

Care for design in care

*Experiences with cross-over research
into living at home with dementia*



fit

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Experiences with cross-over research into living at home with dementia

FIT consortium partners:



Credits

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The quotes included in this publication are from members of the project. They were interviewed during the period June-July 2017 by Nazli Cila (Amsterdam University of Applied Sciences) concerning expectations about and the outcomes of their cooperation with the FIT project.

This project was made possible by the leading sectors Life Sciences & Health and Creative Industries.



Table of Contents

Foreword	6
1. Care for design in care	8
2. Cross-over cooperation	12
3. Designing with care	16
4. Surprising results	18
5. From cross-over research to practice	24
6. Reflections and conclusions	26
References and further reading	30

Foreword

This document, *Care for Design in Care*, is a publication on the research project FIT, carried out as part of the *Create Health* programme.

Create Health links up the leading sectors Creative Industries and Life Sciences & Health, and also stimulates cooperation between creative designers and businesses, patients, care professionals, institutes and researchers. Together, they develop and validate smart, innovative products and services for use in the health and care sectors, specifically in relation to the theme “Healthy and Active Ageing”. The aim of *Create Health* in this respect is to contribute to resolving the social challenges concerning growing older in a healthy, active manner.

The FIT project was implemented under the motto *Retaining Independence with Dementia*. In this project, a ‘fit’ was sought between supply and demand in relation to supporting products and services for people living at home with dementia. Creative partners contribute their expertise in order to guide the design process, and to involve the users in this as much as possible. This facilitates the development of user-friendly solutions that work as well as they possibly can. Within project FIT, this has resulted in solutions, insights and products that help people with dementia and allow the care professionals to provide even better care.

From the point of view of both leading sectors, we are pleased with these initial results of this cross-over cooperation within *Create Health*. It is our hope that the experiences

described in *Care for Design in Care* by the FIT consortium will act as a source of inspiration and information for you if you too are considering such cooperative projects because the result is greater than the sum of its parts.

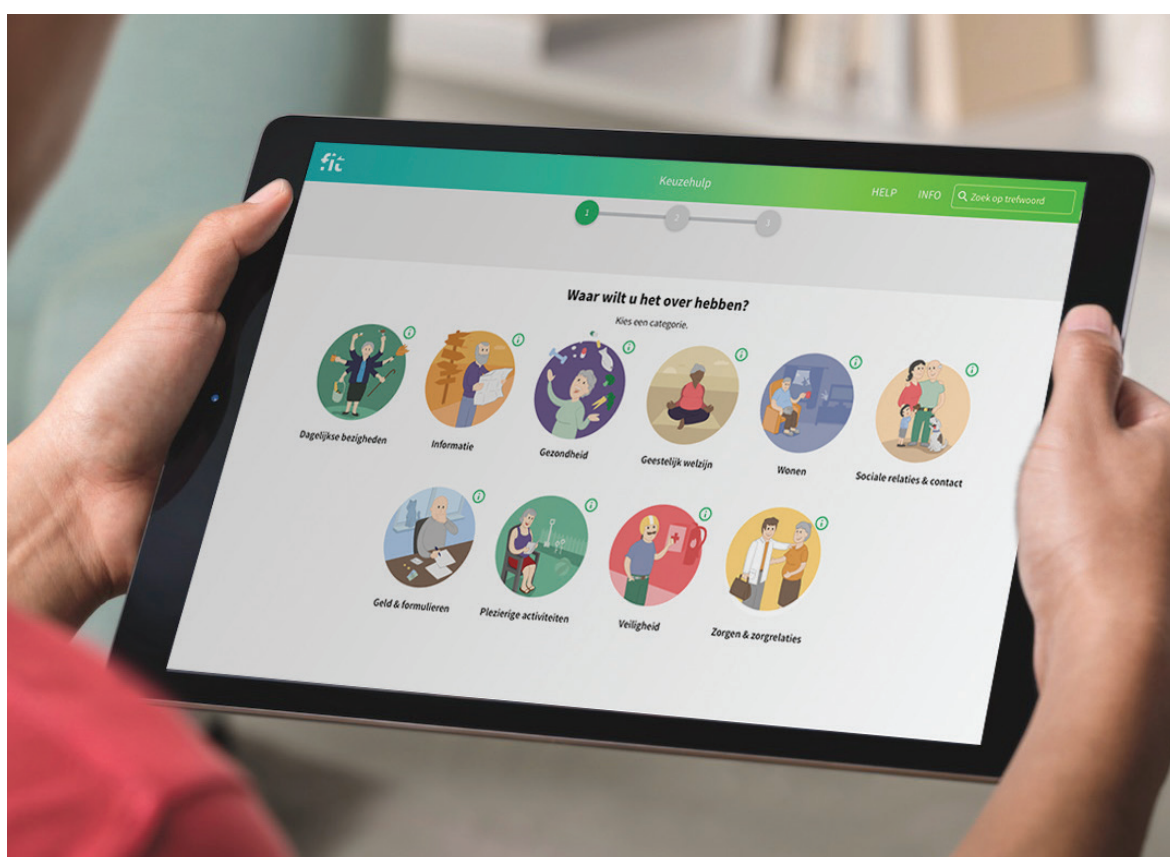
Nico van Meeteren

director Bureau
Topsector Life
Sciences & Health

Bart Ahsmann

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“One of the problems in the care sector is that care providers often don’t have a good overview of all the products on the market. On the other hand, there are so many ICT and health-tech companies offering solutions for supporting people with dementia living at home. Can’t we start a project about this? That’s how FIT started.” (professor, AUAS)



The decision aid from project FIT

1. Care for design in care

“Working together in cross-over forces you to constantly re-explain your own expertise within someone else’s thought framework.” (project coordinator, AUAS)

A cross-over cooperation is a way of approaching social issues that require knowledge drawn from different fields. ‘Care for Design in Care’ describes the experiences of a diverse team with the cross-over project FIT. The social issue to be tackled in this project concerns people living with dementia and how they can find suitable products and services that correspond to their needs for living independently at home.

The research project was given the name FIT because we are seeking a ‘fit’ between supply and demand. To ensure that this ‘fit’ corresponds to and is useful in practice, professionals from different sectors worked together: care professionals, the interest group, entrepreneurs (focusing on the provision of services to people with dementia) and researchers from the creative industries and the social sciences. People suffering from dementia and their (family) carers were involved in thinking about and giving feedback on the results at every phase of the research process. The products and services developed were extensively tested in the ‘living lab’ Gooi en Vechtstreek Region.

Our aim with this publication is to show, from the perspective of the FIT project, how it is possible to become inspired by working together in teams where different disciplines provide input and within which common, useful results emerge (in co-creation with the target group), but also to identify the pitfalls along the way.

