
GUIDEMENTIA

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**Abstract**

A growing number of people are suffering from dementia. These people are in need of caregivers. This pictorial describes an iterative design process towards a concept supporting the independency of people with dementia. The result is **GUIDEMENTIA**, a service consisting a device for the person with dementia and an application for the caregiver.

GUIDEMENTIA supports the person with dementia by completing multistep activities and thereby unburdening the caregiver. The term "*Final design*" in this report does only implicate the state of the design until this point in time. The design has many positive aspects, but also many possible improvements for the future, such as developing in a state that the device can easily be used and testing it with more prospective users.

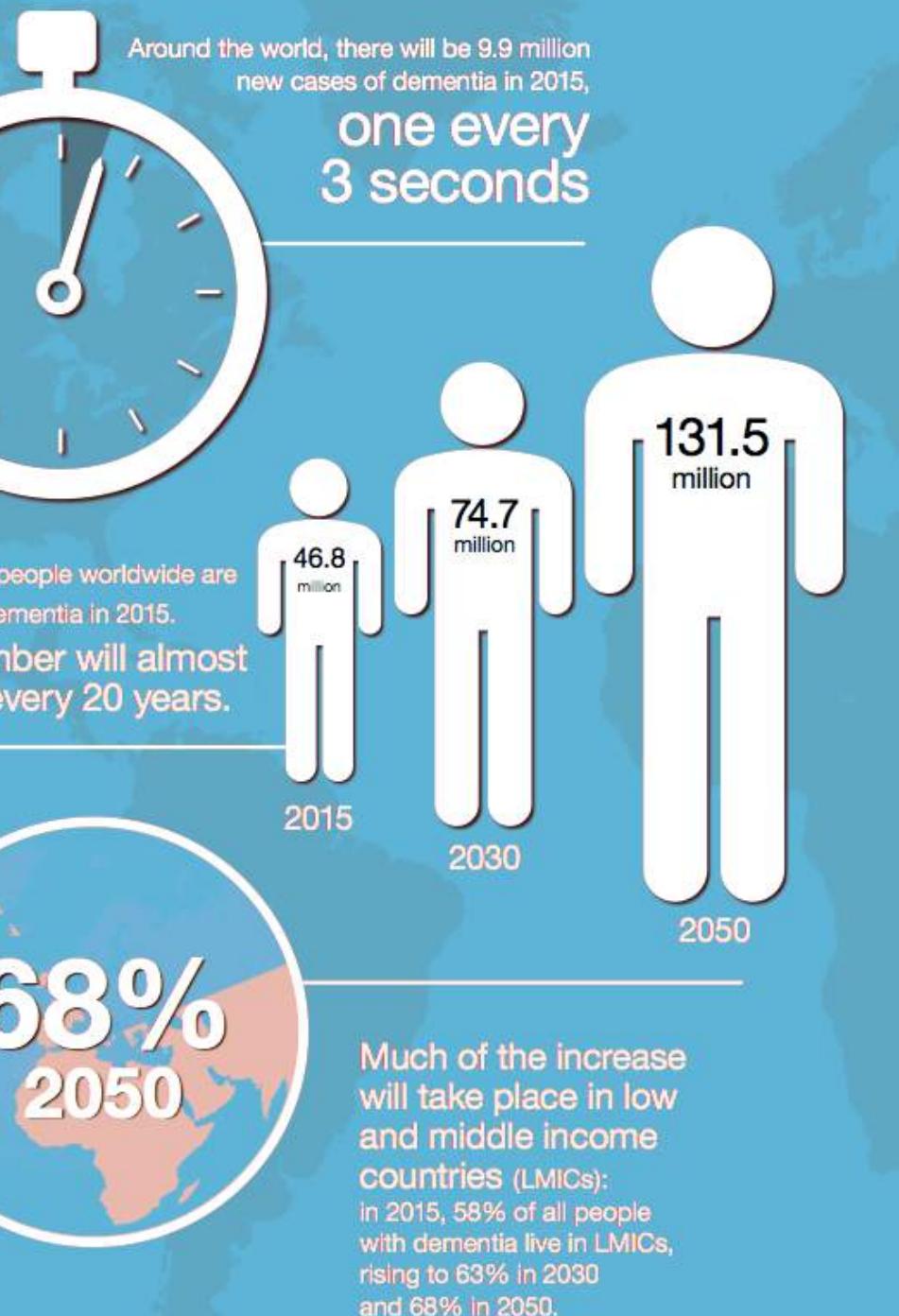
Authors Keywords

Dementia; early stage; independency; daily activities.

