; 90% in TCD. CYB and TCD used broadband and Wi-Fi, ISI used broadband and Cable (ADSL). In rank order, the

Internet was used in CYB on devices such as laptops, IPads, desktops and smartphones and tablets. In ISI (in rank order), it was used on PCs, smartphones, laptop, tablets and smart TVs. Frequency of Internet usage for both ISI and TCD samples ranged from daily use to weekly use. CYB participants used the Internet daily. With regard to the use of AT 57% in CYB, 82% in ISI and 89% in TCD. Types of AT used in CYB, in rank order, were care alarms, stair lifts and bath entries. Types of AT used in ISI, in rank order, were emergency/panic buttons, alarm systems (not specified) and adapted mobile phones. Types of AT used in TCD, in rank order, were pendant alarms, adapted seating, swivel seat over bath for assisted showering, stair lift, second generation telecare, adjustable beds, powered wheelchairs, peritoneal dialysis kit and a baby monitor.

4.3 Persons with long-term conditions (interviews)

The caregiving in the UK was carried out by a family member. No data were available for Spain. Persons cared for have issues and/or problems with their hearing and sight, a snapped Achilles tendon, hip and knee replacements, COPD, diverticulitis, osteoporosis, paralysis, Thalidomide's syndrome, chronic muscle fatigue and fibromyalgia.

Sample characteristic n or %	Cybermoor Services LTD (CYB), UK	Iniciativa Social Integral (ISI), Spain	Trinity College Dublin (TCD), Ireland
n	2	5	No data
Gender			
Female	100	60	
Male	0	40	
Age (in years)			
Mean	80	65.6	
Range	77-83	50-83	

Table 5 - Participant profile of the people with LTCs interviewed per country

The number of hours that they are cared for per week on average are 89 hours (range 10-168 hours) in the UK and 101.2 hours in Spain (range 2-168 hours). Their health status ranged from poor to fair (UK) and bad to good (Spain). In the UK, 50% of cared for persons lived with their carer; 60% in Spain. The carers not living with the cared for lived up to 14 miles away (phone contact every day) or up to 15 minutes, walk away. For those not living with their carer the phone contact frequency ranged from every-day (UK), to daily-frequency (Spain). Health and social care support occurred 50% in CYB and 60% in Spain. The type of help in CYB was a cleaner. The UK sample did not have medical cover as they had the NHS provision available in the UK). In Spain, all persons with a LTC were assisted by the National Health Public System (NHPS). In the UK, 50% of participants used the Internet; 60% in Spain. CYB used broadband and Wi-Fi, ISI used Cable (ADSL). In rank order, the Internet was used in CYB on devices such as laptops. In ISI (in rank order), it was used on smartphones, PCs and laptops and tablets. The UK sample used the Internet daily. Spanish counterpart's usage ranged from rarely to daily. The entire UK sample used AT however the type was not specified; 80% of the Spanish sample used AT, which included panic buttons.

4.4 Health and social care professionals (interviews)

Health and social care professionals interviewed included an occupational therapist working in Community Adult Social Care having worked with persons with neurological conditions, stroke, MS, Huntingdon's, dementia and varied disabilities in the past, a Community Nursing Sister with 27 years experienced currently working with persons with cancer, congestive heart conditions and consequences of stroke(s), and a social worker in the council service helping people with dependency having worked as a caregiver and social worker for 6 years with handicapped and the aged.

Sample characteristic n or %	Cybermoor Services LTD (CYB), UK	Iniciativa Social Integral (ISI), Spain	Trinity College Dublin (TCD), Ireland
n	2	2	No data
Gender			
Female	50	100	
Male	50	0	
Age (in years)			
Mean	57	37	
Range	48-66	33-41	

Table 6 - Participant profile of the professionals interviewed per country

All the participants used the Internet; broadband. In rank order, the Internet was used in CYB on devices such as laptops, smartphones and desktops. In ISI (in rank order), it was used on smartphones, laptops, tablets and desktops. Frequency of Internet usage for the UK was every day to every week; daily for Spain. All participants used AT. In the UK, checking systems, care alarms, smoke detectors and equipment for the visually impaired were used; in Spain, the red alarm button and fixed assistance telephone lines.

4.5 Formal carers (focus groups)

In general, the formal carers were caring for persons with dementia, MS, Parkinson's, problems consequence of stroke(s), COPD, older age related issues, mobility issues and Alzheimer's.

Sample characteristic n or %	Cybermoor Services LTD (CYB), UK	Iniciativa Social Integral (ISI), Spain	Trinity College Dublin (TCD), Ireland
n	6	6	11
Gender			
Female	90	100	100
Male	10	0	0
Age (in years)			
Mean	No data	No data	No data
Range	No data	No data	No data

Table 7 - Participant profile of the formal carer interviewed (focus group) per country

The mean length of time as a carer was 5.6 years (range 15 months – 12 years) for CYB, 8.9 years (range 2.5 – 23 years) for ISI and 7.5 years (range 3-14 years) for TCD. The health status for CYB ranged from fair to good and good to excellent in TCD. No data were available for ISI. In the UK and Spain 83% used the Internet, 64% in Ireland. The UK and Ireland used broadband, Spain Cable (ADSL). In rank order, the Internet was used in CYB on devices such smartphones, desktops, laptop, IPads and tablets. In ISI, in rank order, it was used on laptops, PCs, smartphones and tablets. In TCD, in rank order, desktops, laptops, tablets and smartphones. The UK participants use the Internet on a daily basis; the Spanish sample never to daily and the TCD sample daily to weekly. All UK participants used AT, 50% in Spain (types unspecified) and 27% in Ireland. In the UK, in rank order, fall alarms, possums, care alarms, assisted chairs and fire and heat sensors. In Ireland, in rank order, fall alarms and log in/out landline systems.

4.6 Informal carers (focus groups)

In general, the informal carers were caring for family members with LTCs e.g. father, mother, husband, wife, daughter and/or brother. These carers were caring for persons with dementia, MS, Parkinson's, problem consequence of stroke(s), COPD, cancer, old age issues, mobility issues, Alzheimer's, amputees, limited autonomy, Down's syndrome, autism, epilepsy, intellectual disability and mental health issues.

Sample characteristic n or %	Cybermoor Services LTD (CYB), UK	Iniciativa Social Integral (ISI), Spain	Trinity College Dublin (TCD), Ireland
n	No data	6	5
Gender			
Female		50	90
Male		50	10
Age (in years)			
Mean		No data	65.2
Range		No data	54-78
Employment status			
Employed		No data	20
Retired		No data	No data
Other (including unemployed and housewife)		No data	60
Not known		No data	No data

Table 8 - Participant profile of the informal carer interviewed (focus group) per country

The Irish sample stated that they care for the person with LTC(s) 24 hours a day, 7 days a week. No data was available for Spain. Their health status ranged from bad to good in Spain and fair to good in Ireland. Some of the carers lived very close to the cared for person, mothers more than an hour away. There was daily phone contact with a cared person in Spain; No data was available for Ireland. Health and social care support occurred 60% in Ireland; specified help was home help. No data was available for Spain.

There was medical cover in 60% of cases in Ireland (the type not specified); no data from Spain. In Spain 67% used the Internet (broadband), 60% in Ireland (not specified). The Spanish sample used their mobiles to access the internet whilst the Irish sample used their laptops and desktops (in rank order).The Irish participants use the internet every week to less than on a monthly basis; no data from ISI. In the Spain, 83% of cases used AT (not specified), 40% in Ireland. The types of AT used in Ireland included mobile phones and pendant alarms (in rank order). All UK participants used AT. 50% in Spain (types unspecified) and 27% in Ireland. In the UK, in rank order, fall alarms, possums[2], care alarms, assisted chairs and fire and heat sensors. In Ireland, in rank order, fall alarms and log in/out landline systems.

[2] Telecare product and services - http://www.possum.co.uk/products-and-services (Accessed on January, 2014)

5 Findings

5.1 Concerns of formal carers, informal carers and health and social care professionals

The main concerns of the formal carers, informal carers and health and social care professionals regarding the person(s) they are caring for with a long-term condition(s) (LTC) varied. It should be noted that the persons with LTCs stated that they believe that their carers are worried about them for the following reasons: breathing difficulties, falling and fall detection, having limited help to care for them, dependency, being housebound and having a lack of autonomy.

5.2 Concerns of carers and health and social care professionals with regards to self

Carers and health and social care professionals have concerns about the impact of caring for the person with LTC has on their own personal and social life. Other concerns include exhaustion, lack of familial support and respect, financial burden, incompetency in certain situations, own health and safety, physical and psychosocial health, pressure, recognition, relationship with person with LTC, sleeping, time constraints, future ability to be able to provide adequate care and lack of knowledge about the person's needs. The main concerns of the formal carers, informal carers and health and social care professionals regarding the person(s) they are caring for with a long-term condition(s) (LTC):

Concerns of the formal carers, informal carers and health and social care professionals
• Ability to do activities of daily living safely. • Being warm enough. • Care usefulness. • Consistency of care. • Death. • Distress. • Domestic accidents. • Drinking. • Eating (pattern). • Economic/money handling issues. • Falling. • Fire. • Health deterioration. • Isolation. • Lack of autonomy. • Loneliness. • Losing consciousness. • Medication management. • Mobility issues. • Motivation. • Overall wellbeing. • Psychological health.

• Security. • Sleeping (pattern). • Stigma around mental illness. • Stranger danger. • Wandering outside.

Table 9 - Concerns of the carers and professionals

5.3 Identified aid and/or support for carers and health and social care professionals

The following support and/or aids identified to help in caring for the person with a LTC(s) and which would make their life easier are listed in alphabetical order.

Aids to help in caring for the assisted person
• Access to help for practical and specialist support. • Assisted technology including alarms, detectors, handling and lifting devices, internal cameras, monitoring systems, pressure pads, movement and door sensors ("new technological and affordable aids which can be used for improving the quality of the care"). • Family support. • Financial support. • Home help. • Managerial support. • Occupational therapy assistance. • Psychosocial support. • Respite. • Social support and stimulation. • Support groups. • Support networking. • Training for carers.