We will be covering both the (essential) tensions of such a cross-over and the strengths and dynamics this involves. To arrive at new insights, in this project we adhered to the starting points for co-creation in order to stimulate ‘collective creativity’. We will describe the co-creation approach and the mindset that ensures a flexible, open process,

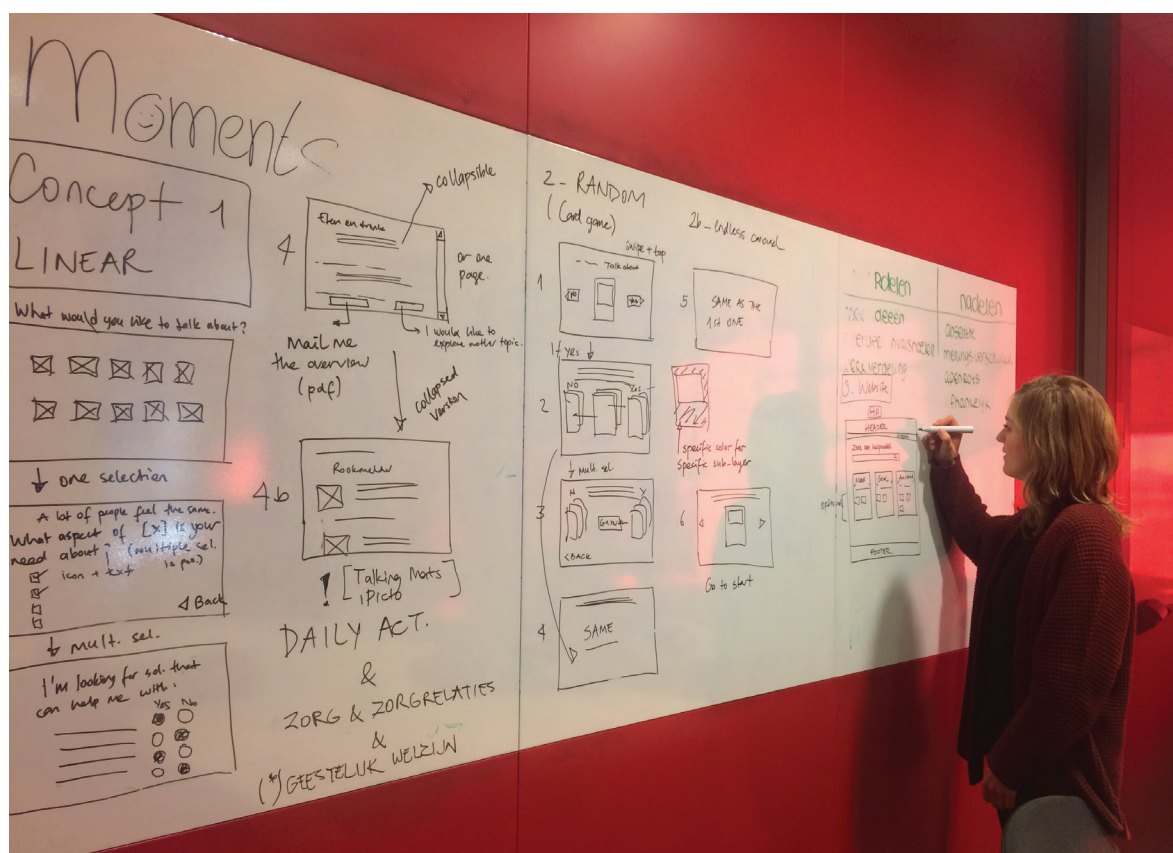
within which there is scope for unexpected ideas. We support our own experiences with the underlying theory and research data.

Mindset for co-creation

An open attitude towards one another was one of the major strengths of the FIT project. Previous experiences with the process of co-creation led to the formulation of a set of attitudes (mindset), which are important to achieve constructive cooperation between people from very different backgrounds:

- ✧ **Be optimistic:** Think in possibilities (instead of problems), believe in a solution, be constructive and practical; convince others to adopt a positive attitude;
- ✧ **Be flexible:** Adapt to new environments; allow others to change the direction of travel; switch between going in-depth and remaining on the surface.
- ✧ **Experiment:** Both success and failure lead to new insights; test your hypotheses; allow yourself to be surprised; try something new.
- ✧ **Be sensitive:** Put yourself in the other person’s place; really get to know people and show empathy; allow yourself to be influenced; test your assumptions.
- ✧ **Be practical:** Make things concrete; create while you are thinking; adopt a practical and pragmatic attitude; you can only improve something that is real.
- ✧ **Be bold:** Dare take a leap of faith; be open to criticism; trust your intuition; being unsure is allowed.
- ✧ **Be critical and responsible:** do not simply accept the normal; accept different expertise; ask why; keep the bigger (social) goal in mind.

Source: Results of the European BigPicnic project (www.bigpicnic.net), in which Waag Society developed a co-creation brainstorming kit.



Designing the decision aid

Social issue of living at home with dementia

As a society, we are facing a huge challenge. In 2040, one in four people in the Netherlands will be older than 65. More than 8% of people aged 65 and older suffer from dementia. The risk of dementia increases strongly with age (Alzheimer Nederland, 2017). Generally speaking, people who face dementia want to continue living at home for as long as possible. However, for them to be able to continue living at home, a number of applications is required. The market is currently awash with products and services that provide for these, but this means that people who are living with dementia are confronted by an excessively confusing array of options. What support do they need? What is available in this area? And how do they go about getting this? What is lacking is the right 'fit' between supply and demand.

The government is increasingly arguing for more 'looking after one another'. This is a response (in part) to a financial challenge – if people live at home for longer, this saves money. The cost of dementia in the Netherlands was 4.8 billion Euros in 2011. This corresponds to 5.3% of the total cost of health care in the Netherlands for that year (Volksgezondheidszorg.info, 2017). The lion's share of this went to the approximately 70,000 people with dementia who are cared for as in-patients. In-patient care cost an average of approx. 60,000 Euros per user per year in 2011 (CBS, 2014). If just 1% of this could be saved by better support of people living at home, this would represent a cost saving of 42 million Euros a year.

“Thanks to the cooperation with the creative industries, we could achieve something that looks good and is user-friendly. On a several projects before, we had technologists but no designers in the team. I believe the added value of the FIT project lies in being able to combine many different expertises.” (researcher, VUmc)

Providing care together with you

Living at home for longer with dementia raises issues in relation to the care of people with dementia. As the focus shifts from ‘caring for you’ to ‘providing care with you’, we are initially looking at informal care provision, such as support from family and voluntary carers. In this scenario, dementia is not (or no longer) simply a matter of care, but also a social issue. Making living at home with dementia an acceptable situation means that those involved with the person concerned have to learn to deal with this. Increasingly, home care workers try, together with the client and his or her (family) carers, to determine what help is needed in order to continue to live at home, and what people can do for themselves. They need support which enables them to have this conversation.

The vast majority of people with dementia wish to continue living at home. It is often the case, however, that this represents too great a burden for the (family) carers. It is necessary to offer them greater support. Nevertheless, products and services aimed at supporting people with dementia who

live at home are infrequently used. There are several reasons for this. One of these reasons is that people with dementia and their (family) carers are often simply not aware of the possibilities (van der Roest et al., 2009). Or they don’t know who could help them find solutions for everyday problems (Coe & Neufeld, 1999). Another reason is that they think the solution offered won’t help (Winslow, 2003). Other issues signalled are that the instructions for products are often unclear (van der Roest et al., 2009) and that services are insufficiently tailored to the individual needs or situation (Lauriks et al., 2007, Meiland et al., 2017, van der Roest et al., 2007).

The aim of the FIT project was to arrive at a solution that would allow people to easily find tailor-made products and services for people living with dementia. Solutions that actually work for them, and that are easy to install and use. What exactly these solutions should be and what they would look like was not known in advance – only that the result should facilitate a ‘fit’ between supply and demand.