ACM Classification Keywords

H.5.2. User Interfaces: User-centered design.

The global impact of dementia



Introduction

Alzheimer's Disease International estimated in World Alzheimer Report 2015 that 46.8 million people worldwide were living with dementia in 2015 [13]. Moreover, "this number will almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050" [13]. These numbers are explained by the drastic increase of commonness of dementia with increasing age [13], and the fact that our society is ageing [14].

Because of the dementia, people become more dependent on others and thus are in need of caregivers. Even though caregivers report positive feelings about caregiving, the emotional well-being of caregivers often gets deteriorated [3]. The vision of the authors was to both relieve the stress of the caregivers and give back some autonomy to the people with dementia. This means that it is important to guide the people with dementia through the different stages of dementia and support them while performing everyday tasks. If (s)he is lacking the ability (mentally, emotional, physically or spiritually) to achieve certain everyday tasks, either people or technology will have to make up for that inability.

This pictorial describes the development of **GUIDEMENTIA**: a product that supports people with dementia in their daily life. First this pictorial will dive more into the context of dementia.

Figure 1

Infographic about Dementia [13]

Context of Dementia

Dementia is characterised as the loss of cognitive functioning [4, 7]. Multiple sources describe symptoms of dementia [1, 2, 4, 7, 8], e.g. the ability to think, remember and reason [7]. The most important symptoms for this pictorial are difficulty completing familiar tasks at home, misplacing things and losing the ability to retrace steps [2].

A common cause of dementia is Alzheimer's disease: a degenerative brain disease [2]. In Alzheimer's disease, nerve cells are damaged and demolished which eventually affects other segments of the brain [2]. This includes brain segments that give the person the ability to carry out basic bodily functions, e.g. walking and swallowing [2].

Timlin and Rysenbry differentiate three stages of dementia; early, mid and late stage [8]. In the earliest stage, some symptoms start to show. The person with dementia may have some problems with lacking the ability to complete tasks that (s)he were familiar with before [8]. In the mid stage, short-term memory loss will show up [8]. It also will become more difficult to manage everyday life and completing tasks [8]. In the late stage, the demented people are in need of high level assistance while accomplishing everyday life activities [8]. This late stage is characterised by extensive memory loss and they may be unable to determine the function of familiar objects [8].

Because of the memory loss that comes with dementia, it might be hard to introduce new technology in the user's life. To get familiar with the technology nonetheless, it is important to introduce the technology at an early stage of the disease [6, 12, 15], possibly even before the person with dementia needs the technology [9]. For this reason, the authors focus on the early stage of dementia with the goal to make the product useful for the mid stage as well.

