The Challenges of Creating Design Requirements for Products for People with Dementia

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Abstract

With an ever-growing number of people with dementia, no cure, treatment or effective prevention effort is available to bring medical relief to deal with this condition. Therefore, efforts should be made to support people to live well with dementia and design can contribute to this by the creation of better care services, products and environments. A European research and implementation project was set up to tackle this, with the aim to promote and support the development and quality of products designed to enhance the daily lives and care of people with dementia, including the creation of a certification quality mark. In order to set up that certification quality mark, a series of requirements for 'good' design for people with dementia need to be developed. This has presented several challenges due to the diversity and complexity inherent to dementia, as well as to the wide range of products on offer. This paper presents the initial phase of this ongoing research project and discusses the uncertainties and critique regarding the creation of design requirements and how the consortium overcame them.

Keywords

Design requirements · Dementia · Certification

1 Introduction

In recent years, pharmaceutical research focusing on finding a treatment for people with dementia has not provided a lot of hope that a cure would be found in the near future. In 2018, two pharmaceutical companies working in this area announced that they were ending their research into finding a drug that could cure or prevent dementia [1, 2]. In addition, many prevention efforts are limited to actions that are generic such as maintaining a healthy lifestyle, avoiding obesity, diabetes and smoking, emphasizing exercise and the engagement of social interaction with others [3]. At the moment, then, there is no medical solution that will bring relief to the ever-growing numbers of people with dementia. This results in a situation in which the response from design includes the creation of better care services and better products (and environments) to support people with dementia in their daily life and care.

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R. Brankaert et al. (eds.), *Dementia Lab 2021: Supporting Ability Through Design*,
Design For Inclusion 2, https://doi.org/10.1007/978-3-030-70293-9_2

This paper highlights the first months of the *Interreg North-West Europe Certification-D* project. The goal of this European research and implementation project is twofold. On the one hand, it wants to provide a framework that enables companies to design better products for people with dementia. On the other hand, it wishes to support people with dementia and their network of family and caregivers in selecting products that will be suitable for them or their loved ones with dementia, through the creation of a certification quality mark for products for people with dementia. The project includes a variety of partners (care, advocacy groups, academia and industry) and comes from five different European countries. The products being examined deal with three categories: ‘safety and security’, ‘enabling’ and ‘leisure time’. Four Living Labs involving people with dementia were created to support product evaluation and the development of the certification process, each focusing on one of the three mentioned categories. The authors of this paper are part of one of the Living Labs, which deals with leisure products. The greater goal of Certification-D is to enable people with dementia to live longer and in a qualitative way at home and thus, it includes a strong focus on quality of life.

The development of a certification procedure and accompanying certification quality mark includes developing requirements that propose what a good design for a person with dementia can be. In this paper we focus on the research that was used to create these requirements. This list of requirements will serve as a basis for evaluating specific products and to check whether a quality mark can be granted (a mark that would indicate that the product is made in a dementia friendly way), as well as a set of considerations for designers and manufacturers who aim to make products for people with dementia.

In the following sections, the paper will discuss the challenges and uncertainties that arose in the first research phases, related to the complexity of creating a list of requirements to evaluate products for people with dementia. The paper will give an overview on how the consortium tried to overcome these challenges, through an expert-led study including a preliminary workshop with consortium members, a Delphi Study with experts outside the consortium, and the already mentioned setup of four Living Labs. It is important to indicate that the first research acts, the preliminary workshop and the Delphi study, did not directly involve people with dementia. Despite the authors’ extensive experience and sincere belief in the involvement of people with dementia in every research phase, the Delphi study only involves people who do not have dementia. In our view, the Delphi study is no more than the necessary run-up to the participatory phases (the Living Labs) where the involvement of people with dementia is key. We are confident that even without involvement in these initial phases of the research project, we are not ignoring the voice of people with dementia. Moreover, we believe that the way the project was set up puts people with dementia central, meaning that, from the very beginning of the project, those who advocate for people with dementia were involved in defining how the project should be set up and come about. As Hendriks et al. [4] indicates, having a care organization as a primary participant in research projects, instead of as secondary or contextual partners, is important in the organization of design research projects. Without this specific inclusion of care partners and organizations as full partners, projects such as this run the risk of creating a power imbalance, in which a ‘cult of experience’ exists. Academic partners and partners from industry (who often take the lead in design projects) become positioned as experts and ‘lay’ partners, in this case coming from care, can be less experienced in design and research projects. This immediately created a working position in which the nuances, challenges and complexity of working with and for people with dementia was prioritized.