"Empathy with the target group is important to the success of a project. But empathy alone is not enough." (project leader and care professional, iZovator)



Test session for the FIT prototype

2. Cross-over collaboration

“A delicate balance is required: a lot of different people together give you more knowledge, but if the group gets too big it becomes unworkable. By meeting in alternating small groups and every now and again in larger groups, we were able to maximise the number of cross-overs.” (researcher, Vivium)

A cross-over cooperation brings together disciplines and parties of highly diverse natures, each with their own perspectives and interests. FIT is a typical example of such a cooperation: knowledge and methods from a range of different fields or expertise are contributed in order to explore a complex social issue. For example, people with dementia are involved versus care professionals, entrepreneurs versus (family) carers, and researchers versus designers. During the process, two major points for attention in relation to a cross-over process emerged: building bridges and dealing with different interests.

Building bridges

Within the FIT project, we faced the challenge of conveying ways of thinking about life with dementia from the point of view of care to designers from the creative industries. In addition, it was necessary for researchers from the various disciplines to gain insight into one another's research methods. Research methods are different in the creative industries and within the care sector. In the case of a cross-over cooperation, this requires that researchers go beyond the boundaries of their own comfort zones and be open to approaches that are 'different', but nonetheless validated. It was also necessary for care professionals and researchers to learn to speak and understand one another's languages, and to build up trust and respect in spite of the differences in approach.

From the very beginning of the FIT project, a great deal of time was invested in getting to know one another's ways of working. For example, a reading club was set up, at which people from different disciplines took turns to discuss relevant articles from their discipline with the others. This allowed members of the project to gain knowledge of one another's fields of expertise, as well as getting to know one another better. There was plenty of opportunity to ask 'stupid' questions and for discussion.

Good communication is important. Regular consultation took place, particularly in the beginning. Alongside meetings at which concrete matters were discussed, the project manager maintained intensive contact with the various parties within the project group, so that everyone was always aware of the steps being taken by the others and the ideas current among them. The benefits this brought about include an open attitude from the members and tangible commitment to the project.

And it was not limited to talking: a lot of design was done to facilitate the research process. An example of this is the joint design session (co-creation session) held with researchers, designers, care professionals, data specialists and entrepreneurs, at which use was made of portraits of people with dementia and their (family) carers. These portraits describe a person in word and images, and are drawn up on the basis of conversations.



Working on portraits

Portraits help to experience the challenge – linking up ‘supply’ and ‘demand’ in a new way – from the viewpoint of the end user. These portraits also helped increase understanding between those involved in the project, and in the building of bridges. Where one person may have a great deal of knowledge about dementia mainly from the point of view of the social sciences, another may be an expert in resources for providing support and decision-making models. The session in which the portraits were used made it clear to everyone who it was they were ultimately designing for. A common awareness was created that ‘people with dementia’ is not a homogeneous group, although people often think and talk as if this were the case. It also became clear that many people with dementia and their (family) carers may not have had a clear idea of a ‘demand’, in relation to which they are looking for a ‘supply’.

During the initial exploratory phase, an interdisciplinary research group was formed in which respect was shown for one another’s expertise and in which this expertise was welcomed. A common foundation was laid, and all disciplines were united behind the common goal: to design a solution for people with dementia that would represent a real benefit to them.

Dealing with different interests

Alongside great unity in terms of content, a cross-over process also demands attention for the different interests of the participants. After all, parties from different disciplines and sectors do not have the same requirements:

- ✨ For the knowledge institutions, the starting point is that new knowledge must be


*“Success factors for a cross-over project are good expectations management. Really working together - not just updating each other about what you’re doing - but investing in creating an understanding of each other’s language and methods. “
(researcher, TNO)*

obtained, and that publications can be made concerning this. They wish to acquire this knowledge in a painstaking manner and they want maximum openness;

- ✧ The aim of the affiliated care institutions in participating in the process is to generate solutions to problems they encounter in practice. Generally speaking, they will expect that the solutions designed can then be used in the long term. They are often not interested in the commercial operation of a solution, or in publishing about this in academic journals;
- ✧ Entrepreneurs from the small and medium-sized business sector (SMEs) participate because they are interested in new solutions and in potentially implementing and operating these within their own businesses. This means that they have an interest in keeping competitors at arm’s length and keeping the findings of the research within the project.

In practice, it is essential that different expectations are expressed, and that all participants contribute to thinking about the next steps.

During this project, for example, it turned out that expectations concerning implementation were different. Partners from the care sector and entrepreneurs didn’t understand how so much money could be spent on research without concrete results being implemented and made sustainable. Surely the results (in the form of a prototype) were at hand? But the researchers were still fully occupied with the responsible completion and delivery of this prototype. The researchers were under the impression that the entrepreneurs and care partners could take care of the implementation. The entrepreneurs, in turn, were hampered by the arrangements in place for public-private partnerships; it is not permitted to use subsidy funds for the implementation of project results within their own companies while the project is under way. Public funds may not be used to advance the interests of private businesses. Thanks to their participation, entrepreneurs do benefit in terms of knowledge, but small and medium-sized companies are not always able to take advantage of this financially. As a consequence, each party focuses on fighting its own corner, with the inherent risk that the project results are then not developed further.



Sonja, 75 years old


"At day care nobody has dementia. We never talk about it."

Sonja is in an advanced stage of Alzheimer's. However, she is not aware of this (anymore). Every now and then she is picked up to go to another place where she meets other people of her age. She quite likes it over there. But more than anything she likes to spend her days at home working in the garden. She really loves that. If she goes out for a stroll her husband Bob gives her a small device that he calls a 'Spotter'. What the device does exactly, Sonja doesn't know. Sometimes Sonja and Bob go to the doctor but is not clear to her what the doctor is saying. She thinks it's for Bob. He seems so tired lately...

Use of technology: only passive use; Spotter.

Additional information

Living situation:	together with informal caregiver
Symptoms since:	± 5 years
Received care:	homecare 1x p/w; daycare 4x p/w
Open about restrictions?	<input type="checkbox"/>
Limited by restrictions?	<input type="checkbox"/>
Desired level of independence:	<input type="checkbox"/>
Can appeal to relatives?	<input type="checkbox"/>
Knowledge of / trust in technology:	<input type="checkbox"/>



Bob, 77 years old


"I still tell her lots of things, but it doesn't really come through. I am losing her more and more..."

Bob cares for his wife Sonja on a daily basis. Sonja is in an advanced stage of Alzheimer's. The difficulty for him is that she does not seem to realize this. Sometimes she gets frustrated when things do not work out the way she is used to, but if he tries to explain what is happening in her head, she gets angry at him. He decided to stop explaining, although it is difficult to keep his temper at times. Due to the situation Bob doesn't invite people to their home any longer. Going out alone is not possible for Bob either. This makes him feel lonely lately.

Use of technology: smartphone, internet.

Additional information

Relation with care recipient:	partner
Symptoms care recipient, since:	± 5 years
Additional care:	homecare 1x p/w; daycare 4x p/w (for Sonja)
Desired level of control:	<input type="checkbox"/>
Inventiveness:	<input type="checkbox"/>
Level of self-sacrificing:	<input type="checkbox"/>
Can appeal to relatives?	<input type="checkbox"/>
Knowledge of & trust in technology:	<input type="checkbox"/>



Johan, 61 years old


"There is no point denying it, unfortunately. I just try to live with it."

Johan is living with Alzheimer's since a few years. The symptoms slowly crept in. He used to be manager at a large office. Soon after he retired, he got confused. His wife Wilma and he thought it was due to the disappearance of a daily structure, but it happened to be Alzheimer's. Johan tries to stay independent as much as possible. Wilma is his great support in this; in several ways she helps him retaining his independence.