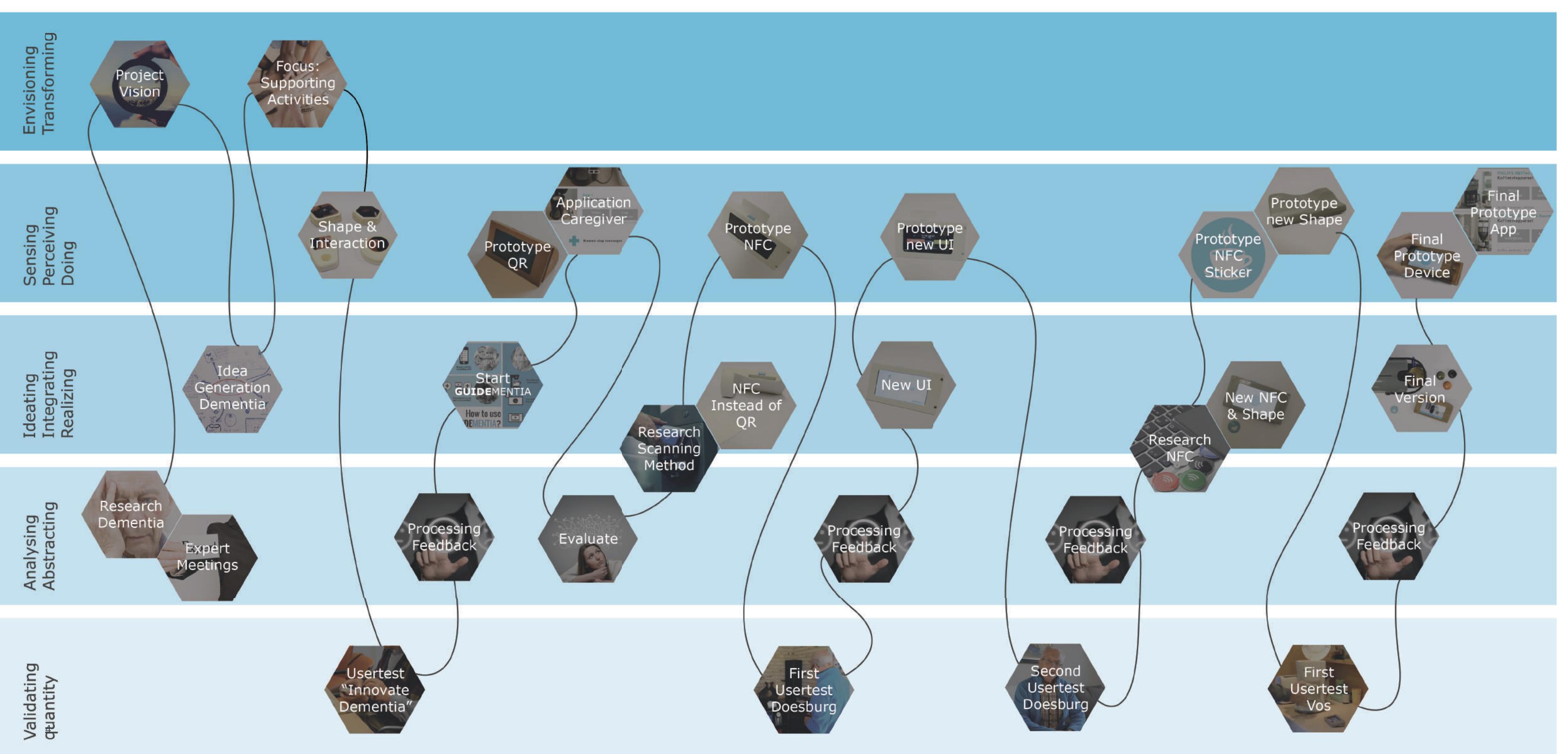
Designing for Dementia

It is important to develop new technologies to compensate for cognitive problems with daily activities to maintain independency and maximise the quality of life for people with dementia [10, 15]. These can be simple prompts, e.g. an alarm that makes you aware of taking your medication, or more complex sequences of prompts taking the person through the sequence of subtasks, e.g. the steps you have to follow to wash your hands [10].

In expert meetings with C. Datema (healing environment consultant) and W. de Kinderen-van Heeswijk (care counsellor at Netwerk Dementie Eindhoven) it became clear that the technology should be simple and easy to use. It is important not to overwhelm the user by limiting the options and thereby decreasing the decision-making stress [1].

According to an expert meeting with F. Vos (a person who is suffering from Alzheimer) and his partner, it was found that it is important to provide structure while performing daily activities, which is also reported in literature [11]. By providing structure and increasing the complexity of an activity or dividing the activity in subtasks, a person with dementia can complete an activity successfully [11].

Within this pictorial, the authors focus on supporting the person with dementia while performing daily activities. When developing a technology for this purpose, it is important to support the person with dementia with audio feedback. According to W. de Kinderen-van Heeswijk, audio feedback will help a person with dementia better understand explanations of the subtasks of an activity. Not only audio feedback is important, also colour schemes with high contrast ratios [7] and enlarged buttons and text within the user interface are important for those that have poor vision [1].

**Iterative Design Process**

After the main research into the issue of dementia the authors defined a vision statement. The latter guided the start of an iterative design process (figure 2). The statement pointed out the importance of independency and the lack of it in the lives of individuals suffering from the illness. In the following part of the pictorial, the iterative design process towards a concept supporting the independency of people with dementia, is elaborated. The total process is clarified by discussing the different steps and decisions taken throughout the process to get to a final concept.

Figure 2
Iterative Design Process



Figure 3
Several Forms & Interactions

Preliminary Investigation

From the vision the following requirements were derived:

The concept should:

- increase or maintain independency for people with dementia;
- be easily accessible in terms of price;
- at least be applicable for the early and the mid stage of the illness;
- be able to adjust its complexity according to the stage of the dementia;
- have a relatively big impact on the emotional state of the target group (caretaker & caregiver).

These requirements supported the first idea generation session (appendix A).