2 Challenges & Uncertainties About Creating a List of Requirements for 'Good' Products for People with Dementia

The basic idea of creating a list of requirements to evaluate products for people with dementia was initially met with criticism. The authors of this paper were, from the start, critical towards the overly ambitious goal that *Certification-D* set forth. There was little belief that a one-size-fits-all series of requirements could be used to evaluate each and every product. Their awareness of the condition of dementia added to this critique. In addition, they were concerned that a list of requirements could be understood as a recipe that can be applied too rigorously in the hope of leading to a satisfying outcome, without the need to take into account the situation or context of use.

Specifically for this project, the context of use involving people with dementia, makes the creation of a list of requirements difficult. Dementia affects each person very individually: one person might have difficulties speaking or remembering words, while others won't; one might have to deal with impaired motor skills while another might hardly be affected by this. Besides being a very personal condition, dementia also evolves over time, resulting that a certain ability might be lost after a couple of weeks or months. Apart from the condition of dementia, the idea of evaluation as a tool to define whether a design is well or ill-suited, also includes critique [5]. Different standards and expectations of each individual make it hard to create one tool for evaluation that would be suitable for them all. It is thus correct to say that the unpredictability of a person's wants and needs, and the way dementia affects someone makes certification a challenging task.

The amount of research documenting similar efforts in finding a type of standardization or set of rules to design for people with dementia is limited. The remainder of this section presents a summarized overview of a literature study, looking at research regarding design requirements, guidelines, recommendations and design considerations, and including references from academia and (inter)national dementia associations and networks, such as the Alzheimer's Society or the Dementia Engagement and Empowerment Project (DEEP).

The endeavors to create lists of requirements mostly came from the research and process of designing a specific product or group of products. These included, on the one hand, specific criteria based on primary research and/or on literature, to be addressed by the product that was to be designed (e.g. [6–8]); and on the other hand, learnings yielded from the experience of designing a product and often testing it with people with dementia. These learnings are usually shared in the form of generalized guidelines or recommendations for similar types of products (e.g. [6, 9–13]). Other approaches from research sought to define general recommendations and were put together as principles or criteria for successful designs of a specific kind (e.g. technology-based products, environmental design, etc.). These were often based both on literature and on a broader body of experience from different projects developed in that field (e.g. [14–17]); or they were framed as more general considerations, focusing not only on how to design for people with dementia but also on how to codesign with them (e.g. [18–24]). Dementia associations and networks often presented more practical, short and direct bullet-point guidelines (e.g. the DEEP guides [25]) regarding specific topics such as language or dementia-friendly websites.

This literature review suggests that, in some cases, it might be possible to establish a precise set of guidelines, namely for specific types of products or regarding particular aspects of products, such as the Dementia Digital Design Guidelines [26], or the recommendations on sensory rooms for care homes made by Jakob and Collier [16]. However, it seems difficult to create requirements that encompass a wide range of products. Although the literature study identified research that resulted in guidelines and criteria, no published findings could be found that had a similar goal as *Certification-D*: to bring together a series of requirements that would define a good design (regardless of the product being a digital or physical one; being used in group or individually; etc.) and that would go beyond general recommendations. This made us consider whether creating such a list would even be possible.