Table 10 - Aids to help in caring for the assisted person

Those being cared for believe that cleaners, psychosocial and physical support from others are needed to help the person(s) who care for them. Regarding the indoor video-based monitoring system, the table below shows the acceptance/non-acceptance of cameras in the home of the person with a LTC(s) and under what circumstances (if any) these are acceptable:

	Cybermoor Services LTD (CYB), UK				Iniciativa Social Integral (ISI), Spain				Trinity College Dublin (TCD), Ireland			
	Formal carer	Informal carer	Assisted person	Professionals	Formal carer	Informal carer	Assisted person	Professionals	Formal carer	Informal carer	Assisted person	Professionals
Daily routine knowledge	Yes	Yes	No data	Yes	Yes	No data	No data	Yes	No data	No data	No data	No data
Risky situation knowledge	Yes	Yes	No data	Yes	Yes	Yes	No data	Yes	No data	No data	No data	No data
Location and/or activity in home knowledge	Yes	Yes	No data	Yes	Yes	Yes	No data	Mixed views	No data	Yes	No data	No data
Social activity knowledge	Yes	Yes	No data	Yes	Yes	Yes	No data	Mixed views	No data	No	No data	No data
Use of cameras in emergency situation	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No data	No data
Use of cameras in non-emergency situation	No data	No data	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No data	No data
Self-installation	No	Yes	No data	Yes	No	No	No data	Mixed views	No	Yes	No data	No data

Table 11 - The acceptance/non-acceptance of cameras in the home

	Cybermoor Services LTD (CYB), UK				Iniciativa Social Integral (ISI), Spain				Trinity College Dublin (TCD), Ireland			
	Formal carer	Informal carer	Assisted person	Professionals	Formal carer	Informal carer	Assisted person	Professionals	Formal carer	Informal carer	Assisted person	Professionals
Use of cameras in emergency situations												
1st option	C	F	No	G	A	A	A	A	A	A	No data	No data
2nd option	G	No	No	A	B	C	G	B	No option	D	No data	No data
3rd option	D	A	No	B	C	D		C	No option	No option	No data	No data
Use of cameras in non-emergency situations												
1st option	No data	No data	No	A	N	D	No	B	No data	No data	No data	No data
2nd option	No data	No data	No	G	G	C	A	E	No data	No data	No data	No data
3rd option	No data	No data	No	No option	B	A	G	No option	No data	No data	No data	No data

Table 12 - Use of cameras under which circumstances (see Appendix 2)

A	Show real footage of a person in the room	**E**	Show an empty room if there is no cause for concern
B	Show only silhouettes of the person	**F**	Show the person's location within the room if there is a query about the person's safety or wellbeing
C	Show the person as a stick figure	**G**	Show the person's position and posture, or even real footage, if the system thinks that the person needs help
D	Show cartoon-like people in place of real		

Table 13 - Legend of table 12 (use of cameras under which circumstances)

5.4 Formal carers

In rank order, the UK sample stated that the preference of type of notification of emergency situations was smartphone/text message, both, webpage, email then neither. In Spain, the preference was smartphone/text message, webpage and both (in rank order). Information to be centrally monitored was agreed upon in the UK and Spain but mixed views were held in Ireland. The type of information from the central system monitoring included whether the person with LTC(s) was having a good or bad day and mobility issues (UK). Neither Spain nor Ireland specified types. Monitoring information to be sent to health professionals was agreed upon in the UK and Spain but not in Ireland. Types of information to be monitored including capacity, habits, lifestyle, routine, medication, mobility use of AT, falls, medical issues, to co-ordinate services in the UK and appropriate service dedication, biometric and medical parameters, guidance and support and Images of LTC person in Spain.

Both UK and Spanish samples agreed that information regarding the person with an LTC should be available; Ireland had mixed views. The types if information specified by the UK were contact numbers for professionals, family and friends, handling issues, information on certain illnesses and what help and what has happened earlier, information re medical condition(s) and medication. Spain specified emotional needs, medication information, protocols of care and AT advances. Ireland specified correspondence from medical services and medical symptoms. The UK sample decided that they would like support if the carer were not available; no data was available from ISI and TCD. All participants across the countries stated that monitoring of the health and wellbeing of informal carers and peer support was important and needed.

With regard to the completion of on-screen questionnaires and on-screen diaries, the UK agreed to do this and Spain agreed but stated that training was needed. Ireland had mixed views about the former; no data was collected for the latter. Payment for the system was thought to be the responsibility of the family and NHS in the UK (National Health Service), the NHS (Spanish National Health System), private company and service users (in rank order) in Spain and the government, family and funding programmes (in rank order) in Ireland.

5.5 Informal carers

Notification of emergency situations was preferred in the form of both and smartphone/text message, (in rank order) for the UK and Spanish samples; Smartphone/text messages, both, webpage from Irish sample. Monitoring information to be sent to health professionals was agreed upon in the UK and Spain but not Ireland except for guidance and reflection. The types of information to be monitored including episodes of ill health, falls (UK, falls/accidents, medical guidance, reasons for problems (Spain). All participants in the 3 countries agreed that information regarding the person with an LTC should be available. Types of information specified by the UK were Medical symptoms (UK), medication (Spain), practical information such as medication and psychosocial health (Ireland). All participants in the 3 countries said that they

would like support if the carer(s) were not available. All participants across the countries stated that monitoring of the health and wellbeing of informal carers/peer support was important and needed. However, in Spain, some who agreed to the monitoring said no to the peer support and vice versa.

With regard to the completion of on-screen questionnaires and on-screen diaries, the Irish sample was not prepared to do either. The UK participants agreed to implement both methods, as did the Spanish sample with training specified. In the UK, payment for the system was regarded as free, the responsibility of the family, government (rank order) in the UK, NHS, family, SUs, insurance company, private company in Spain and government, HSE, health board, revenue, carers association (in rank order).

5.6 Health and social care professionals

Notification of emergency situations was preferred in the form of webpages, email, both (in rank order) in the UK and both in Spain. There was no data from TCD. Monitoring information to be sent to health professionals was agreed upon in the UK (to assess risk) but not in the Spain. There was no data from TCD. Both UK and Spanish samples agreed that information regarding the person with an LTC should be available; there were no data from TCD. The types of information specified by the UK were specialist support, who and how to get it, use of AT; advice, emergency protocols, how to manage AP, medical information specified by Spain. The UK sample decided that they would like support if the carer(s) was not available; Spain had mixed views. No data was available from TCD.

There were mixed views about monitoring the health and wellbeing of informal carers/peer support in the UK; Spain said no to the monitoring but that peer support was needed. There were mixed views by the UK participants on completing on-screen questionnaires; there was no data from ISI. UK participants said no to the completion of on-screen diaries; there was no data from ISI. Payment for the system was thought to be the responsibility of the government and social services in the UK and private companies, NHS, families and SUs in Spain.

5.7 Persons with long-term condition (LTC)

These persons stated that they would like their carers to be notified in emergency situations; UK participants did not specify how they would like to be notified; Spanish participants stated smartphone/text message, both (in rank order). Support when carers were not available was a request from the participants in both countries.

The UK persons did not want to complete on-screen questionnaires and had mixed views about completing the on-screen diaries. Their Spanish counterparts agreed to compete the on-screen questionnaires but not the diaries.

6 Qualitative analysis of the data

The data from the interviews and focus groups were transcribed verbatim in English and content analysed using the technique outlined by Downe-Wamboldt (1992). This involves the analysis of words, phrases and categories, so that themes can be identified. Participant anonymity and confidentiality were maintained at all times with identifiers. The extraction process involved highlighting any phrase and/or a sentence made by participants that referred to the use of AT in general, BREATHE software/hardware in particular, its acceptability, usability and general e.g. ease of use, under what circumstances, willingness to complete on-line documentation. A research psychologist independently coded all the transcript data according to the project protocol for data analysis to ensure homogeneity of procedure. All coded data were in English.

6.1 Results from the thematic analysis

It is apparent from the data that the carers and health and social care professionals have varied and quite extensive concerns about the person(s) they care for, identified as physical, psychosocial and encompass activities of daily living. Concerns regarding themselves include physical and psychosocial needs, economic, quality of life and competency. Identified support for these persons appeared to be bio-psychosocial, training and education. The acceptance of cameras and the circumstances (if any) under which they would be acceptable plus data sharing and data collection were examined from a qualitative standpoint.

6.2 Formal carers

From the analysed data, the following 2 broad themes were identified for the formal carers primarily from CYB and ISI; there are limited data from TCD. These will now be discussed with illustrative quotes from the data.

6.2.1 Usefulness of the technology

Under the umbrella of this broad main theme falls qualitative data with regard to the availability and accessibility of the equipment, impact of the care role, the importance of the continuity and/or communication of care and peer support. In general, both countries feel positive that BREATHE is generally a good system whereby they could potentially ‘care’ for the person with a LTC(s) with peace of mind as well as having support for them as carer.

Formal carers main feelings about the usefulness of the technology
• *I think the camera would be a huge help (TCD).*
• *It is good to have debriefing as you can close the door and go home with peace of mind (CYB).*
• *It would be wonderful. In case of emergency healthcare professional can manage the situation even in a remote way. Professionals can coordinate the most appropriate emergency service too (ISI).*
• *Sounds like Breathe will be a very positive proposal for caretakers (ISI).*
• *If it could be used to record client concerns or worries, so the information is passed on to their next carer (CYB).*
• *BREATHE project sounds really good even for me that I don´t understand anything related with technology (ISI).*
• *You can share experiences, advices and new tools and techniques (ISI)*
• *Good way to avoid isolation and improve networking between colleagues (ISI).*

Table 14 - Examples of formal carers main feelings about the usefulness of the technology

Data showed the following concerns from the formal carers. Concerns included their knowledge of technology, complexities that may be associated with it, time for data sharing and collection and focus on the technology instead of the person with a LTC(s).

Formal carers main concerns about the usefulness of the technology
• *The caretakers might not be technologically savvy (ISI).*
• *It seems a little bit complex (ISI).*
• *I think that BREATHE is quite complex. I have some doubts about its real usability. It should be a technologically accessible project (ISI).*
• *I have not access to multimedia neither technological devices like tablets/PC (ISI).*
• *Quite often clients don't have any signal, so not sure whether this would be possible (on-screen 'paperwork) (CYB).*
• *It´s important this only takes a few minutes/day (on-screen questionnaires and diaries, otherwise, it´s not practical (ISI).*
• *Not sure that it would be possible within the timeframe allocated for visits (on-screen questionnaires) (CYB).*
• *Would need to cut down/replace paperwork (on-screen questionnaires) (CYB).*
• *The more time I have to spend with technological systems i.e. fill in questionnaires in front of a PC, the less I can dedicate to the assisted person. I prefer to put the focus on the assisted person and not in the technology (ISI).*

Table 15 - Examples of formal carers main concerns about the usefulness of the technology

6.2.2 Invasion of privacy, confidentiality issue and access to information acquired

Data from UK formal carers clearly showed that the use of cameras would be an invasion of privacy in general (even if it was beneficial i.e. in emergency situations). Carers from Spain looking after elderly persons with LTC(s) did not think that the assisted persons would agree to cameras in their homes. Not only was the privacy of the assisted person an issue, the Spanish carers had concerns with regard to their own privacy and the quality control of their work. The findings from this group of participants show a discord in the UK between the usefulness of the technology and the privacy of the person with a LTC(s).

Formal carers main concerns about the invasion of the privacy
• *It would be an invasion of privacy (CYB).* • *Both clients and carers would be uncomfortable with video monitoring. Is it taking away their rights? Would need to ensure that this information didn't infringe on confidentiality (CYB).* • *The cameras are all grand and all, but do you think that the families will feel that their privacy is being taken away, what they do when we are not there is none of our business if you know what I mean. Some families will think, I have a carer coming in for an hour, I just want her to know this amount, I don't want her to know what I do with my family outside of those times. Is it not an invasion on their privacy? (TCD).* • *If the elderly people have to agree (to sign an informed consent) with the installation of cameras inside home, I think that this service won´t be a reality (it´s impossible they accept that) (ISI).* • *(Acceptable) if system allows to watch only to the caretaker and not to other persons. People will be afraid about cameras: how can I ensure they are not recording anything? I have fear that BREATHE will control the quality of my work. I have fear that the system will be used to control the quality of my job (ISI).*

Table 16 - Examples of formal carers main concerns about the invasion of the privacy

6.3 Informal carers

From the analysed data, the following 2 broad themes were identified for the informal carers from CYB, ISI and TCD. These will now be discussed with illustrative quotes from the data.

6.3.1 Usefulness of technology

Comparably to the formal carers, the sample in all the countries feel positive that the BREATHE technology would support them as carers so that they would be able to go about their life with peace of mind. Whilst data from ISI shows that formal carers are not generally keen on cameras in the home of those they care for, the informal carers have a different view.

Although there was some ambivalence using the on-screen questionnaires and diaries, data sharing and collection was generally regarded positively and viewed as a way to improve continuity of care and communication between carers. Peer support was viewed upon as particularly useful in Spain.