Use of technology: tablet to play games and for skype-call with his children (only with help of Wilma).

Additional information

Living situation:	together with informal caregiver
Symptoms since:	± 2 years
Received care:	none (besides informal care)
Open about restrictions?	<input type="checkbox"/>
Limited by restrictions?	<input type="checkbox"/>
Desired level of independence:	<input type="checkbox"/>
Can appeal to relatives?	<input type="checkbox"/>
Knowledge of & trust in technology:	<input type="checkbox"/>



Wilma, 58 years old

"I try to solve many things myself. It would be great to have a book with practical tips and tricks for helping John better at home."

Wilma finds it hard to see her husband, Johan, suffering. About three years he was diagnosed with Alzheimer and he is experiencing a steady decline in his functioning ever since. Some rather complex things, like making coffee, he is still able to do, which surprises her at times. However, closing up the zipper in his pants is a problem. Wilma tries to help John with all sorts of 'home made' interventions, for example replacing zippers by velcrostraps. Sometimes she worries if she's doing things right, especially because she works three days away from home.

Use of technology: smartphone, tablet, internet.

Additional information

Relation with care recipient:	partner
Symptoms care recipient since:	± 2 years
Additional care:	none
Desired level of control:	<input type="checkbox"/>
Inventiveness:	<input type="checkbox"/>
Level of self-sacrificing:	<input type="checkbox"/>
Can appeal to relatives?	<input type="checkbox"/>
Knowledge of & trust in technology:	<input type="checkbox"/>

Examples of portraits

3. Designing with care

“The designers listened well to all the parties involved, and also to the clients. Their starting point was an open, flexible attitude: ‘Tell us how things are, and how we can improve them.’ In this process, the designers took both the content and the design of the application into account.” (researcher, Vivium)

Expectations in relation to cross-over projects are high; that solutions can be found to social problems that cannot be found through a monodisciplinary approach. Many such issues are complex, and in addition it is often also unclear what exactly the desired outcome is. These kinds of issues benefit from an iterative, collective approach whereby it only becomes clear what problems and potential solutions are being tackled during the process. Such an open approach demands robust direction. In the FIT project, we used a co-creation approach and methods drawn from design thinking to – among other things – jointly draw up a decision aid.

Co-creation describes every form of creativity shared by two or more people (Sanders & Stappers, 2008). For example, between designers, end users, researchers and developers. By working together on solutions, knowledge and ideas that reinforce one another are exchanged. A major precondition for this is that every participant is seen as an expert based on his or her own experience, and contributes in this way to the development of new insights (Sanders & Stappers, 2008). So everyone is equal and every contribution counts. Involving all interested parties in the co-creation process increases the chances of the solution created corresponding to the experiences and possibilities of the user or users. This also creates broad-based support for the solution.

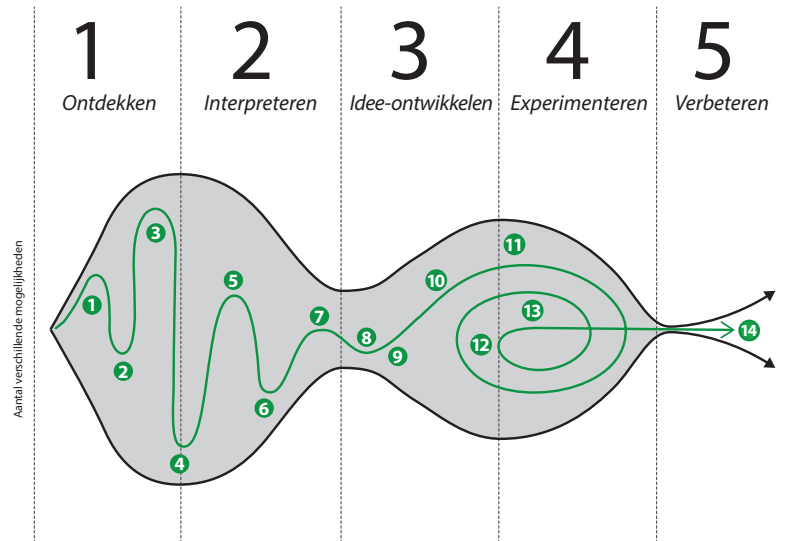
Creation plays a major role in the co-creation process; creating drawings, texts or prototypes makes thoughts, values and assumptions tangible and facilitates understanding between those involved. The playfulness of creative work also helps bring people closer together.

Design as the backbone of the process

The designers within the FIT project used methods drawn from design thinking to structure the design process. The method of design thinking is made up of five steps: discovery, interpretation, idea development, experimentation and improvement. Within these steps, as many insights and ideas as possible are collated (divergent thinking), and then boiled down to a single starting point (convergent thinking); these ways of thinking alternate within the process.

In the FIT project, designers and researchers first brought together as much knowledge as possible concerning supply and demand for people with dementia wishing to continue living at home. During the **discovery phase** of FIT, literature was read, knowledge exchanged, discussions held on the basis of portraits, and interviews were done with people suffering from dementia (and their (family) carers) at home. During this phase, the richest possible impression was created (divergent).

During the next step, **interpretation**, the information collected was examined in a critical manner. What are the needs and wishes of the various users involved? Where do these needs overlap, and where do they not? Where are the challenges and opportunities? This phase was convergent: the design objective was defined on the basis of the analysis. An important conclusion during this phase was that people with dementia do not have a very good idea of what their needs are, and that the expression of the demand must take up a significant place in the solution to be designed. This phase of the FIT project was defined in part



Systematische weergave van de ontwerpstappen en resultaten in project FIT, volgens de design thinking fasen van IDEO, Tim Brown.

During the discovery phase of FIT, literature research was conducted (1), interviews were conducted with people living with dementia, and caregivers (2). Focus groups were organised using the experience booklet (3). An inventory has been made of the existing supply of products and services (4). In the interpretation phase, a model questionnaire was prepared (5). Based on portraits, the design goal was defined (6), and a conceptual framework developed (7). Then, in the phase of idea development, a database was developed in which 'demand' and 'supply' have been linked (8). A first paper prototype of a possible decision aid was then made, consisting of a set of ten cards (9). Then three concepts for digital decision assistance were designed (10). In the experimental phase, these prototypes were tested (11) and processed into a final concept (12). This concept has been re-tested (13) and adapted to the final decision aid (14).

by the translation of knowledge into models: what are the characteristics of the supply and demand? What are the problem areas? Based on the information collected, a database was developed during the **idea development** phase in which 'supply' and 'demand' were linked, and three concepts for a digital decision aid were designed. In the **experimentation phase**, several prototypes were made to allow the feasibility and the effect of the design to be tested with the users. This led to insights about how the design could be adjusted to bring supply and demand together. Shuttling back and forth between design and testing with the end users, the designers **improved** – in consultation with the other partners – the concept and arrived at a final prototype.

Roles

Co-creation can succeed through the contributions of all those involved in the design phases. This does, however, require robust direction. This direction is provided by the designer, who involves the various 'experts' in all phases of the design process and provides them with resources to express

their expertise and creativity so everyone is able to make a contribution based on his or her role (Sanders & Stappers, 2012). The designer also plays an important role in translating the input and ideas contributed into concrete solutions and concepts, and ensures that everyone's voice is heard.