In short, the basic premise of *Certification-D* was met with some criticism at first: ending up with a list of requirements was perceived as highly challenging due to the wide range of products involved, the diversity of the dementia condition and the individuality of expectations and needs of each person. In addition, literature showed a difficulty in defining these types of lists, as they were mostly too product focused. Moreover, the variety of products integrated in the project made it even more important to reflect beyond one specific product category. However, as indicated above, we felt this project touched upon a necessary thing, namely, to make better products for people with dementia.

3 Tackling the Challenges and the Uncertainties

3.1 Expert-Led Study

As indicated, in order to take into account the complexity of the dementia condition, caregivers and advocacy groups were put central in the project. However, to cater for the variety of product categories, also other experts (e.g. product designers, SMEs creating digital tools for people with dementia, researchers focusing on quality of life, etc.) were added to the consortium or were asked to join at least one of the three phases of the creation of the requirements. A preliminary workshop was conducted with the consortium partners and wished to create the initial list of requirements for each product category (enabling, leisure, safety/security). These and other experts were involved in the other phases: a Delphi study contributed and validated these initial lists and the creation and use of Living Labs, which allowed for people with dementia and their family and caregivers to further validate and add to the resulting lists.

Preliminary workshop. As a leadoff for reflection, a workshop was organized in order to gather input from the *Certification-D* project partners for the development of an initial certification list, using existing products for people with dementia. In the workshop, participants were divided into three groups. Each group evaluated three different products (a total of nine products were evaluated), ranging from analogue objects like a coloring book to electronic items, such as a tracking device. After receiving a product and additional information about it, groups wrote down general and detailed requirements concerning the product. The workshop ended with a discussion facilitated by an interactive mural with post-it notes providing insights into recurring categories for each product category (Fig. 1).

Delphi study. Following the preliminary workshop, a Delphi study was set up. A Delphi study aims to collate expertise in order to generate consensus, usually over several rounds of participation [27]. For each category, a pool of experts from dementia care and dementia-related design research and practice (e.g. companies that make products for people with dementia) was created. Based on literature, on the outcomes from the preliminary workshop and on the concerns described earlier, lists of requirements were created for each of the three different product categories: leisure, enabling and safety/security. These three lists were the starting point for the experts' contributions, who were asked to add to, delete and comment on the list regarding the category they were assigned to. The Delphi study was composed of 3 rounds and was conducted over March and April 2020, with 22 experts participating in at least one of the rounds.

Living Lab evaluation. Four Living Labs (i.e. Belgium, France, Germany, and The Netherlands) have been set up to involve people with dementia [28], to validate and further refine the lists of requirements that resulted from the Delphi study. As mentioned earlier, the authors of this paper are part of one of these Living Labs,

Fig. 1. Discussing requirements during the preliminary workshop

which focuses specifically on products created for leisure.

In order to evaluate the list of requirements, people with dementia and their caregivers were invited to try different products already on the market that have been deemed as ‘good products’ (i.e., tested and successfully used together with people with dementia). By evaluating ‘good products’, the intention was to identify potential flaws in the lists of requirements. The evaluation of these products took place in the real-life environment of the participant, meaning the homes of the people with dementia or a day care center where they reside. In the Living Lab that the authors of this paper are responsible for, the participants used and evaluated a product for two weeks and were asked to answer product-specific question-cards. The first time the participants used the product was observed by the researcher. After the two weeks, the researcher went back to the participants for the reflection phase; an open interview guided by the answers to the question-cards. The aim of the interview was to understand whether requirements were missed and to identify necessary changes that could be made to the list of requirements.