Not unlike the formal carers, the informal carers had some concerns about the BREATHE system especially those from the UK, namely the lack of human-centred support, who was being recorded and the consequences of that, and the need for training to use the system in general.

Informal carers main feelings about the usefulness of the technology
• *That's actually a very, very good idea the remote monitoring via camera. I think that is a brilliant idea. I think that's a fabulous idea. Something like that would actually make me feel more confident about going out (TCD).* • *It would be really useful if any room at my parent´s home have a camera installed which let me know what they are doing at any time. It would be great? (ISI)* • *Well I suppose if you got used to doing it, it wouldn't be a problem, it would be normal (on screen questionnaires and diaries) (TCD).* • *Think it would be good to have a way of recording people's concerns and how they feel in some verbal way when it happened, because people often forget things they are worried about by the time someone next comes to see them or it doesn't seem as bad the next day, so they don't mention a concern/issue they had the previous day (on-screen diaries) (CYB).* • *I think it would help with continuity of care and be more efficient (on-screen questionnaires) (CYB).* • *It would be nice to share experiences with people in the same situation (ISI).* • *A more person-centred approach to backing up the informal care system role (CYB),* • *Would the system also monitor carers, as I have concerns that this could be an issue that they might worry about e.g. checking up how often they visit, lead to a blame culture, potential legal implications. Would be very interested in taking part in a pilot project, talking to others about its usefulness in real life scenarios (CYB).* • *I think training in using the equipment/systems would be essential to making it work, perhaps have a 'model' setup, which could be used to both demo the system and for training purpose (CYB).*

Table 17 - Examples of informal carers main concerns about the usefulness of the technology

6.3.2 Invasion of privacy, autonomy of the assisted person and access to information acquired

The informal carers seemed uncertain about invading the privacy of their loved ones and/or the person with a LTC(s) that they care for and seemed to be concerned with the assisted person's autonomy. Concern was also noted for extensive monitoring of the assisted person. The generation issue was also noted from the carers in the three countries.

The carers from the UK and Ireland had concerns with regard to access of the information acquired during monitoring. The overall impression given by this group of carers is that they are not so keen or comfortable with the BREATHE system at present due to the age of the assisted person and would perhaps need to see how it works in 'real life'.

Many of the informal carers live with the assisted person and have commented that such a system would not be necessary as they spend a lot of time with them and know their daily routine, location and activity (including social) in the home and outside of it.

Informal carers main concerns about the invasion of the privacy
• *Do we monitor for accidents? (CYB).*
• *Do we interfere and take away what independence she has left? (CYB).*
• *If I have technology and see something inappropriate but not harmful, am I creating more work and disturbing her more?*
• *24 hours a day monitoring worries me. I do not know if I would want to do this or am ready to do this. I am not too sure because it is private and it would be an invasion of his privacy (CYB).*
• *You don't want someone monitoring you the whole time, morning noon and night (TCD).*
• *That is getting into her privacy and that is Big Brother (CYB).*
• *He would think this an intrusion. He now has an alarm but it took a while for him to say it was (CYB).*
• *It´s important to ensure dignity of our seniors (ISI).*
• *That means passing the barrier of privacy (social activity) (ISI).*
• *Some people will find it intrusive, especially with the generation that we are dealing with. We're used to it, they are not and people have to bear that in mind, before they go and do anything like that, that you basically have to be aware that sometimes, and I know there are lots of courses trying to bring the older generation up to speed with computers, but there are certain elements of the older generation who will not take to computers and all the rest of the technology (TCD).*
• *But surely they use a PIN number or something to get in to the camera? (TCD).*
• *Yeah and you would have to have a password for them to get into the computer. Privacy has a lot to do with it (TCD).*
• *Privacy and data protection are ringing bells big time (ISI).*
• *If you are close to the caretaker you don´t need that info (ISI).*

Table 18 - Examples of informal carers main concerns about the invasion of the privacy

6.4 Health and social care professionals

From the analysed data, the following 3 broad themes were identified for the health and social care professionals from CYB and ISI; there was no data from TCD. These will now be discussed with illustrative quotes from the data.

6.4.1 Usefulness of technology

In general, technological aids are supported by the health professionals to help and/or support those caring for persons with LTC(s). However, there is some scepticism about the use of the BREATHE system and the division in experience of carers to use such a monitoring system. Once again, the Spanish participants are concerned with the absence of the human element of the BREATHE system.

Although carers are busy people the health professionals believe that the collection of on-screen data sharing and collection can be viable and useful. However, there exists a counterargument about the data collection being unrealistic and the purpose behind the tasks.

Professional´s main feelings about the usefulness of the technology
• *There is a lack of conscious about the use of technological aids. People think that those elements are not useful at all. They only notice the price they have to pay. In my opinion, a lot of people would improve the care and their own quality of life with that kind of devices (ISI).* • *I am sceptical as with the level of success you would get. With experience of "Just Checking", it is remarkable how variable professionals and carers find the concept. Some are brilliant and find it easy, others not Individual support not generic training would be needed for a reliable system (CYB).* • *Technological system can´t work on human feelings (ISI).* • *Useful as a sounding board, especially if it could give impartial advice back (CYB).* • *This is not practical neither realistic. Professionals have a lot of things to do (huge number of patients). I think this information would only disturb professionals (ISI).* • *It would depend on how much they trusted the system and providers. I would have to be assured of a good track record (CYB).* • *I am a little bit sceptical this would be useful. I can't see how this would be achievable (CYB).* • *It could be useful from a health or social care professionals point of view if completed, but I don't think it is likely to be achieved (CYB).*

Table 19 - Examples of professional's main concerns about the usefulness of the technology

6.4.2 Consent and privacy issues

Concerns by the health and social care professionals with regard to the BREATHE system centred around capacity to consent to the monitoring, the invasion of the privacy of the assisted person(s) and their dignity, the reluctance of formal carers to be monitored, and monitoring acceptance of the older generation.

A professional from the UK stated something pertinent. These are questions that the technological team need to address – who's opinion and needs matter more? Those of the carers, health professionals or the assisted person(s)? Under what circumstances is the monitoring acceptable and why? Clearly, these circumstances differ across the countries and groups (see tables 12 and 13).

Professional´s main concerns about the invasion of the privacy
• *There are issues around more detailed electronic surveillance, i.e. videoing, for lots of service users. Do they have the capacity to make informed decisions? I would like to reiterate my major concern over "informed consent" of the service user, particularly with cognitive impairment (CYB).*
• *We have to preserve dignity too; to install that kind of devices inside home is quite controversial (ISI).*
• *In my experience, home care agencies are very unlikely to be happy for their staff to be videoed in the process of day to day care delivery (CYB).*
• *The most complicated point about privacy is when BREATHE system will be managed by third-parties: formal carers or another private company. If behind the cameras are the relative it does not mind but in the other case I think is quite complex. You have to get an informed consent from the person (ISI).*
• *The most worried thing for me is how to face with the privacy and ethical issues. To install a camera (even they are not recording anything) inside home is not an easy task. Elderly people are quite unwilling about new technologies (ISI).*
• *I am unsure from the system proposed who the decision maker would be (CYB).*
• *Think live proper footage could be an invasion of the person's privacy, but would be very dependent on the person's personal circumstances (CYB).*
• *There are lots of different aspects that need to be considered and everyone's personal circumstances, personalities and conditions and care arrangements are so different (CYB).*

Table 20 - Examples of professional´s main concerns about the invasion of the privacy

6.4.3 Support for carers

The health and social care professionals recognise that it is in everyone's interest that carers are supported. Many carers face isolation, frustration, physical and psychological ill health. Many carers give up an income, future employment prospects and pension rights to become a carer. Some work and juggle jobs with their responsibilities as carers. The majority of carers struggle alone and do not know that help is available to them. The BREATHE system aims to add to that support with carer monitoring and peer support. This what the health and social care professionals stated.

Professional´s main concerns about the support of carers
• *Good to talk to other people going through a similar experience and share sad, funny, stories, etc. so they didn't feel so isolated and they were the only person going through it (CYB).*
• *They need psychological support too (ISI).*

Table 21 - Examples of professional´s main concerns about the support of carers

6.5 Persons with a long-term condition(s) (LTC(s))

From the analysed data, the following 2 broad themes were identified for the person(s) with a long-term condition(s) from CYB and ISI; there were no data from TCD. These will now be discussed with illustrative quotes from the data.

6.5.1 Technology: apathy versus interest

The use of technology in general and the BREATHE system in general has provoked some strong opinions in the persons with LTC(s). There is an obvious divide between the participants in the UK and Spain. Spanish participants are keen to use the

technology to help themselves and assist/support those caring for them. However, there does seem to be a confusion between the difference between AT in general and the BREATHE system.

Data from CYB showed that persons with a LTC(s) were not keen on technology and the BREATHE system and were reluctant to use or accept the system. There is an assumption in today's society that everybody can use a computer, from the young to the older. This had been captured by a quote from a UK participant. Perhaps a fear or lack of knowledge is the reason for the responses from the UK participants in this instance. The Spanish participants once again focused on the human element of the system and its accessibility to all.

Assisted person´s main concerns about the usefulness of the technology
• *I like everything that helps my daughter to take care about me (ISI).* • *The more features the system has, the better for me (ISI).* • *All things explained regarding BREATHE system sounds very nice. It seems BREATHE will be a useful system (ISI).* • *I don´t understand why I have to purchase a new system like BREATHE if I have the AT system. They are equivalent, aren´t they? (ISI).* • *I cannot see the point of a camera unless the person in unconscious. Is the mike going to be on all the time? There must be some way of putting it on and off. I still say categorically never, ever, ever cameras. The idea is abhorrent. Mikes yes cameras no (CYB).* • *I would not be prepared to use the system (CYB).* • *There is an assumption that everyone can use computers (CYB).* • *You have to put the focus on implementing universal and accessible solutions, otherwise some people will be excluded. (ISI).*

Table 22 - Examples of assisted person´s main concerns about the usefulness of the technology

6.5.2 Privacy and autonomy

Data from CYB shows that cameras in general are not acceptable in any situation. Their Spanish counterparts were more receptive to the monitoring although they still wanted their privacy preserved. The persons with LTC(s) whilst enthusiastic about the system (ISI data) seemed confused and bewildered by the aspects of it. Perhaps they are puzzled by the system in the hypothetical sense and need to consider and experience it in 'real-life' with their carers to foster further opinion.

With regard to those who are not accepting of the system and/or technology in anyway, perhaps it would be useful to interview them further in an unstructured format to gain an understanding of why they hold adverse opinions or example cultural reasons and/or previous bad experiences.