The designers within the FIT project devoted special attention to understanding and involving the end users, particularly people with dementia and carers. For many with dementia, taking part in this process was not natural, and they did not always understand what the designers were asking. The designers, in turn, sometimes found it difficult to interpret feedback they received from the people with dementia. Additional literature, as well as discussions with (family) carers, professionals and experts in the field of dementia and in designing for people with dementia led to a better understanding of the situation. The designers also sought a great deal of contact with people with dementia; they visited them at home or at meeting places, took the time to talk with them and carried out small-scale tests with various design solutions.

4. Surprising results

“Working with the designers was very refreshing. They were prepared to approach us and really listen to us. And this is reflected in the results. It really was developed together. I think that’s really great.” (district nurse, HilverZorg)

The cross-over research method is characterised by the surprising insights and products it can lead to, which were not anticipated in advance. This is thanks in part to the process of co-creation, and also to research that makes use of design thinking. During the research and design process within the FIT project, various products and services were developed alongside the FIT decision aid. This is characteristic of the open approach we chose in this cross-over. Coming up with innovative ideas and solutions requires flexibility. The outcomes of the various steps in the design process have led to applications that have proven relevant in practice, even though this was not set out as a goal in advance. We will describe a number of these surprising results.

Booklet for the care institution aimed at exploring demand

During the first phase of the project, people with dementia and (family) carers were approached for discussions on day-to-day living with dementia and their requirements in terms of support. In preparation for these discussions, participants were given an ‘experience booklet’ (also known as a ‘probe’). An experience booklet is a method commonly used in design research to collect qualitative, fragmented data on the world as experienced by the target group. The advantage of this method is that the participants have time to think about their answers in advance, are able to do so in their own surroundings, and formulate these answers straight away on paper in their own words. Questions can then be asked about the underlying motives

for these answers during the discussion.

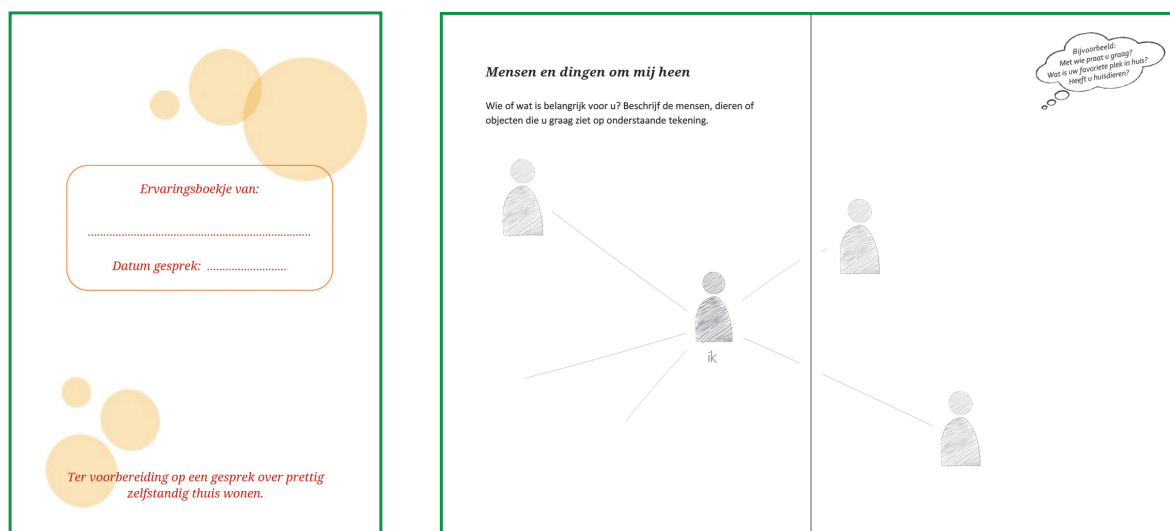
The experience booklet was initially designed to support the FIT research. But the booklet was then embraced as a product by employees of the participating care institutions because it offers opportunities to take a look into how people with dementia and their (family) carers experience the world. Lives in which dementia is not the dominant factor. Questions such as ‘What do you do during the day?’, ‘Who are the important people around you?’ and ‘What would you like to do (more)?’ are central to the experience booklet. There is also space to write down associations concerning needs-related themes – for example, security or emotional wellbeing.

In the concluding phase of the FIT project, this probe was translated into a useful booklet for the care sector, for familiarisation with the experiences of people who become involved with care and a need for support.

Do-it-yourself solutions

During the first phase of the research, an inventory was drawn up of the existing supply of resources and services available. We saw that people with dementia and (family) carers often came up with solutions themselves: do-it-yourself solutions. For example, a basket that contains everything necessary for personal care: toothbrush, toothpaste, comb and moisturiser. This can act as a reminder for someone who is no longer as familiar with personal hygiene routines: all the products have to be used. Another example is the wide range

"I think the experience booklets are a real expression of creativity. For the 'care' sector, it takes a different partner to achieve something like this. It really corresponds to how users experience the world." (innovation manager, HilverZorg)



The experience booklet has been published in Dutch under the Creative Commons license. You can download it here : <http://waag.org/fit> under 'Publicaties'.

of modified diaries and diary management; from an elastic band that holds the right day in place to colour-coding for different tasks. These do-it-yourself solutions are interesting; they indicate possible opportunities for product development (there is demand, but apparently no existing or suitable solution as yet). They also show how inventive people with dementia and their (family) carers can be in coming up with their own solutions. These do-it-yourself solutions inspired one of the FIT project researchers to set up a potential platform through which (family) carers can share such solutions.

FIT card set

The first prototype of the FIT decision aid consisted of a set of ten paper cards, each of which showing a 'need category'. On the back, a number of examples of products and services. This first design solution was used principally by homecare employees approaching people with dementia about taking part in the evaluation survey for the Gooi en Vechtstreek region. This card set could be seen as an 'emergency solution' until the digital decision aid became available. Nevertheless, it proved an extremely successful intervention. The homecare

employees reported that the cards were a good means of starting a conversation about requirements for support in living at home. The cards provided a structure, and therefore a concrete starting point for a discussion. In the rest of the process of testing the decision aid, it turned out that the cards were used again and again; during the first orientation meeting, the iPad with the digital decision aid was often not taken out, but the cards used instead. This prompted us to develop the card set further in the final style of the decision aid, and to make it into a stand-alone product.

Care tech market

n order to inspire the care employees and familiarise them with a number of (technological) solutions, an afternoon was organised at which a number of suppliers (e.g. Sensara BV, Dementia-app, RSVO-alarmering) demonstrated their products to care professionals (homecare employees, case managers, WMO [Social Support Act] consultants). The essence was that the visitors could handle and try out the products. This afternoon was a great success. From the evaluation session, it emerged that many visitors feel awkward about trying out new



The first prototype of the FIT card set



The final FIT card set

products, let alone recommending these to clients, and that this afternoon helped them overcome this threshold. A scenario was drawn up in advance that can easily be applied by other parties wishing to organise something similar. This scenario can also be used for a meeting with (family) carers. We count the care tech market among the results of the FIT project.