3.2 Creating the Initial Lists of Requirements: Person-Centered Dementia Care and Quality of Life as a Starting Point

The ultimate aim of *Certification-D* is the provision of quality of life for people with dementia, namely those still living at home. Through their own experience as researchers and designers, the authors were aware that the context of home and the concept of quality of life creates a very complex research space. Not only does it balance between concepts of independence and identity, but the concept of home is a divergent care context. In order to tackle the challenge of the complexity inherent to the diagnosis of dementia and to what means to live well with dementia, as well as the diversity included in the range of products for leisure, we used dementia care literature to ground our initial list of requirements and to complement the insights collected during the preliminary workshop. In this way, instead of starting from specific products or product types (as is often seen in literature), we returned to Dementia Care, using the idea of Quality of Life (QoL) for people with dementia and the values of person-centered dementia care as starting points to organize and formulate the initial lists of requirements for each category that were presented to experts in the Delphi study.

Ettema et al. [29] studied dementia-specific instruments to measure QoL and concluded that the domains of QoL that are more often considered are affect, self-esteem, activities, enjoyment and social interaction. In a more recent study on QoL of people with dementia, Verloo et al. [30, pp. 2141–2143] identified four major factors for QoL: (1) "human dignity and acceptance", that highlighted the importance of being accepted and maintaining social relationships with family and friends; (2) "development and existence", concerning the importance of activities and hobbies, seeing them as "recreational moments that allow them to feel real pleasure"; (3) "functionality and health", regarding the maintenance of both physical and psychological health (which goes beyond managing their illness); and (4) "recognition and safety" that emphasized the importance having respect for everyone's privacy, life history and personality.

These perceptions on QoL are also aligned with the psychological needs of people with dementia identified by Kitwood [31, pp. 80–84], and further developed by Brooker [32, pp. 96–99], which are comfort, identity, attachment, occupation, inclusion and an overall need for love.

The ideas on QoL and psychological well-being of people with dementia suggest that not only utilitarian aspects of designed products are important but also those that go beyond functionality. Hassenzahl [5] takes an explicit stance in this by distinguishing between pragmatic and hedonic qualities of products. The pragmatic quality refers to the functional aspects of a product, and to how these functions are provided (usability), while the hedonic aspects concern the potential of a product to create pleasure through use and psychological well-being [5, 33, 34] (Fig. 2).

Certification-D product categories (enabling, leisure, and safety/security) cover a wide range of products with different functions, supporting the achievement of a variety of actions. Drawing further on literature, Gibson et al. [35, p. 6] distinguished three main types of assistive technology for people with dementia, based on their context of use (who and in what way is the product used): (1) devices used *'by'* people with dementia independently, which support them in their everyday activities (devices that support orientation, prompts, reminders, aids, etc.); (2) devices used *'with'* people with dementia, that promote collaboration, communication and interaction between the person with dementia and others (communication aids, reminiscence and leisure products); and (3) devices used *'on'* people with dementia, which do not involve the engagement of the person with dementia with the product, although used to support the person's life (such as telecare, monitoring and safety devices, etc.) (Fig. 2).

Broadly related to the categories defined for this project, this arrangement is useful to distinguish different kinds of actions and motivations for actions and contexts of use, which are relevant for defining the criteria to evaluate the different categories of products. Although pragmatic and hedonic qualities are important for all kinds of products, they might be more or less relevant, according to a specific product. For example, a device used 'on' people with dementia (e.g. gas alarm) is more likely to focus on pragmatic qualities (the alarm needs to ring when needed), while hedonic aspects like stimulation, evocation, identification and aesthetics are less relevant (although one might not want to have a gas alarm that visually interferes too much with the space where it is placed). However, this can also be defined by the situation [33]. If the product is, for instance, a GPS tracker to be