Assisted person´s main concerns about the invasion of the privacy
• *The idea of cameras is abhorrent and would be even if I was bedbound. Definitely no cameras. (CYB).* • *If I wanted anyone to know I would let them know (regarding daily activities in the home and/or non-emergency situations) (CYB).* • *If there isn´t an emergency situation I don´t want that my carers can´t see anything regarding myself neither; my home (ISI),* • *I think this is useful for emergencies. I want to keep privacy in non-emergency situations (ISI).*

Table 23 - Examples of assisted person´s main concerns about the invasion of the privacy

7 Discussion

- The profiles of the ICs in all 3 countries who participated in this WP study, fit the common profile of an IC according to the EUROFAMCARE project (2011) i.e. a woman (76%), aged around 55, quite often the child or child-in-law of the assisted person, less than a half of them are employed, and they dedicate around 46 hours/week, 60 months (5 years) of total length of care. Tables 3 and 6 and sections 6.2 and 6.6 provide evidence for this tally.
- Supporting findings by Bass et al. (2012) and Malhotra et. al. (2012), section 7.3 has identified the aid and/or support for carers and health and social care professionals when caring for a person with a LTC(s) including psychosocial support, financial support and access to help for practical e.g. aids, and specialist support e.g. advice.
- In support of work by Rowan and Mynatt (2005) and Consolvo et al. (2005), the ICs felt positive that the BREATHE technology would support them as carers so that they would be able to go about their life with peace of mind (section 8.3.1). Technologies marketed towards the family and friends of older people rather than the older person themselves would be beneficial from the perspective of the IC(s).
- In accordance with work by the likes of Nehmer (2006), Olivier et al. (2009) and Vergados (2010) all ICs across all the countries would be interested in the technical capability of home monitoring systems to reliably and automatically infer activities and routines of the person with a LTC(s) i.e. daily routine knowledge, risky situation knowledge, location and/or activity in home knowledge, social activity knowledge.
- It has been suggested that many older people are concerned that such technologies may have a negative impact on IC relationships with the person with a LTC(s) (Beach et. al. 2009). Unfortunately, this was not discussed within the 'interview' so no data exists to support or oppose such a claim.
- The thematic analysis (section 8) showed the following themes relevant to each group of respondents. The consistency in themes is evidence of pertinence and relevance. What is noteworthy is that the technology should not be burdensome, be beneficial and above all respect the privacy of all involved in its usage.

Formal carers	Informal carers	Health and social care professionals	Persons with LTCs
• Usefulness of the technology • Invasion of privacy, confidentiality issue and access to information acquired	• Usefulness of the technology • Invasion of privacy, autonomy of the assisted person and access to information acquired	• Usefulness of the technology • Consent and privacy issues • Support for carers	• Technology: apathy versus interest • Privacy and autonomy

Table 24 – Most relevant themes to each participant

7.1 Evaluation of methodology for WP1

7.1.1 Attitude survey (individual interviews)

Wyse (2012) discusses the strengths and weaknesses of survey design in general. The advantages of adopting a survey of attitude are as follows - easy administration, cost effectiveness and short time development in comparison to other data collection methods. Numerous questions can be asked about a subject, giving extensive flexibility in data analysis and a broad range of data can be collected e.g., attitudes, opinions, beliefs, values. These benefits resulted in the intention use of such a design. However, the reliability of survey data is dependent on many factors - respondents may not feel encouraged to provide accurate, honest answers, respondents may not feel comfortable providing answers that present themselves in an unfavourable manner, respondents may not be fully aware of their reasons for any given answer because of lack of memory and/or understanding on the subject. Confirmation of a sound understanding of the BREATHE system by respondents and indeed those collecting data would have been useful e.g. the difference between BREATHE and AT. Data errors due to question non-responses may exist. The number of respondents who choose to respond to a survey may be different from those who chose not to respond, thus creating bias.

7.1.2 Focus groups

Focus groups were chosen as the method of data collection offering the opportunity for peer support, exchange of ideas and sharing of common values (Nachmais et al. 2008, Savin-Baden & Major, 2013). One of the assumptions underpinning the use of focus groups is that the group dynamic can assist participants to express and clarify their views in ways that are less likely to occur in a one-to-one interview. The group environment may offer a sense of ‘safety’, to those feeling anxious for whatever reason (Harding, 2013). Nevertheless, there are specific limitations of the focus group technique, which may have influenced the findings. Carey (1994) identifies censoring and conforming as major pitfalls when conducting focus group interviews. These processes occur when a person withholds and/or alters his/her responses to correspond with the other group members and/or the leader. The processes of conforming and censoring may have potentially influenced the results.

The focus groups were carried out by a variety of experienced and inexperienced people which resulted in some questions not been followed up by sufficiently probing questions. It is unclear if any training was provided for those collecting the data (those inexperienced), and if questions were pilot tested. This was evident by the lack of probing questions and the variations across the groups. Certainly follow-on questions would have been very useful as well as confirmation of a sound understanding of the BREATHE system by respondents and indeed interviewers e.g. the difference between BREATHE and AT, therefore interviews and focus group with technology available would be useful.

Unfortunately, the sample size was small in only three sites and some of the promised data was missing. Nonetheless, whilst generalizability is limited and perhaps trends cannot be accurately determined, one needs to ask whether the small sample affects the results as small studies do allow us to examine the behaviour of individuals to a much greater degree (Samsa, 2013).

8 Outcomes: BREATHE High Level Requirements

Although it is relatively simple to find several technological services and applications on the market nowadays[3], most of them focus on the specific needs of the person cared for and few support the needs of the carer. The BREATHE project takes advantage of this opportunity filling the gap by providing an ICT-based solution (platform) specifically focused on the informal caregivers (family carers) needs. The solution provides the carer with the guidance and support required to improve their quality of life as well as their working conditions (and achieving, as a consequence, a greater efficiency of their care). The outcome of the project BREATHE, the platform will comprise two different modules or sub-systems namely: the AAL home system and the informal caregiver tool. The first module comprising cameras, and multi-function sensors with associated software, will be installed at the assisted person´s home. The function of this module is to collect information periodically and automatically extract information about the assisted person's daily routine, moods, behaviours and activities. The second module, the informal caregiver tool, does not reside in the home of the assisted person, but will be located on servers at the service provider receiving information from the AAL home system. The informal caregiver tool will deliver a variety of services to the informal caregiver community in need of support.

In order to promote the take-up of the BREATHE technology and minimise barriers to adoption by the informal caregivers community (typically a person with limited ICT skills), the available services at the end of the project must meet the initial requirements to ensure acceptance. The aim of this document is to uncover the needs and concerns of carers from the analysis of the data gathered in the individual interviews and focus groups done with informal caregivers in United Kingdom, Spain and Ireland during WP1. The analysed report will provide sufficient information regarding the informal caregivers needs, other actors involved in the care cycle and their relationship with family carers (our focus end-user) and possible marketable scenarios which will help to understand the role played by BREATHE in a future market exploitation.

[3] Long-term care challenges in an Ageing Society: the role of ICT and migrants. European Commission.

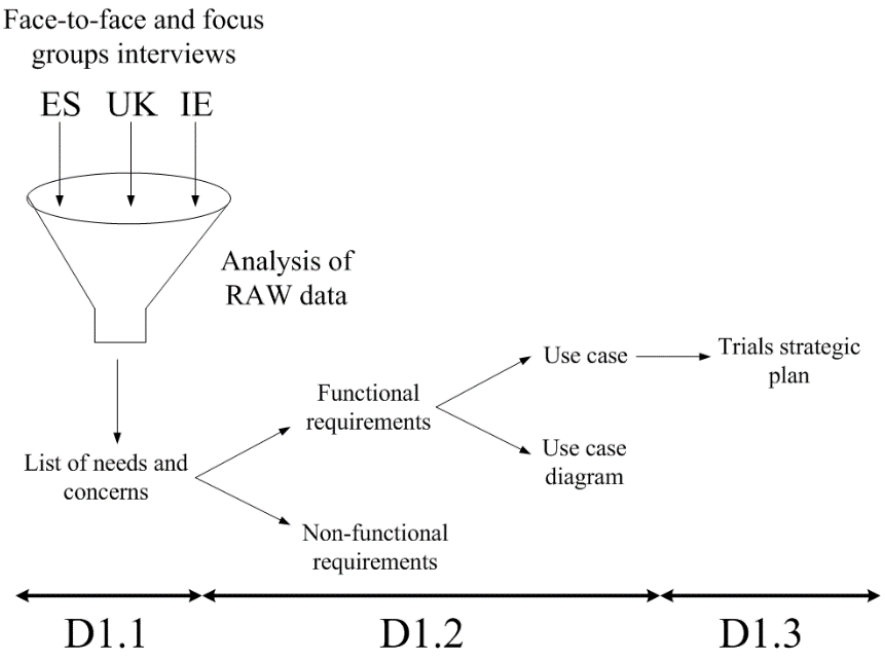

Figure 1 - Relationship between WP1 deliverables

The table below compares profile of the informal caregiver obtained through the consulted bibliography[4] prior to project with the data from all the informal caregiver´s interviews done in WP1 in the three involved countries:

Informal caregivers profile through the consulted bibliography	Informal caregivers profile from BREATHE interviews analysis (UK, Spain and Ireland)

• Female (76 %)
• Mean age (in years) around 55
• 46 hours/week dedication
• Total caring process 60 month (5 years)
• Less than half are employed
• Limited computer skills
	• Female (73 %)
	• Mean age (in years) around 54.8
	• 52 hours/week dedication
	• Unknown data
	• 64 % are unemployed and/or housewife
	• Limited computer skills BUT:
	  ○ 97 % used the Internet (daily-weekly frequency of use)
	  ○ Owned devices like desktops, laptops, tabletsPC and smartphones
	  ○ Users of social media and instant messaging mobile applications
	• 56 % live with the cared for person
	• Cameras accepted as assisted technology in emergency situations (100 %)
	• The majority of ICs accepted cameras as assisted technology in non-emergency situations

Table 25 - Informal caregiver profile (bibliography vs BREATHE analysis of data)

[4] EUROFAMCARE Project. http://www.uke.de/extern/eurofamcare/ (Accessed on January, 2014).

In addition to the informal caregivers, our target end-users, there are two other actors who play an important role on a daily basis and whose characteristics, needs and concerns should be analysed in order to get a better understanding of the desired system as a whole. The aforementioned actors are both the assisted person and the formal carers. The relationship between informal carers and assisted people is clear and it lasts for as long as the residential/home care is performed. In contrast, the relationship between the informal and the formal carers is optional (not always present) and depends on the current situation of the family carer (stress, overwork, etc.) who may resort (or not) to a third-party paid carer. The tables and images below present the analysed data from the point of view of the three actors who will play a different role in the value chain of BREATHE. That information will be taken into account as the starting point of the deliverable D1.2 for defining the use cases required as prior step before the development stage starts.