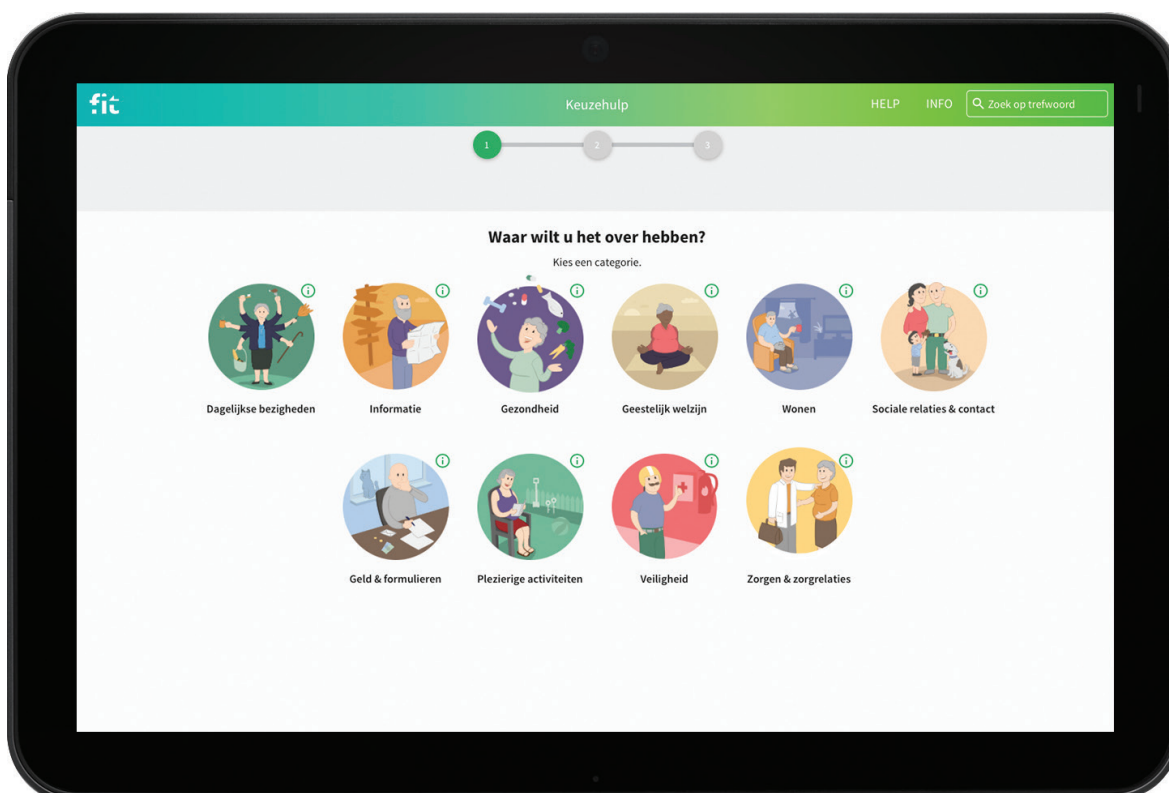
Dementia product library

We discovered that people don't always want (or are not always able) to purchase a product. For example, because they are not sure whether it will really help (in their situation); because they will probably only need the solution temporarily, as the dementia will progress, or because solutions can be expensive and are not always covered by insurers. On the basis of the FIT project, the initiative was taken to set up a 'dementia

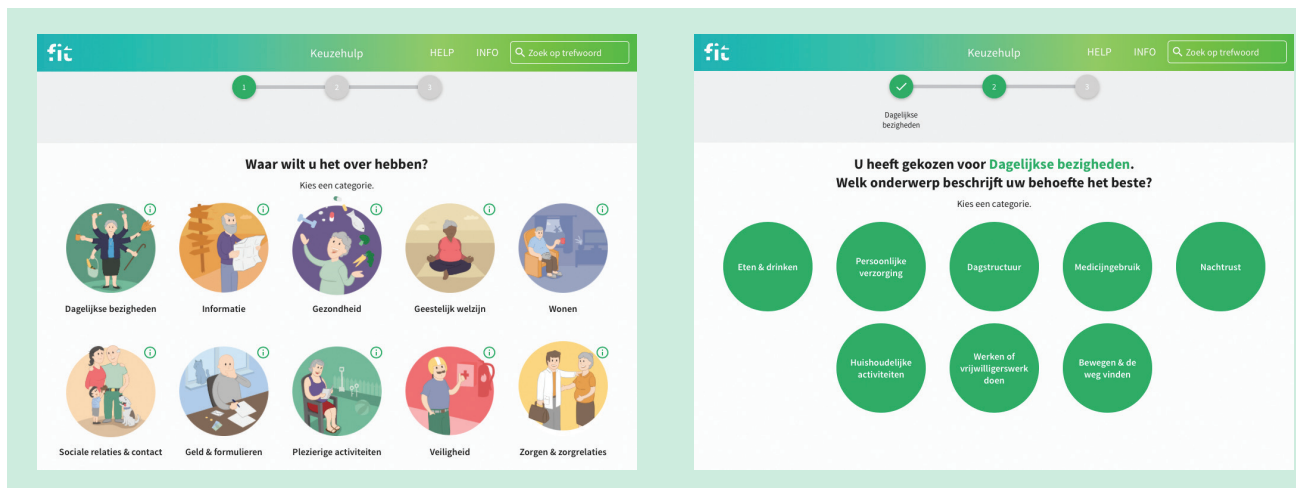
product library' run by Inovum, an organisation that lends out products to support people with dementia. Some people are hesitant about using suggested products at home. They want an assurance that things can be returned if they are not satisfactory.

FIT decision aid

One of the results of the FIT project was a decision aid to support people with dementia and their (family) carers in choosing the right products and services for living at home independently. The decision aid is to be used on a computer or tablet (see also <http://www.fit-keuzehulp.nl>).



The decision aid website (can also be used on a tablet).



Recognising needs in three steps: 1) Day-to-day activities (requirements category), 2) Daily structure (sub-requirements) and

Linking up supply and demand

The decision aid supports the linking up of demand (needs) to supply (existing products and services) in various different ways. By supporting the user in recognising and expressing his or her needs: the expression of demand. A concrete need can also be linked to one or more product categories, and for each product category information can be provided on obtaining and paying for these.

The decision aid is intended to provide access to as complete as possible an overview of solutions for particular needs. This concerns not only needs related directly to the consequences of dementia (such as 'sense of time' or 'incontinence'), but above all also needs that concern a pleasant, full life (such as 'feeling secure' or 'life having meaning'). In addition, the decision aid also supports the needs of (family) carers, who care for a loved one with dementia (for example, 'balance between providing care and charity'). Many needs are included several times in the decision aid, in order to make potential solutions easier to find. For example, support in the use of medicines can be found not only under 'day-to-day activities' but also under 'health'.

Discussion help

The decision aid is designed to be used together. The decision aid is meant to enable the conversation between people with

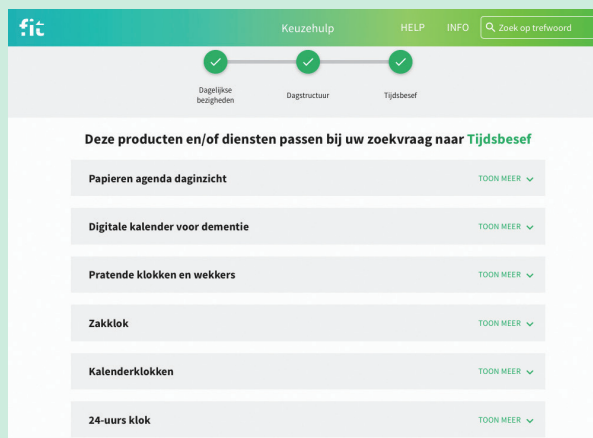
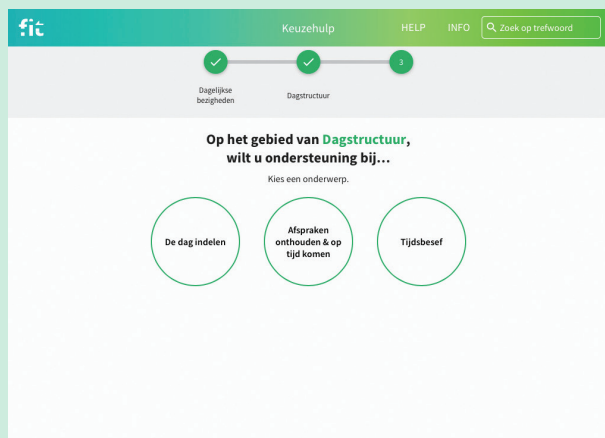
dementia and (family) carers; between care professionals and people with dementia; or between care professionals and (family) carers. One question is always asked – read out loud – to open and stimulate the discussion.