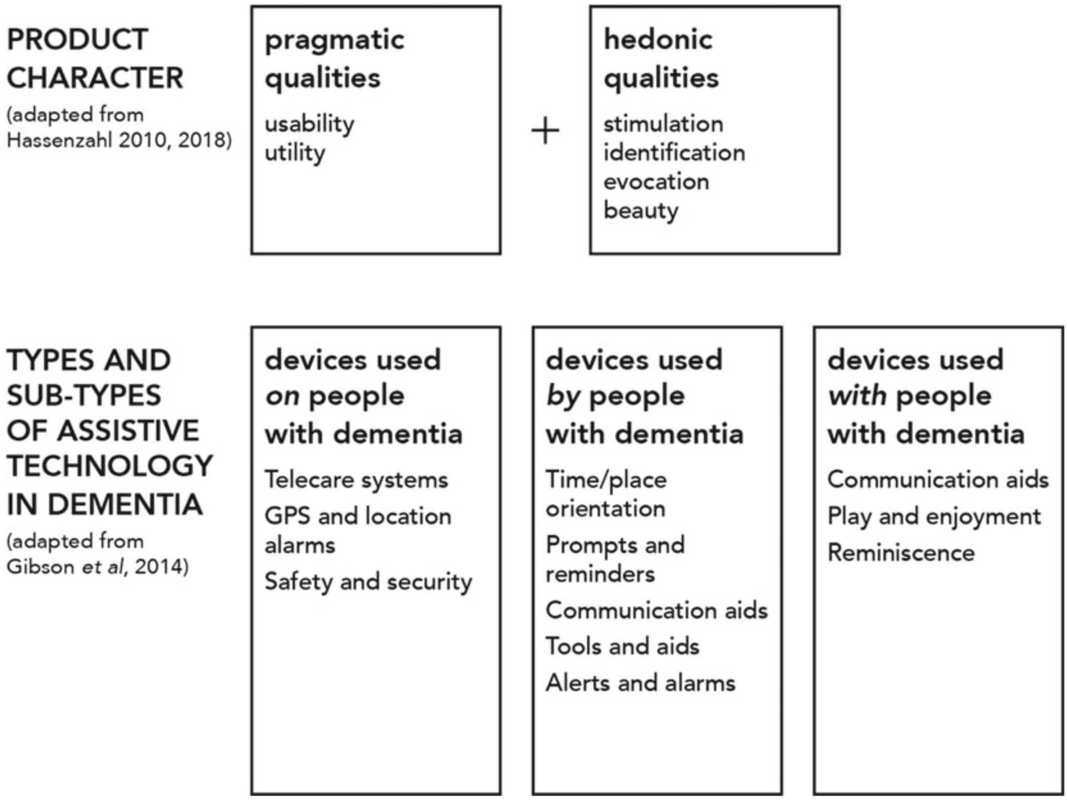

Fig. 2. Product character, adapted from Hassenzahl [5, 34]; Types and sub-types of assistive technology in dementia, adapted from Gibson et al. [35]

visibly carried by the person with dementia, then the hedonic quality plays an important role, namely the aesthetics and identification aspects.

3.3 Rethinking Design Requirements for Products for People with Dementia

For *Certification-D* the list of design requirements not only needed to deal with dementia as a condition that affects people in different and very diverse ways, but it would also need to encompass the complexity of dementia experience and include a broad group of products that differ in function (the three categories: enabling, safety/security and leisure) and in "type" (e.g. digital, electronic, analogue). In order to be used in a certification process, these requirements needed to be general enough to cover this variety as well as leaving space for the specificities of different kinds of products. To address these challenges, the initial list sought to be extensive, combining both general and product-specific *considerations* that should be taken into account when designing a product for people with dementia. Thinking about *considerations* ("something that must be thought about when you are planning or deciding something" [36]) seemed more appropriate to deal with the complexity of dementia and the diversity of products, rather than a strict and fixed list of *requirements* ("something that you need or want; something that you must have in order to do something else" [36]) or *guidelines* ("a set of rules or instructions that are given by an official organization telling you how to do something, especially something difficult" [36]). This list of considerations would serve as a basis for selecting and building a list of specific and pertinent requirements for evaluation, depending on the product category, characteristics and context of use. In addition, this list is seen as a "go-to" document that could be used by designers and manufacturers. It will offer not a definite list of criteria with boxes to tick off, but rather provide considerations that will aid in the design of better products for people with dementia.