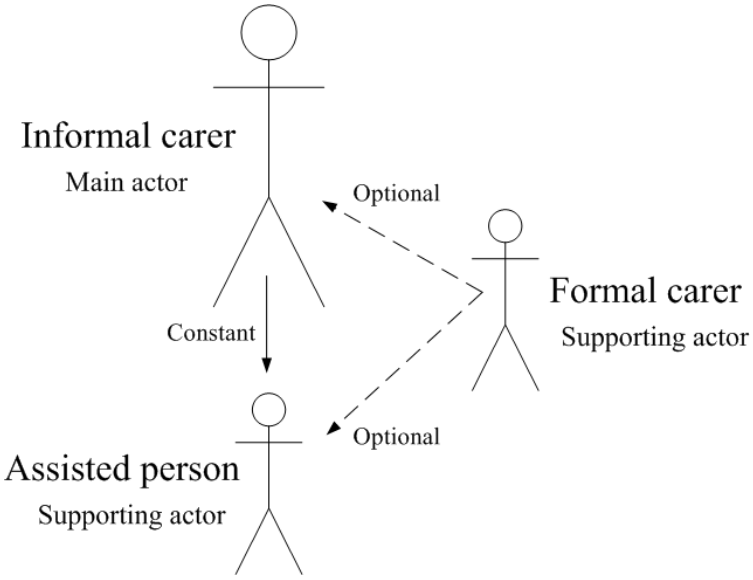

Figure 2 - Involved actors and relationship in BREATHE

Actor	Informal caregiver
Definition	Typically family carers who may or may not live with the cared for person and who care for a person with at least one LTC
Role	Caring for family members e.g. husband, wife, father, father in law, mother, mother in law, uncle, grandfather and in some cases a friend or a neighbour. These carers were caring for persons recovering from cancer, those with problems consequences of pneumonia, visual impairment, problems associated with ageing, Alzheimer, osteoporosis, kidney and heart failure, diabetes, incontinence and catheter, mobility problems, diverticulitis, peripheral arterial disease, general unsteadiness, mental health problems, respiratory, problems with the heart, COPD, disabilities related to stroke(s), Parkinson's and arthritis.
Relationship with other actor/s	Assisted person and formal carer (optionally)
Profile	• Gender: 90 % female and 10 % male (UK) / 67 % female and 33 % male (Spain) / 67 % female and 33 % male (Ireland) • Mean age (years): 59.7 (UK) / 50.8 (Spain) / 54 (Ireland) • Range age (years): 50-81 (UK) / 42-65 (Spain) / 43-65 (Ireland) • Retired: no data (UK) / 50 % (Spain) / 100 % (Ireland) • Unemployed and housewife: 71 % (UK) / 58 % (Spain) / no data (Ireland) • Average of caring hours (per week): 49.1 hours (UK) / 50.8 hours (Spain) / 54 hours (Ireland) • Health status range: fair-excellent (UK) / fair-good (Spain) / poor-good (Ireland) • Live with their cared person: 29 % (UK) / 50 % (Spain) / 89 % (Ireland) • Distance between carers and cared for people when they are not living together: next door-15 minutes walking away (UK, Spain and Ireland) • Contact way for those not living with carers: phone (UK, Spain and Ireland) • Phone contact frequency range: 3 times a day-daily (UK) / daily-3 times a week (Spain) / daily (Ireland) • Medical cover assistance: all of them (UK, Spain and Ireland) • Use of internet: 100 % (UK) / 100 % (Spain) / 90 % (Ireland) • Frequency of use of internet: daily-weekly use (UK and Spain) / daily (Ireland) • Main technological device for accessing on the Internet: laptop (UK) / desktop (Spain) / no data (Ireland) • Secondary technological devices for accessing on the Internet (in rank order): iPad, desktop and smartphone (UK) / smartphone, laptop and tabletPC (Spain) • Use of assisted technology: 57 % (UK) / 82 % (Spain) / 89 % (Ireland) • Types of assisted technologies used (in rank order): care alarms, stair lifts and bath entries (UK) / panic button, alarm systems and adapted phones (Spain) / pendant alarms, adapted seating, swivel seat over bath for assisted showering, stair lift, adjustable beds, powered wheelchairs and baby monitor • Daily routine of the assisted person should be monitored by cameras: yes (UK) / no data (Spain) / no data (Ireland) • Risky situations of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) / no data (Ireland) • Location/activity in home of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) / yes (Ireland)

<table>
<tr><td></td><td colspan="2">• Social activity of the assisted person should be monitored by cameras: yes (UK) / no (Spain) / no (Ireland)
• Acceptance of cameras as assisted technology in emergency situation: yes (UK) / yes (Spain) / yes (Ireland)
• Acceptance of cameras as assisted technology in non-emergency situation: yes (UK) / yes (Spain) / yes (Ireland)</td></tr>
<tr><td>Concerns about cared person</td><td>UK (rank order)
• Fear of falling/fall detection
• Medication prompts
• Kitchen appliances unattended e.g. gas, cooker
• Breathing difficulties
• Becoming unwell
• Stranger danger
• Wandering outside and becoming lost
• Smoke and/or fire detection</td><td>SPAIN (rank order)
• Eating
• Stress levels, mobility e.g. physically getting to the bathroom or shower
• Falling, Loneliness and isolation
• Accidents in general e.g. domestic accidents from cooking (fire risk)
• Sleeping
• Disorientation
• Opening front door of house at night
• Memory issues
• Traffic accident (to be knocked down by a car in the street)</td></tr>
<tr><td>Concerns about self</td><td colspan="2">• I am often stressed and cannot sleep. Now he is peg-fed we don’t have a social life anymore. I worry about where my life is going and how I will cope. I cannot be stuck in the house all the time. (3)
• It is always good to talk to people who know where you are coming from and how you feel. (3)
• I am often stressed and cannot sleep. Now he is peg-fed we don’t have a social life anymore. I worry about where my life is going and how I will cope. I cannot be stuck in the house all the time. (3)
• It is always good to talk to people who know where you are coming from and how you feel. (3)
• It would be like a help group and I could talk. I often think I am the only one going through this problem. Share ideas and chat with others going through the same as you are. (4)
• I am not well and she is a heavy lady. I work and wonder how long I can continue to go away to work. I may have to give up my job. (5)
• I just have to get on with it. I am very pragmatic and if it is to be done then I just do it. I have friends I can whinge to and do not need a network. (5)
• People don’t realise you are a carer sometimes and you can share experiences. Things can be done in an easier way shared. (5)</td></tr>
</table>