It can be difficult for people with dementia to use the decision aid by themselves, partly owing to the deterioration of their ICT skills, cognition and concentration. For this reason, the decision aid is aimed at (family) carers and care professionals as the primary users of the decision aid. By addressing people with dementia we involve them when the decision aid is being used. This has also been explicitly taken into consideration in the design and language used.

Recognising needs

Many people with dementia find it difficult to think about what they need to retain their independence. Recognising – or accepting – needs is an important first step on the way to finding a suitable solution. This expression of demand step is supported in the decision aid by the 'Start the decision aid' route.

The starting point for the expression of demand consists of ten need categories: day-to-day activities, pleasant activities, health, mental wellbeing, social relationships & contact, care & care relationships, living, security, money & forms and information.



3) Sense of time (goal), 4) The corresponding solutions for 'Sense of time'.

Each requirement category is sub-divided into several sub-requirements, and then into concrete aims. In the decision aid, the user is led step-by-step through this process of demand expression (see Figure: 'Recognising needs in three steps'). (Relevant) products and services are then shown for the goal chosen, for example 'Sense of Time'.

User-friendly

The design has deliberately been kept as simple and clear as possible. This means that all the information always fits onto one page (the user doesn't need to scroll); there is only ever one action possible on each page and it is always easy to go back a step. The path the user follows in the decision aid is repeated and confirmed in images and text ('You have chosen ...'), so the user remains involved in every step.

In terms of language, simple, positive formulations are preferred, corresponding to the user's experience. We do not ask what someone can't do or misses, but what someone would like to do or improve. For example, 'What would you like to talk about?' (instead of 'What problems are you having?'); or I would like 'someone or something to be with me' (instead of 'I feel lonely').

The illustrations in the decision aid show both men and women, of different ages and backgrounds. Even though we are discussing

potentially challenging situations, no one looks pathetic or sad. The emphasis is not on dementia, but on good, independent living.

User comments

- ☀ "With the decision aid, I talk about my needs earlier. You know you're not empty handed." (District Nurse, AMSTA)
- ☀ "The decision aid helps to focus the conversation, so you can get more in depth." (Nurse, HilverZorg)
- ☀ "It is very valuable to see all the needs in one overview. There are still challenges you experience, but with the decision aid you can prepare for this." (Caregiver)

5. From cross-over research to practice

“One of the participants from a care institution said: ‘It can’t be that after we’ve spent two years working on the FIT project, and learned all kinds of things about what could help, that we then don’t help anyone else?!’ This was the start of the discussion about how we can make the outcomes more sustainable.”
(project coordinator, AUAS)

The prototype for the decision aid was tested in ‘living lab’ the Gooi en Vechtstreek Region, in order to find out whether the products and services selected in the decision aid actually contribute to living at home (longer) in a pleasant, independent manner. Here, we will discuss the experiences of the care professionals who advise people with dementia and (family) carers about support products and services using the decision aid.

People with dementia who participated in the research were open to challenges they faced, and to how continuing to live at home remained possible. This makes these participants an exceptional group. Most people cannot or do not wish (yet) to talk about their illness. Generally speaking, the people were pleased with the products and services offered to them. The (family) carers, on the other hand, stated that they were overburdened and it was difficult to motivate them to invest in the research. Testing new products or services and giving feedback cost them valuable time, which they need to use for providing everyday care. These (family) carers could however be won over in small steps; rediscovering the sense of independence in the people they were caring for was a stimulus to continue to cooperate with the research.

Care professionals and the decision aid

During testing of the decision aid, it emerged that the care professionals first had to overcome their own reservations before

entering into a discussion of products and services. The care professionals had themselves to (learn to) be open to the use of particular (technological) applications. The care tech market itself contributed to this by allowing the professionals to test various applications. It is not enough just to read about various applications; it is important to gain experience yourself. As the care professionals gained greater confidence in their own abilities, they became more enthusiastic about using the decision aid. One frequently heard comment was that the decision aid offers a good structure for entering into conversations with clients.

From acquisition to use

Taking the recommended products into use was complex owing to a range of logistical challenges: Who orders the materials? Where are they delivered? Who installs the products at the people’s homes? It quickly became clear that this ordering and delivery service required a great deal of effort. We will discuss a number of issues concerning this below.

Where are the goods delivered?

Delivery to the person concerned is often not an option: s/he has not ordered it and may well have forgotten what it’s all about. Delivery to the (family) carer also has disadvantages. The (family) carer will often call in care services at the moment s/he is becoming overwhelmed. This is generally not a good time to require an extra effort from this person in terms of getting to know new products



Care professionals test out the decision aid

and learning what they do. Within the FIT project, the delivery of materials was done through the homecare service, a community building or through the care institution.

How do these new products work?

Before a product could be offered to a user, it had to be determined how the product works. Unfortunately, it was frequently the case that it was only discovered at this stage that the manual was completely unintelligible. In the FIT project, we were very grateful that we were able to make use of the services of technical volunteers in this respect. These volunteers tested all the equipment for us in advance. During these tests, it was discovered for example that some 'GPS trackers' looked user-friendly, but that the server was regularly offline. This meant that these trackers were unreliable in use – they were returned to the supplier.

Reactions from the field

Below are examples of responses we received to the products supplied:

- ☀ *The magic box*: an iPad on which the lady was able to look at photos of the place she used to live. Although she has trouble remembering the names of people and places in the present, she is very well able to recall details from the past and to tell stories after seeing these pictures. She enjoys it.
- ☀ *The senior citizens' telephone*: The lady took the care professional by the hand – she wasn't able to remember her name, but led her to the telephone and said: 'You gave me this'. The lady had not made a phone call for at least a year, but since the new telephone has been installed she speaks to her children every day – she is able to recognise them from the photos stuck onto the buttons on the telephone

6. Reflections and conclusions

"It is interesting to see how different people have different ways of thinking. Care professionals think mainly in problems, relationships and processes. Creative people (designers) immediately think in terms of solutions and form. A picture or simple drawing is often enough to make something tangible; it changes the emotion." (project coordinator, AUAS)

The FIT project delivered a lot of knowledge. The main question – how to help people with dementia and their (family) carers to find supply that corresponds to the demand to be able to continue to live pleasantly and independently at home – was answered. In addition, a great deal of experience was obtained in cooperation within a cross-over between care and the creative industries. The FIT project allowed us to experience the added value such a cooperation can represent. The cross-pollination between care, design, research and bringing in the users in a systematic, structured way led to meaningful outcomes. Also, greater understanding for one another was fostered and knowledge broadened, so applications were designed that represent an actual improvement in care. Naturally, it is good to also adopt a critical, realistic attitude on what is possible within a cross-over project. It should be noted that the relationship between knowledge development and the valorisation of this knowledge can be tense. Nevertheless, the context of a cross-over project offers the scope to handle such tensions in an effective way.