4 Integrating the Insights into a Certification List on Leisure

As mentioned earlier, studies on QoL and person-centered dementia care, on user experience and product evaluation, as well as the insights from the preliminary workshop based on the partners' experience with people with dementia were taken into account for creating an initial list of considerations for certification.

Themes related to a product's function such as usability, to its maintenance (e.g. hygiene), to its documentation (e.g. manual of instructions and packaging), as well as to possible risks and ethical issues associated with the product use were highlighted during the workshop as prominent points for product evaluation and certification, and thus included in the initial list.

The values of person-centered dementia care—valuing people regardless of their age and ability, providing individualized care, recognizing each person's perspectives, and promoting a rich social environment [32]—were integrated into the proposed list of considerations, ensuring a deep respect and acknowledgement of the uniqueness of people with dementia across all the document, and particularly emphasized in the ethical issues; the provision of individualized care gave origin to relevant sub-themes such as 'personalization' and 'flexibility'; the psychological needs of people with dementia [31, 32] were also embedded on the theme of utility and usability, which was framed in a way to support comfort and inclusion of people with dementia, and more specifically through the inclusion of a theme on the 'quality of use', with a view to encourage enjoyment and social engagement. The approaches that focus on designing for positive experiences and well-being mentioned earlier were found to be particularly relevant, namely in the case of leisure products whose main functions are usually to promote positive engagement and occupation, and social interaction. Therefore, hedonic qualities were also included in this list, such as stimulation ("the ability of a product to provide opportunities for personal and skills development" [34]), which was also associated with the psychological needs of people with dementia described above.

The Delphi study deepened these considerations, and resulted in the inclusion of additional general as well as product-specific aspects. It also led to other insights, namely whether there is a need to distinguish 'must have' and 'nice to have' requirements, whether product-specific requirements were to be included, the compliance of this certification with already existing standards and regulations, and an overall need to work towards uniformization between the lists of the different product categories (should they be made more uniform or more specific) both regarding their structure, format and content.

Next, we present a brief overview of the final leisure list that resulted after the Delphi study. Although it is mentioned earlier that the list is composed of both general and product specific considerations and requirements, in this overview, we can only present the overarching general themes as the full list is still under embargo. The leisure list is organized into 3 main parts, a first one about the product, its description and the manufacturers' intentions for the product; a second one regarding the user experience with the product; and a third one about other important considerations, such as ethics and risk. Main themes include, in the first part (1) *context of use*, characterizing the situation where product use is intended to take place; and (2) *before use*, regarding features that are important before using the product, such as packaging and instructions on the set-up or installation of the product, as well as aspects that might be important at every time the product will be used, such as recommendations or suggestions of different activities that can be done with the product; in the second part (3) *utility and usability* refers to functional and pragmatic aspects of products, such as accessibility, simplicity and familiarity; (4) *daily use and maintenance* regards non-instrumental activities such as hygiene and maintenance; and (5) *quality of use*, specifically makes space for themes related to the hedonic quality, such as aesthetic experience and stimulation, not only for the person with dementia but for all parties involved; finally, the third part includes (6) *ethics and risk*, which considers not only privacy and safety concerns, but also challenges such as ensuring respect and dignity for the person or concerns related to how products are marketed; (7) *cost and access to the product*; (8) *the inclusion of people with dementia, informal carers and dementia care experts in the design process*; and (9) *sustainability*, related to prolonging the life-time of the product, material choice and product disposal.