Table 26 - Informal caregiver final analysis of data per country

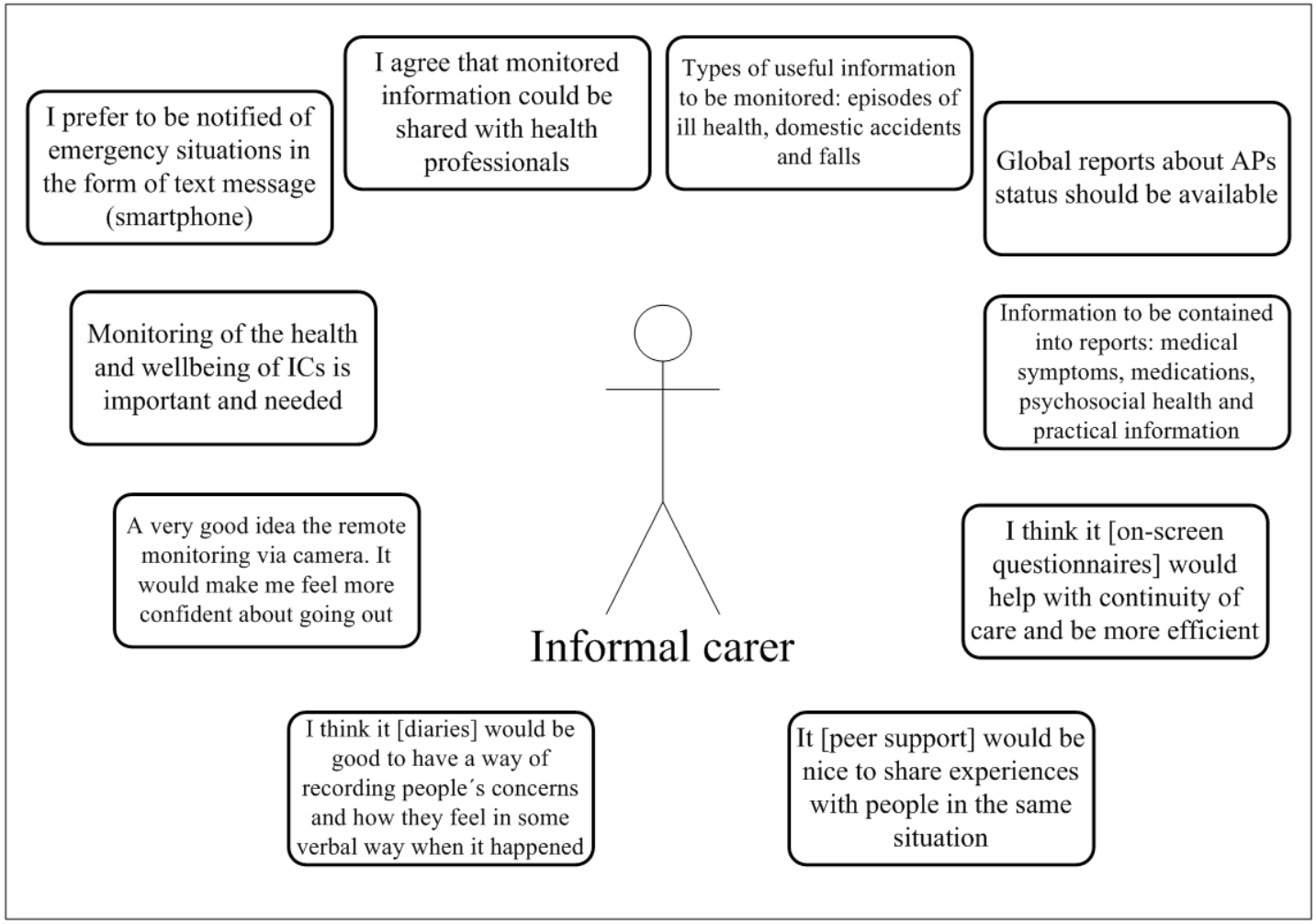

Figure 3 - Informal carer main requirements of the BREATHE system

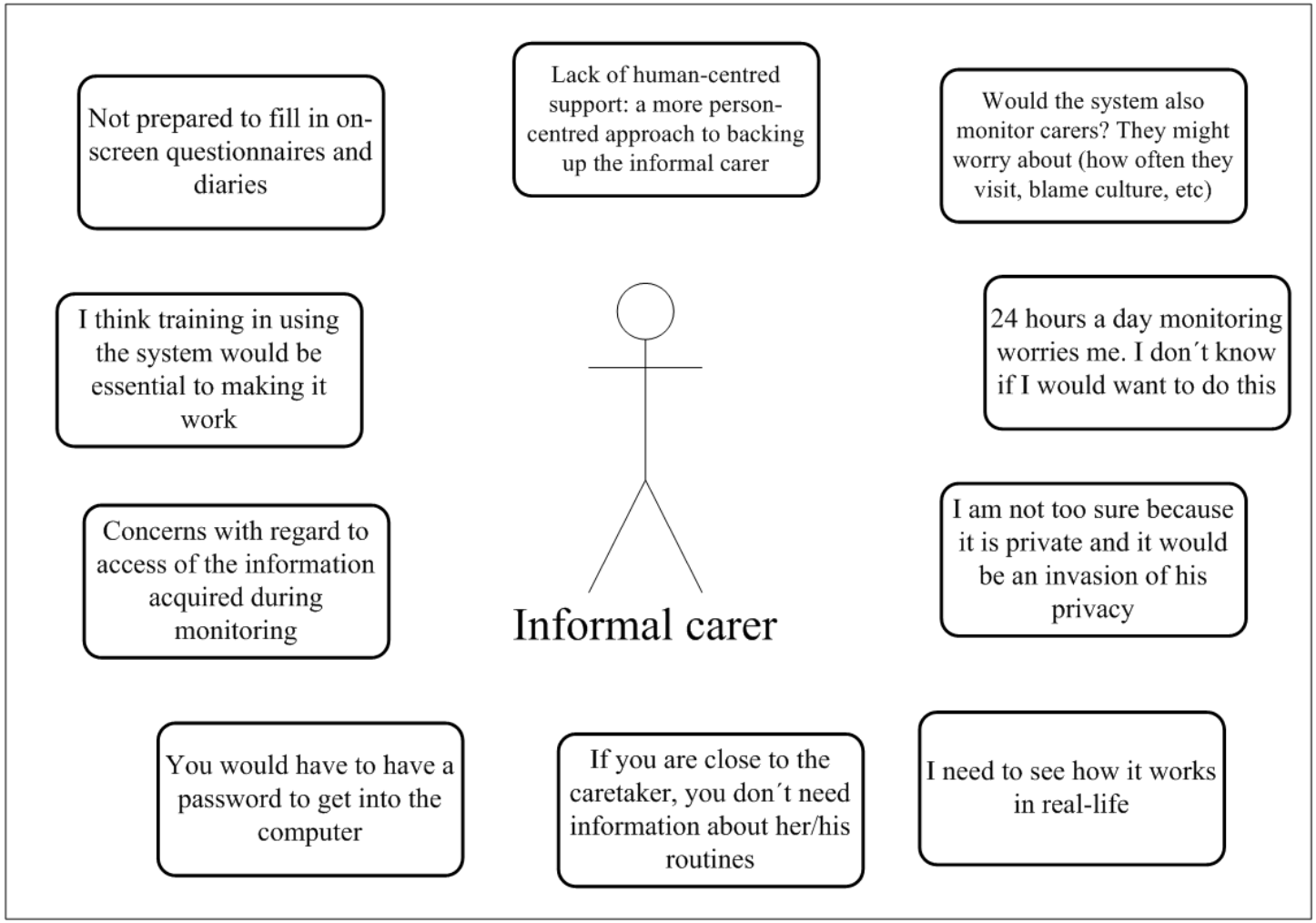

Figure 4 - Informal carer main concerns of the BREATHE system

Actor	Formal carer	
Definition	Officially employed as paid carers who care for one or more people with at least one LTC (also called as assisted person)	
Role	Caring for persons with dementia, incontinence, Parkinson's, Lymphedema, diabetes, physical disabilities, problems consequence of stroke(s), ME, visually impaired, mobility problems, older age related issues, MS, MND, heart conditions, bone problems and high blood pressure	
Relationship with other actor/s	Assisted person and informal carer (optionally)	
Profile	• Gender: 90 % female and 10 % male (UK) / 100 % female (Spain) • Mean age (years): 47.6 (UK) / 48.9 (Spain) • Range age (years): 40-55 (UK) / 37-56 (Spain) • Mean length of time as a carer (years): 9.4 (UK) / 5.3 (Spain) • Health status range: poor-excellent (UK) / good (Spain) • Use of internet: yes (UK and Spain) • Frequency of use of internet: daily use-weekly use (UK and Spain) • Main technological device for accessing on the Internet: laptop (UK) / smartphone (Spain) • Secondary technological devices for accessing on the Internet (in rank order): desktops and smartphones (UK) / laptops, tablets and desktop (Spain) • Use of assisted technology: 60 % (UK) / 100 % (Spain) • Types of assisted technologies used (in rank order): care alarms and home sensors (UK) / panic button (Spain) • Daily routine of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) • Risky situations of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) • Location/activity in home of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) • Social activity of the assisted person should be monitored by cameras: yes (UK) / yes (Spain) • Acceptance of cameras as assisted technology in emergency situation: yes (UK) / yes (Spain) • Acceptance of cameras as assisted technology in non-emergency situation: yes (UK) / yes (Spain)	
Concerns about the cared person	UK • Continuity of care • Danger of falling/fall detection • Medication prompts	SPAIN • No data
Concerns about self	• No data	

Table 27 - Formal carer final analysis of data per country

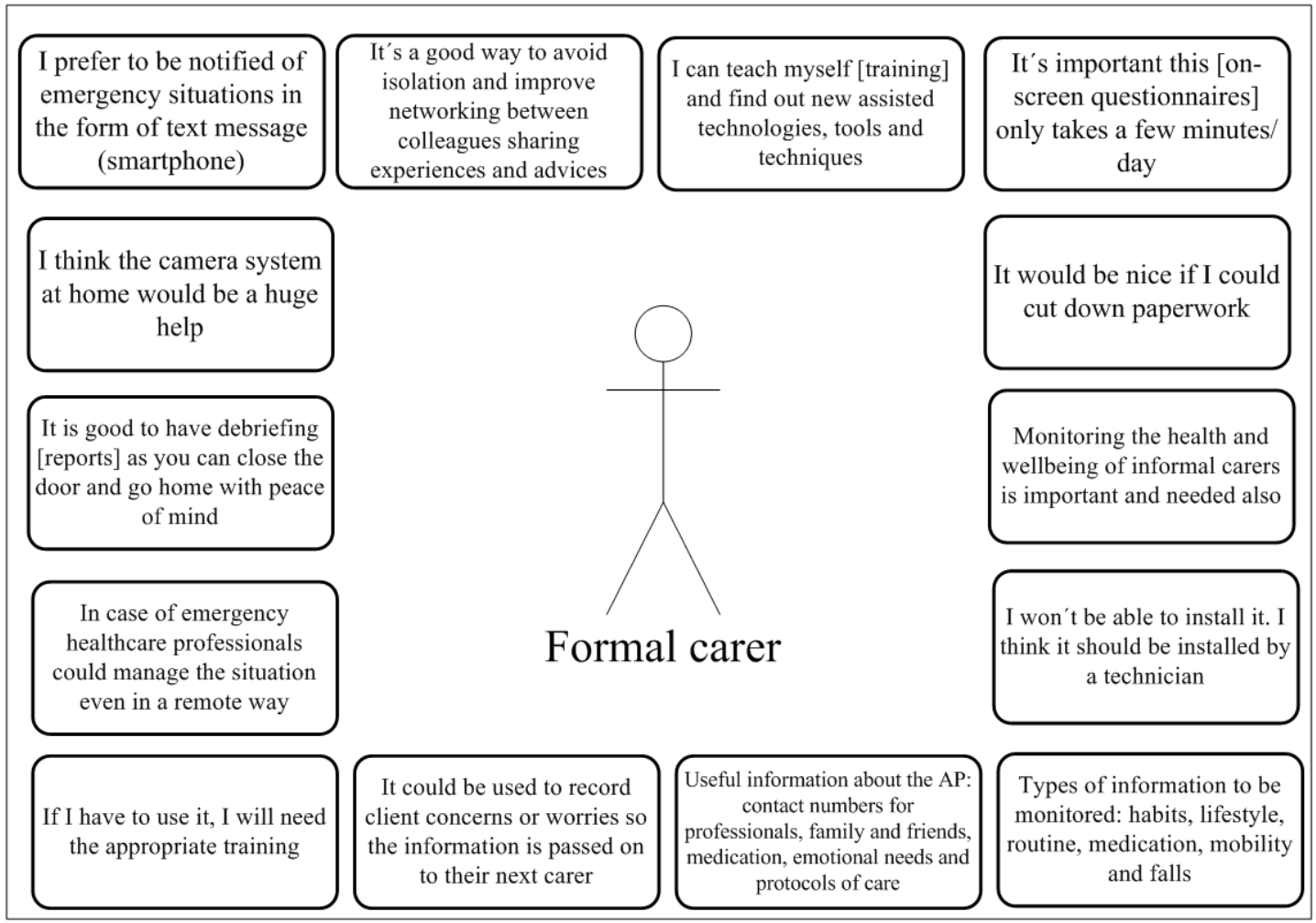

Figure 5 - Formal carer main requirements of BREATHE system

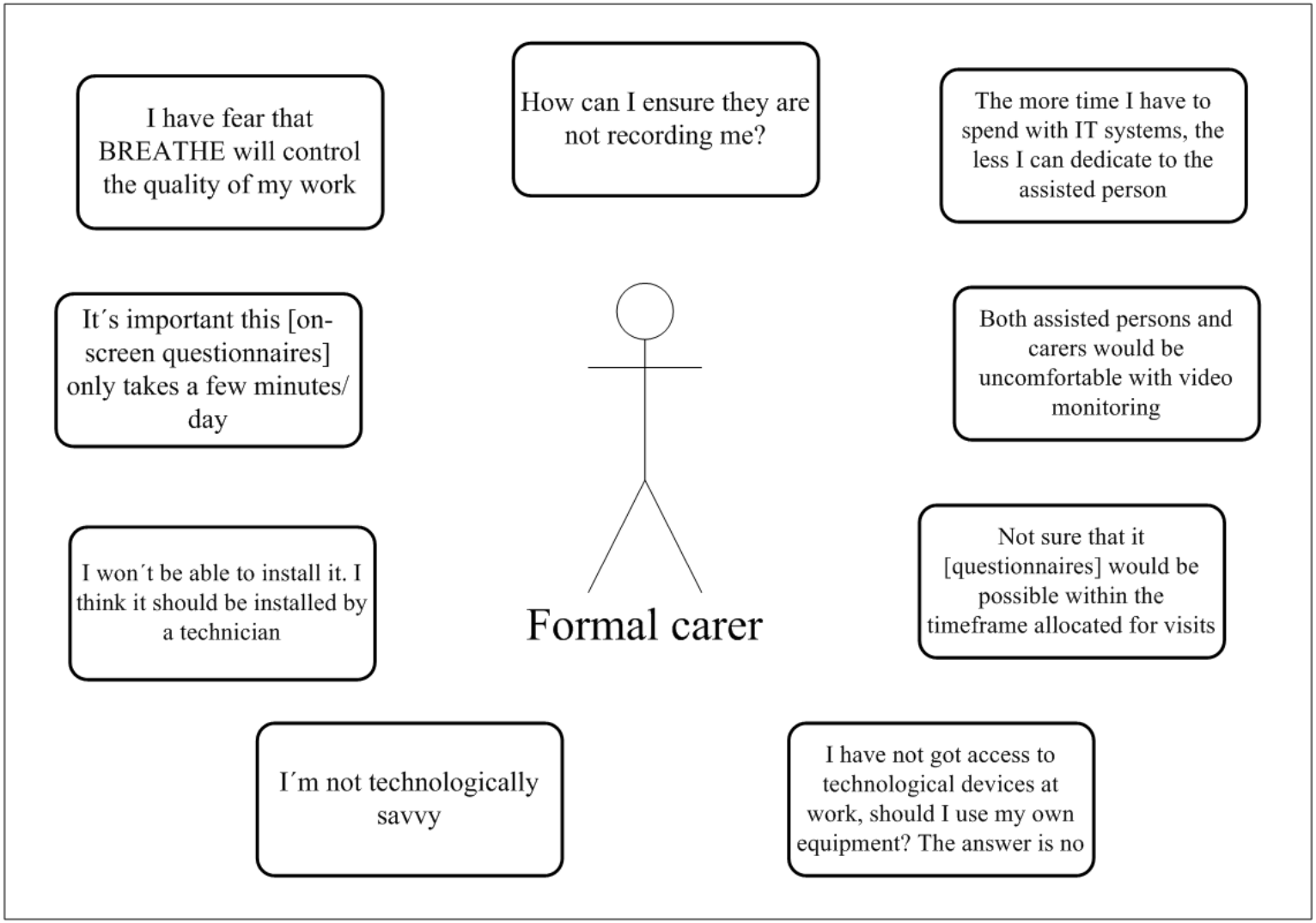

Figure 6 - Formal carer main concerns of BREATHE system

Actor	Assisted person
Definition	Typically people with at least one long-term condition (LTC) who may or may not live with their main carer
Role	Issues and/or problems with their hearing and sight, a snapped Achilles tendon, hip and knee replacements, COPD, diverticulitis, osteoporosis, paralysis, Thalidomide's syndrome, chronic muscle fatigue and fibromyalgia
Relationship with other actor/s	Informal carer and formal carer (optionally)
Profile	• Gender: 100 % female (UK) / 60 % female and 40 % male (Spain) • Mean age (years): 80 (UK) / 65.6 (Spain) • Range age (years): 77-83 (UK) / 50-83 (Spain) • Average of hours that they are cared for (per week): 89 hours (UK) / 101.2 hours (Spain) • Health status range: poor-fair (UK) / bad-good (Spain) • Live with their carer: 50 % (UK) / 60 % (Spain) • Distance between carers and cared for people when they are not living together: 10-15 minutes walking away (UK and Spain) • Contact way for those not living with carers: phone (UK and Spain) • Phone contact frequency range: every-day and more than once (UK and Spain) • Medical cover assistance: any of them (UK) / all of them assisted by the National Health Public System (Spain) • Use of internet: 50 % (UK) / 60 % (Spain) • Frequency of use of internet: daily use (UK) / rarely-daily (Spain) • Main technological device for accessing on the Internet: laptop (UK) / smartphone (Spain) • Secondary technological devices for accessing on the Internet (in rank order): no data (UK) / desktop and laptops (Spain) • Use of assisted technology: no data (UK) / 80 % (Spain) • Types of assisted technologies used (in rank order): no data (UK) / panic button (Spain) • Daily routine of the assisted person should be monitored by cameras: no data (UK) / no data (Spain) • Risky situations of the assisted person should be monitored by cameras: no data (UK) / no data (Spain) • Location/activity in home of the assisted person should be monitored by cameras: no data (UK) / no data (Spain) • Social activity of the assisted person should be monitored by cameras: no data (UK) / no data (Spain) • Acceptance of cameras as assisted technology in emergency situation: no (UK) / yes (Spain) • Acceptance of cameras as assisted technology in non-emergency situation: no (UK) / yes (Spain)
Concerns about carers	• Believe that carers are worried about them for: (1) breathing difficulties, (2) falling and fall detection, (3) having limited help to care for them, (4) dependency, (5) being housebound and (6) having a lack of autonomy
Concerns about self	UK • Fear of falling/fall detection