A good 'cross-over' doesn't happen by itself

In order to make use of the strength of a cross-over, investments are required in the way the various disciplines work together. The parties involved have to learn to 'understand' one another on different levels. This means on the one hand being open about outcomes, and on the other maintaining tight direction. In the FIT project, a highly active, committed

and communicative project leader and application of the mind-set required for co-creation (see: Section 1) helped achieve both the required openness and the direction. These efforts are indispensable. Working with an uncertain outcome is often an adventure in itself. Generally speaking, the parties involved want clarity about where exactly a project is leading, and what they can or cannot get from the project. This tension only becomes greater during the process.



Kick-off of the FIT project



Co-creation between a designer and a care professional

Co-creation presents appropriate solution

Because people with dementia cannot always put into words themselves what they need, different people are involved in linking up the demand to the supply of services and products. (Family) and professional carers also play a role; both in finding a suitable product or service, and using this. This means that an intervention – in our case the decision aid – has different end users, with different wishes in relation to the use of the product or service.

Cooperation by researchers and designers with these different end users is necessary for a good understanding of how a product or service should be designed and developed. This co-creation approach has led to the aim of the research being more closely defined,

and the emphasis shifting to the expression of the demand, instead of 'simply' focussing on supply and demand. There were also some unexpected discoveries made during the process, which the participants in the project were able to take into use immediately.

In practice, use of the decision aid allowed the care professionals to fulfil a need they themselves were not (yet) aware they had: to have a good conversation on the possibilities for supporting living at home and to provide good information on what is possible outside of regular care. As with the people with dementia and their (family) carers, it is not self-evident yet that there are other possibilities than care for the home situation. The efforts of the FIT project made this clear to the participants.

"Each project starts off with a getting-to-know-you phase. You first have to spend time together, let things happen, before you can really work together. The reading club was very useful for this. It gave us the chance to get to know one another's backgrounds, to experience different ways of thinking and working."
(researcher, TNO)

Ownership of the end product

Once a choice for a particular type of support has been made using the decision aid, the product or service then still has to be ordered. A person with dementia will not always be able to do this. However, family and professional carers are often already under great pressure. Care professionals generally have little time to look into new applications due to pressure of their work providing care. If the decision aid works well – and we have every reason to believe that this is the case – it will be necessary to also make good arrangements for ordering and installing the products and/or services chosen.

As we progressed in the process of the design and development of the decision aid, the question of which party could or would operate the application became ever more relevant. As the very openness of a co-creation process means that the outcome is not clear in advance, this also means that no potential operator is known at this stage. In the case of solutions to complex problems tackled by means of a cross-over, it's often not clear who the 'owner' of the problem is. The power of a cross-over process – from which the decision aid was born – is also its weakness.

"In a project like this, you should sometimes go beyond the brief. If you just rigidly stick to the assignment, you would never get a dementia product library, or a Care Tech Market. You would just do what is in the description." (project leader and care professional, iZovator)

References and further reading

References

Alzheimer Nederland (2017). Factsheet on dementia. Available online: www.alzheimer-nederland.nl/sites/default/files/directupload/factsheet-dementie-algemeen.pdf

Statistics Netherlands (CBS) (2014). Gezondheid en zorg in cijfers [Health and Care in Figures] 2014. E-book available online: www.cbs.nl/nl-nl/publicatie/2014/45/gezondheid-en-zorg-in-cijfers-2014

Coe, M., Neufeld, A. (1999). Male Caregivers' Use of Formal Support. *West. J. Nurs. Res.* 21, 568–588.

Dröes, R.M., van Hout H.P.J., van der Ploeg E.S. (2005). CANE Camberwell Assessment of Need for the Elderly, Dutch translation, VU medisch centrum.

Roest, H. G. van der, Meiland, F.J.M., Comijs, H.C., Derksen, E., Jansen, A.P.D., Hout H.P. van der, Jonker, C., Dröes, R.M., What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *International Psychogeriatrics* (2009), 21(5), 949-65.

Winslow, B.W. (2003). Family Caregivers' Experiences with Community Services: A Qualitative Analysis. *Public Health Nurs.*, 20, 341–348 (2003)

Lauriks, S., Reinersmann, A., Roest, H. van der, Meiland, F.J.M., Davies, R.J., Moelaert, F., Mulvenna, MD, Nugent C.D., Dröes, R.M. (2007).

Review of ICT based services for identified unmet needs in people with dementia. *Ageing Research Reviews*, 6(3):223-46

Meiland, F.J.M., Innes, A., Mountain, G., et al. (2017). Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics, *JMIR Rehabil Assist Technol*, 4(1):e1.

Van der Roest, H.G., Meiland, F.J.M., Maroccini, R., Comijs, H.C., Jonker, C., Dröes, R.M. (2007). Subjective Needs of People with Dementia: A Review of the Literature. *International Psychogeriatrics*, 19, 559–592.

Sanders, B.N., Stappers, P.J. (2008). Co-creation and the new landscapes of Design. *Codesign*, 4(1), 5-18.

Sanders, B.N., Stappers, P.J. (2012). *Convivial toolbox: Generative Research for the Front End of Design*. Amsterdam: BIS Publishers.

Volksgezondheidszorg.info (2017). Kosten van zorg voor dementie [Cost of Care for Dementia]. Available online: www.volksgezondheidszorg.info/onderwerp/dementie/kosten/kosten#node-kosten-van-zorg-voor-dementie

Further reading

Bosch, L., Janssen, M., Wildevuur, S.E. (2016). Producten en Diensten ter Ondersteuning van Thuis Wonen met Dementie. [Products and Services for the Support of Living at Home with Dementia.] Waag Society, Amsterdam. Available online: <https://waag.org/sites/waag/files/public/media/publicaties/fit-producten-diensten.pdf>

Cila, N., van Zuthem, H., Thomése, F., Otten, W., Meiland, F., Kröse, B. (2017). FIT Decision Aid: Matching the Needs of People with Dementia and Caregivers with Products and Services. Interact Conference on Human-Computer Interaction (HCI), September 25-29, 2017, Mumbai, India.

Van Dijk D., Wildevuur S.E., Kresin F. (2011). Users as Designers: A hands-on approach to Creative Research. Waag Society, Amsterdam. Available online: https://waag.org/sites/waag/files/public/Publicaties/Users_as_Designers.pdf

Van Zuthem, H., Wildevuur, S.E., Bosch, L., Janssen, M., Meiland, F. (2016). De mens zien bij dementie. Co-creatie onderzoek naar behoefte aan ondersteuning thuis. [Seeing the person behind the dementia. Co-creation research into needs for support at home.] Waag Society, Amsterdam. Available online: <https://waag.org/sites/waag/files/public/media/publicaties/de-mens-zien-dementie-def.pdf>

Care for design in care

Experiences with cross-over research into living at home with dementia

How can you become inspired by working together with several other disciplines on big social issues? What are the hurdles to be overcome? 'Care for design in care' describes the experiences of a diverse team in the cross-over project FIT. The social issue within FIT concerned how people living with dementia can find suitable products and services that correspond to their need to live at home independently. Both the (essential) tension of a cross-over process and its strength and dynamism are discussed.