The project is now evaluating these lists in the Living Labs. This evaluation will contribute to the development of the final list of considerations, which will eventually result in a certification procedure for products for people living with dementia to receive a mark. Although this is still an ongoing process, thus still no final conclusions can be made, we share a few preliminary points for reflection. After evaluating the selected products within the Living Lab focusing on leisure products, and comparing the reflection of the seven participants, brief specific considerations were added to some of the general themes and sub-themes of the list so far, for instance, regarding the clarity of the product's purpose, information on the possibility and process of personalization, among others. Furthermore, participants also reflected and made suggestions to include different answering options (e.g. scales, checkboxes, answering through observation) in order to make it more accessible during the evaluation procedure. While evaluating the list, and making these additions and suggestions, we realized that several aspects were also having an influence on the evaluation. These aspects were preliminarily organized into two clusters: external (e.g. the caregiver, or requirements of use like Wi-Fi) and internal influences (e.g. the stage of dementia, the person's ability to use and understand of the product's purpose). The impact of these influences on the evaluation will be a topic for further reflection in the course of the project.

The initial Living Lab evaluation of the list can be seen as a pilot project that can be adapted to the evaluation process to receive the *Certification-D* mark. The intention of the development and implementation of this mark is that it will stimulate the production of products for people living with dementia to be able to live longer at home. The resulting final lists will be used twofold: on one hand, they serve as a basis for a reference guide for designers, companies and manufacturers, on the other hand, they can be used to develop scripts for product evaluation.

5 Conclusion and Critical Remark

Initially, the authors of this paper were reluctant in engaging with the *Certification-D* project, namely due to the diversity of products involved, the specific condition of dementia, and to previous failed attempts in creating requirement lists. However, because of the project's ambitious and relevant societal goal, various actions were undertaken to overcome this hesitation and the project's challenges and uncertainties: (a) placing caregivers, people with dementia (and family) and their quality of life central, not only in the initial creation of the lists of considerations, through embedding best practices and values of person-centered dementia care, but also through the setup of Living Labs to involve them in various stages of the project, from the validation and refinement of these lists, to product evaluation, and to the development of the certification procedure; (b) rethinking and reframing design requirements as considerations, including both general and product-specific aspects, and starting from person-centered dementia care and quality of life of people with dementia; (c) a strong engagement of experts from different sectors (care, industry leaders, researchers, designers, people with dementia), through their involvement in the preliminary workshop and on the

Delphi study. At the time of writing, the lists of design considerations are being finalized through their individual evaluations in Living Lab settings, thus giving people with dementia, family and caregivers a voice in the creation of these lists.

Despite the fact that we attempted to overcome these challenges, the actions did not always have the intended result nor did not serve our intended goal. One specific insight concerns the participation of people with dementia. Although we strongly are convinced of a participatory approach, the initial lists that came about after the first preliminary workshop never drastically changed after the Delphi study nor are there any clear indications that the Living Lab evaluation of the list will bring any major alterations. This could mean that the consortium itself (academics, designers, SME's, caregivers, etc.) combined with the expertise of those involved in the Delphi Study was strong enough to come up with a list that is well-defined and described. Interestingly, especially for the leisure list, the first list was detailed and deep, showing a strong body of knowledge, while the market for leisure products for people with dementia is now starting to become well developed. Although it is hard to draw conclusions that go beyond this single case, it might show that the knowledge on design and dementia (be it directly through experts inside of care, design, academia or business or indirectly via literature) is maturing. Consequently, as the first preliminary results of the Living Lab evaluations do not show any significant changes to the structure or the content of the lists, one could question the value of the involvement of people with dementia in this type of study. It is of the utmost importance to stress that the authors strongly believe those affected by design (in this case people with dementia and their family) should be involved in a design's development. However, in this study it is suggested that involvement did not alter or contribute to the results and this may mean that, in some type of studies, involvement should not be facilitated simply as a means to generate better results, but can also come out of purely ideological motivations: it being your duty as a researcher/designer to involve people with dementia in processes which have the potential to impact their current situation or their future.

Acknowledgements The work is supported by Interreg North-West Europe. More information can be found on the project's website: www.nweurope.eu/CERTIFICATION-D. The authors would like to thank all the participants of the Delphi study and Living Lab.

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