Table 28 - Assisted person final analysis of data per country

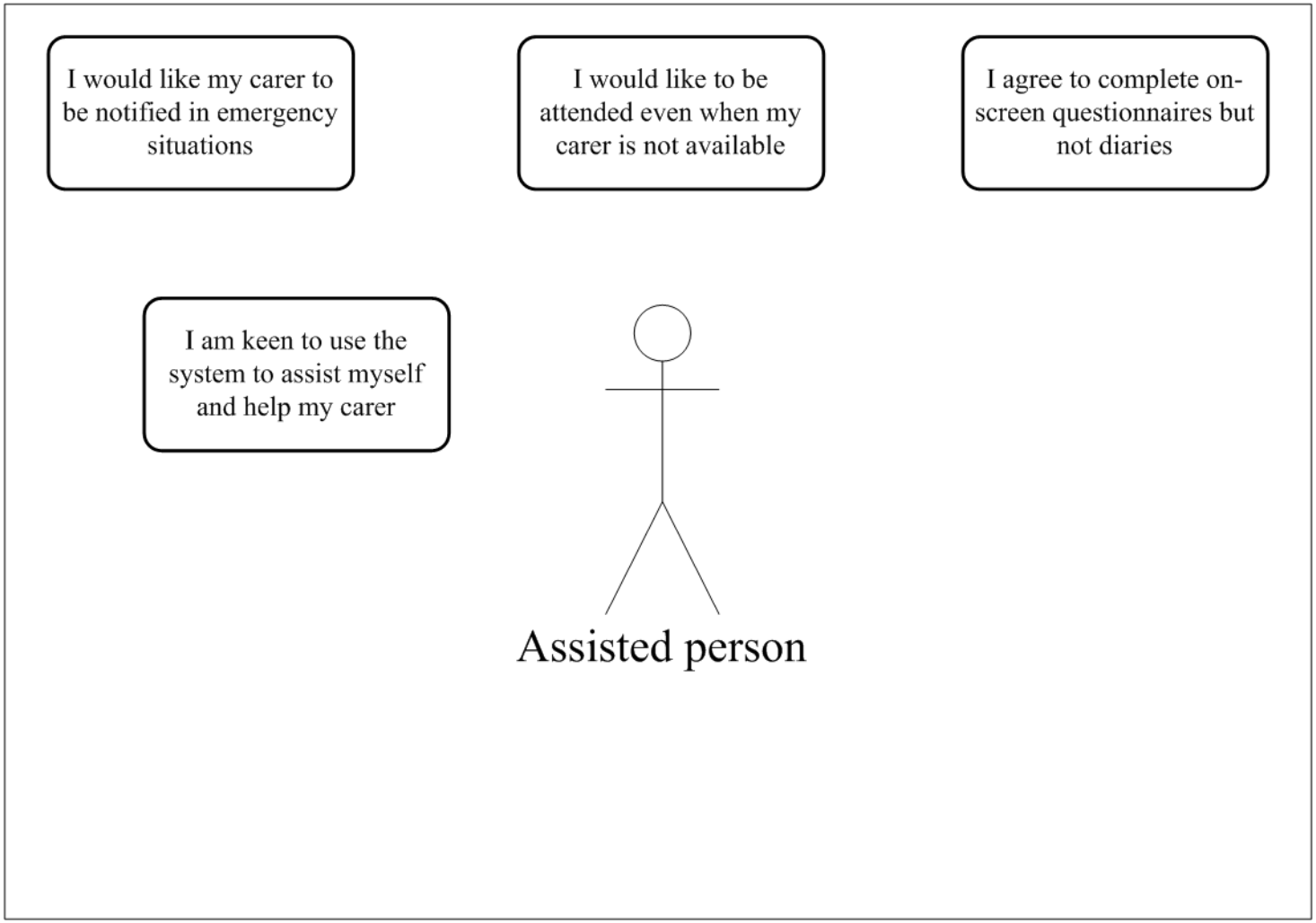

Figure 7 – Assisted person main requirements of BREATHE system

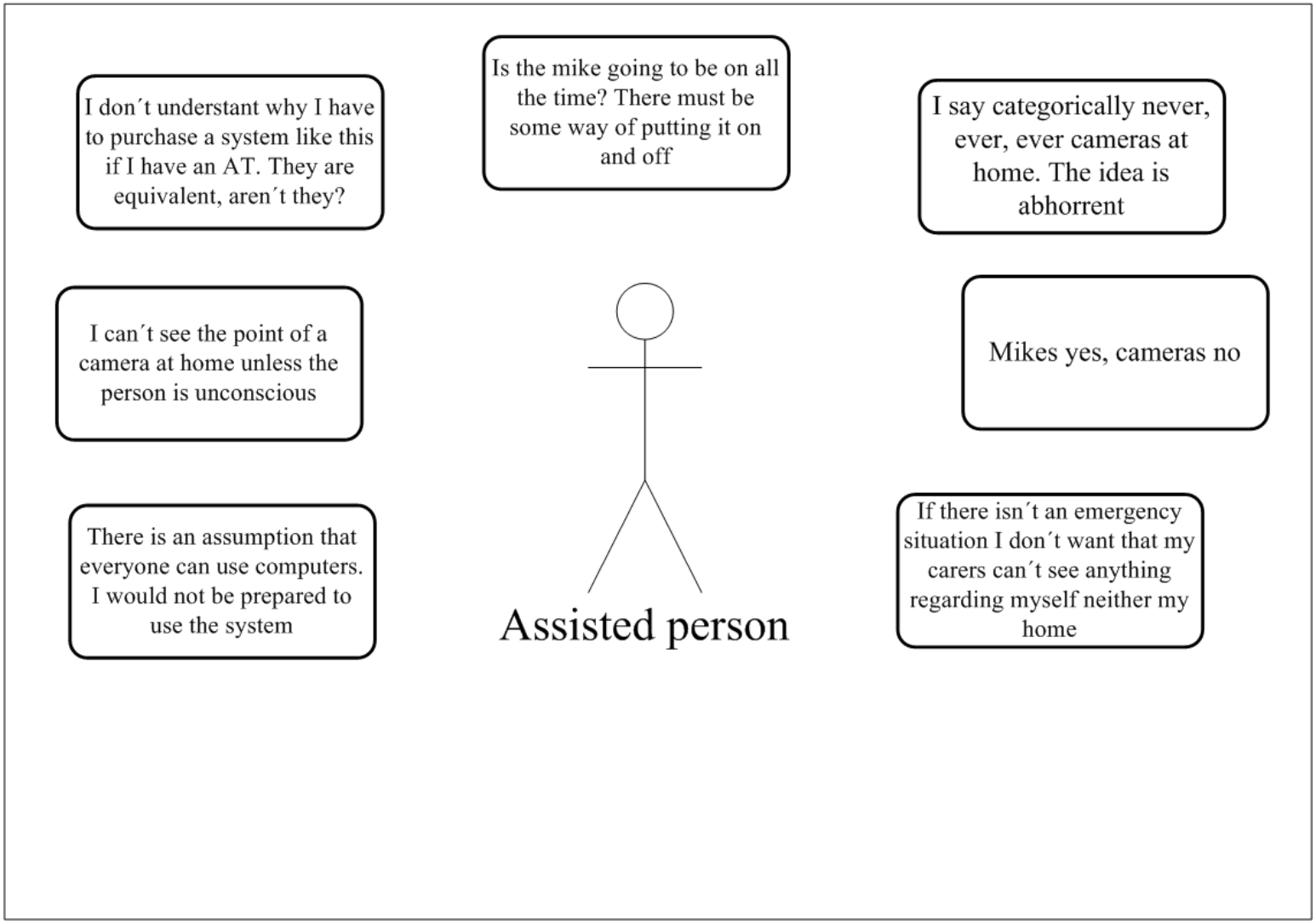

Figure 8 - Assisted person main concerns of BREATHE system

8.1 Business Cases

As part of the job that should be carried out in this deliverable, a first approach to the expected business model of the BREATHE technology should be introduced. To describe the complete business strategy of any new product from scratch requires a in-depth knowledge not only about the core of our business (purpose, target customers, key partners, suppliers, distribution channels, revenue streams, etc.) but also a good understanding of a broad range of other aspects and circumstances (politics, socio-cultural, economic, brand patents, etc.) which are directly related to our opportunities of success. Although at this point of the project we have a lot of blanks regarding the business model (there are two specific deliverables in different moments of WP5 for talking about it, namely, "D5.2 – Draft business models and exploitation plans" and "D5.6 – Final business model and exploitation plans"), as consequence of the conversations done with the involved actors and the exhaustive analysis of the data gathered we are in a good position to start envisaging some scenarios which can be shortly described:

Option 1	
Reference	BC1
Short description	Technological provider develops, installs and maintains the technological system and manages relationships with clients (looking for new ones, registering and unregistering, etc.). All processes are turning around the technological provider since it is responsible for doing everything. No partnerships neither alliances are established.
Involved actors	Technological provider, informal carer and assisted person. Example of entity exploiting: TSB.
Key partners	None
Customer	Informal carer
Value proposition	• Reduce isolation, depression, stress and anxiety levels thanks to the continuous support of the system. • The system provides "eyes" for the family members to know about what happens at assisted person's home through devices like smartphones, laptops, desktop or tablet PCs. • Wide range of configurable alarms that automatically informs the informal carer
Revenue streams	Subscription fees (monthly)

Table 29 - Business scenario (option 1)

Option 2	
Reference	BC2
Short description	Technological provider develops, installs and maintains the technological system. The service provider is the partner in charge for looking for clients and managing them on a daily basis. The technological provider has the solution and the service provider knows the business, where the clients are and how to contact with them Example of entity exploiting: TSB.
Involved actors	Technological provider, service provider, informal carer, and assisted person. Example of entity exploiting: ISI, CYB, TER.
Key partners	Technological provider and service provider
Customer	• Informal carer for the service provider

	• Service provider for the technological provider
Value proposition	For the service provider: • New market opportunities and new revenue channels • A good way to differentiate from competitors For the informal carer: • Reduce isolation, depression, stress and anxiety levels thanks to the continuous support of the system. • The system provides "eyes" for the family members to know about what happens at assisted person's home through devices like smartphones, laptops, desktop or tablet PCs. • Wide range of configurable alarms that automatically informs the informal carer
Revenue streams	For the service provider: • Subscription fees (monthly) For the technological provider: • Licensing

Table 30 - Business scenario (option 2)

Option 3	
Reference	BC3
Short description	The technological provider has the solution and the service provider knows the business, where the clients are and how to contact with them. Apart from that, the Service Provider is an active user in the system providing an added value to the BREATHE system by incorporating the information it provides to their care protocols and processes.
Involved actors	Technological provider, service provider, informal carer, formal carer, and assisted person. Example of entity exploiting: ISI, CYB, TER.
Key partners	Technological provider and Service Provider.
Customer	• Informal carer for the service provider • Service provider for the technological provider
Value proposition	For the service provider: • New market opportunities and new revenue channels • An innovative tool which makes things easier for formal carers • A good way to differentiate from competitors incorporating technology at people's homes and involving the informal carer in the care process. • BREATHE can provide more information about the conditions of the person at home that can make the care process more effective and efficient both for the management of human resources and for the assisted person. For the informal carer and assisted person: • A better care experience to the assisted person and the family thanks to new type of information available. • Reduce isolation, depression, stress and anxiety levels thanks to the continuous support of the system. • The system provides "eyes" for the family members to know about what happens at assisted person's home through devices like smartphones, laptops, desktop or tablet PCs. • Wide range of configurable alarms that automatically informs the informal carer
Revenue streams	For the service provider: • An increase in the fee charged to the user for the home care services, due to the inclusion of new services based in the existence of technology. For the technological provider: • Licensing

Table 31 - Business scenario (option 3)

Legal implications for any installation of the BREATHE system will have to be carefully considered. The AAL home system which will be set up at the assisted person´s home is based on a video-based recognition system (indoor monitoring system) composed by an array of cameras This is always a very controversial issue, this mean BREATHE consortium has to ensure that the final solution preserves the privacy and dignity of all served end-users. Since the first experience with real end-users will be during field trials and the regulations (laws) that have to be taken into account in the pilots will be the same than in a real market exploitation case, the aforementioned analysis of legal and ethical issues have been drawn up in the deliverable D1.3 (Trials strategic plan[5]). This public document can be downloaded from the publications section[6] of the BREATHE project Website.

[5] DoW indicates in the description of "Task 5.1. Business and legal requirements" that the current document incorporate the information about legal framework (laws and regulations affecting exploitation and use of the results). Project partners considered more convenient to reflect this content in D1.3. Trials strategic plan.

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Appendixes

Appendix 1 - Consent forms

Focus groups

You have been invited to participate in a project that aims to develop technology that will help to support carers.

	Please initial in box
1. I confirm that I have read and understood the information sheet for the above study, and have had the opportunity to ask questions	
2. I understand that my participation is voluntary, and that I am free to withdraw at any time, without giving a reason	
3. I agree to take part in the above study	
4. I agree to the focus group being audio recorded	
5. I agree to the focus group being video recorded	
6. I agree to the use of anonymised quotes in publications	

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Individual interviews

You have been invited to participate in a project that aims to develop technology that will help to support carers.

	Please initial in box
7. I confirm that I have read and understood the information sheet for the above study, and have had the opportunity to ask questions	
8. I understand that my participation is voluntary, and that I am free to withdraw at any time, without giving a reason	
9. I agree to take part in the above study	
10. I agree to the interview being audio recorded	
11. I agree to the use of anonymised quotes in publications	

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 2 - Explanation of monitoring technology

This information sheet was used to inform the participants, for reference prior to and during interviews and focus groups. The information sheet describes the proposed technology and in particular the proposed camera systems. The BREATHE system will be a way of supporting carers of people with long term conditions, and will include some types of monitoring of the person for whom they provide care.

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1. Possible types of monitoring using "cameras" in the home

We know that the idea of using cameras to monitor people at home is one which needs careful consideration. In this project, some new types of technology are being considered which can provide better privacy than ordinary cameras. For example, although a camera itself can really see the person in their home, the BREATHE computer system could keep this information secure, and only pass limited visual information to a real person **who has already been given permission to see that information.** So, if a camera is installed in the ceiling of a person's room, the BREATHE system could show the information in the following ways:

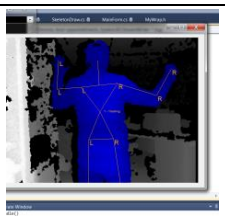
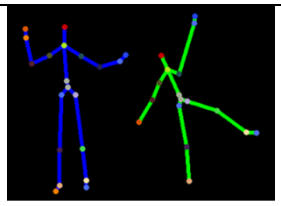
A Show **real footage** of a person in the room	
B Show only **silhouettes** of the person in the room	 OR 
C Show the person as a **stick figure**	
D Show **cartoon-like people** in place of real people	

Table 32 - Types of monitoring using cameras (1/2)

Alternatively, the whole room could be shown as a virtual room, to show the context of the room that the person was in (e.g. whether they were near an appliance or sitting on a piece of furniture), with these options:

E Show an **empty room** if there is no cause for concern, so that the person with long term condition has complete privacy	
F Show the **person's location** within the room if there is a query about the person's safety or wellbeing	
G Show the **person's position and posture**, or even **real footage,** if the system thinks that the person needs help	

Table 33 - Types of monitoring using cameras (2/2)

Appendix 3 - Information sheet

Focus Groups

You are invited to participate in a project that aims to develop technology that will help to support carers. This technology will be part of a system called BREATHE that could provide:

- Monitoring of someone with a Long Term Condition at home, based on technology installed in their home.
- Support and guidance for informal carers, provided on a smartphone.

1. Research aims

This study aims to find out what people think about the BREATHE system which is being developed, in order to make the technology as useful as possible. This is being done by asking relevant people for their views, during interviews and focus groups.

2. Who have we asked to participate in this focus group?

We are inviting people who provide informal care to someone with a Long Term Condition at home to participate in this focus group. In particular, we are looking for informal carers who:
• Are from 18 to 90 years old
• Can give written, informed consent
• Have been in an informal care role for at least six months for a person in at least one of these categories:
  ○ Stroke survivors
  ○ Frail older people
  ○ People with muscle-skeletal conditions or mobility problems
• Do or do not live with the person for whom they provide care
	We are inviting people who are formal caregivers for people with Long Term Conditions at home to participate in this focus group. In particular, we are looking for formal carers who:
	• Are from 18 to 90 years old
	• Can give written, informed consent
	• Have been a formal (paid) carer for at least six months for people with LTCs in a domestic setting
	• Have some experience of caring for people in one or more of these categories:
	  ○ Stroke survivors
	  ○ Frail older people
	  ○ People with muscle-skeletal disease, or mobility problems

Table 34 - Focus group expected participants

3. Who must we exclude?

We are not able to include anyone who is not a native speaker of (primary language of the trial site country).

4. When and where will the study take place?

The focus group will take place at (time)……on (date)……at(location)……...……..

5. How long will the study last?

The focus group will last for approximately 80 minutes.

6. What will you be asked to do?

You will be asked to attend one focus group to discuss your views on the BREATHE system. The other people in the focus group will also have experience as a carer. You will be asked a series of questions about the BREATHE system which is being developed, and you will be given the opportunity to discuss and ask questions about this topic. The focus group will be audio recorded and video recorded. This will enable the researchers to study the answers that you give. The recordings will be kept confidential, and any quotations that are published will be anonymised.

7. How will we maintain your privacy and confidentiality?

Your personal data will be stored in accordance with (state relevant national legislation here).

8. Who is organising and funding the research?

The research is organised by a European research group which has been brought together to design the BREATHE system. Funding is provided by the European Ambient Assisted Living (AAL) Joint Program.

9. What if I have questions about the project?

If you have any queries, or would like to participate, you may contact the Researcher responsible for this part of the study:

- Researcher name…….
- Researcher's position and organisation……...
- Researcher's contact details……

Your participation is always voluntary and you can withdraw from the study at any time without giving a reason.

Individual interviews

You are invited to participate in a project that aims to develop technology that will help to support carers. This technology will be part of a system called BREATHE that could provide:

- Monitoring of someone with a Long Term Condition at home, based on technology installed in their home.
- Support and guidance for informal carers, provided on a smartphone.

1. Research aims

This study aims to find out what people think about the BREATHE system which is being developed, in order to make the technology as useful as possible. This is being done by asking relevant people for their views, during interviews and focus groups.

2. Who have we asked to participate in the interviews?

We are inviting people who provide informal care to someone with a Long Term Condition at home to participate in this focus group. In particular, we are looking for informal carers who:
• Are from 18 to 90 years old
• Can give written, informed consent
• Have been in an informal care role for at least six months for a person in at least one of these categories:
  ○ Stroke survivors
  ○ Frail older people
  ○ People with muscle-skeletal conditions or mobility problems
	We are inviting people who are formal caregivers for people with Long Term Conditions at home to participate in this focus group. In particular, we are looking for formal carers who:
	• Are from 18 to 90 years old
	• Can give written, informed consent
	• Have been a formal (paid) carer for at least six months for people with LTCs in a domestic setting
	• Have some experience of caring for people in one or more of these categories:
	  ○ Stroke survivors
	  ○ Frail older people
	  ○ People with muscle-skeletal disease, or mobility problems
		We are inviting professionals who have knowledge of the informal care of people with Long Term Conditions. In particular, we are looking for professionals who:
		• Are from 18 to 90 years old
		• Can give written, informed consent
		• Are currently working in a healthcare field relating to the care of people at home, with at least 6 months' experience in that role
		• Have some experience of caring for people in one or more of these categories:
		  ○ Stroke survivors
		  ○ Frail older people
		  ○ People with muscle-skeletal disease, or mobility problems
			We are inviting people with Long Term Conditions who receive care from informal care at home. In particular, we are looking for people with Long Term Conditions who:
			• Are from 18 to 90 years old
			• Can give written, informed consent
			• Have had their Long Term Condition for at least six months
			• Have at least one Long Term Condition which fits into these categories:
			  ○ Stroke survivors
			  ○ Frail older people
			  ○ People with muscle-skeletal disease, or mobility problems

Table 35 - Individual interviews expected participants

3. Who must we exclude?

We are not able to include anyone who is not a native speaker of (primary language of the trial site country). We are also unable to include people with temporary or permanent cognitive impairments or current mental health concerns.

4. When and where will the study take place?

The focus group will take place at (time)……on (date)……at(location)……...……..

5. How long will the study last?

The interview will last for approximately 60 minutes.

6. What will you be asked to do?

You will be asked to attend a one-to-one interview with a researcher, to discuss your views on the BREATHE system. You will be asked a series of questions about the BREATHE system which is being developed, and you will be given the opportunity to discuss and ask questions about this topic. The interview will be audio recorded. This will enable the researchers to study the answers that you give. The recordings will be kept confidential, and any quotations that are published will be anonymised.

7. How will we maintain your privacy and confidentiality?

Your personal data will be stored in accordance with (state relevant national legislation here).

8. Who is organising and funding the research?

The research is organised by a European research group which has been brought together to design the BREATHE system. Funding is provided by the European Ambient Assisted Living (AAL) Joint Program.

9. What if I have questions about the project?

If you have any queries, or would like to participate, you may contact the Researcher responsible for this part of the study:

- Researcher name…….
- Researcher's position and organisation……...
- Researcher's contact details……

Your participation is always voluntary and you can withdraw from the study at any time without giving a reason.

Disclaimer

BREATHE Project has been co-funded by the Ambient Assisted Living Joint Programme (Call 5, 2012) and some National Authorities and local Research Programmes in Spain, United Kingdom, Ireland and Italy.