Evaluating all these ideas against the initial requirements clearly showed which of the ideas were most valuable. The most valuable idea, according to the requirements, was a device that could show the person with dementia a step-by-step plan to complete certain tasks. For people who suffer from dementia, "performing tasks that require a lot of steps can be very difficult as this involves a complex process termed 'executive functioning'" [8]. The authors argued that, if a person with dementia (early and mid stage) is not able to complete complex tasks (tasks consisting of multiple steps) all by him or herself, an intuitive step-by-step plan would enable them to perform these tasks again.

Prototype & User Test

In order to test, two assumptions had to be tested first:

- Is it possible to increase the capability of people with dementia to perform certain activities by supporting them with a step-by-step plan of this particular activity?
- How should the information be presented? With sound, text, video, images or a combination?

"Innovate dementia", a project to promote innovative care for people with dementia [5], organized a focus group consisting of seven couples (each consisting of a caretaker and a caregiver). With these couples it was possible to test the assumptions. In order to test those, a step-by-step plan to make coffee was presented to two people with dementia. The participants were individually asked to make coffee by following the steps. The step-by-step plan was presented in three different ways: video, text and images, and video with sound. In order to reduce the learning effect on the outcome of the tests. The instructions were presented in a different order to the second participant. With the other participants of the focus group, several possible forms and interactions of the product were tested (figure 3). The participants were asked whether they understood the interaction and liked the shape.

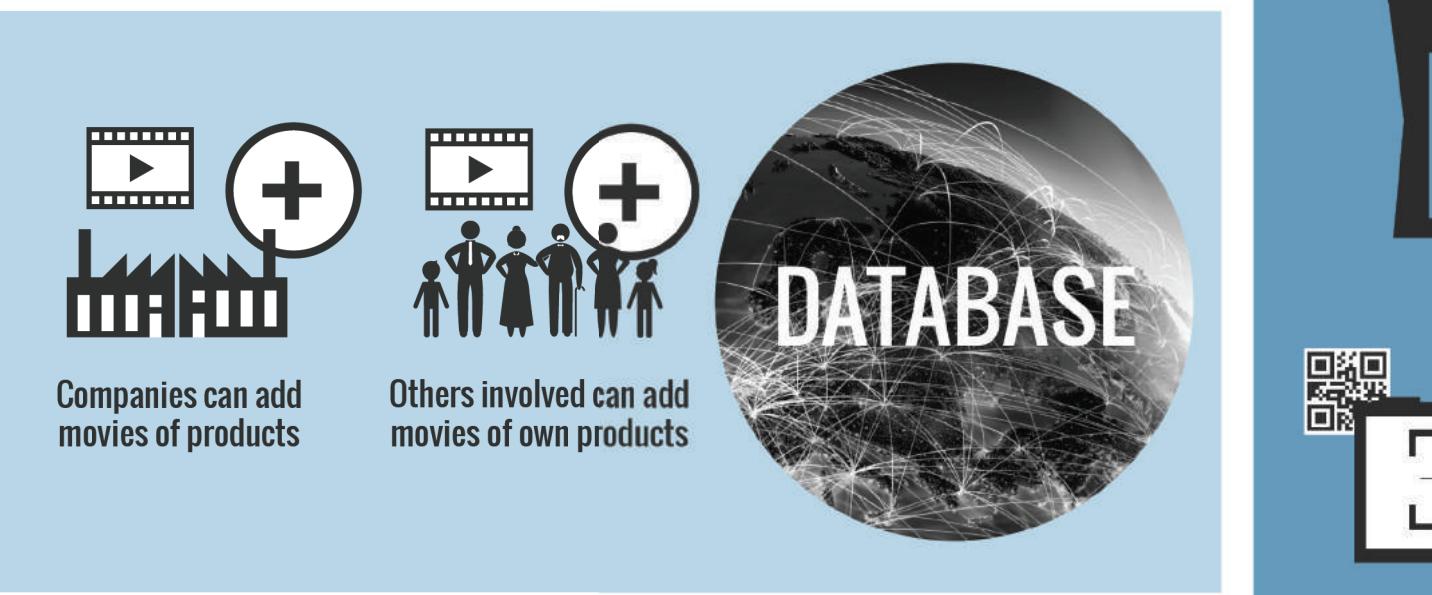
Insights & Decisions

"Innovate dementia" generated many insights that helped to make crucial decisions:

1. People with dementia are able to follow the step-by-step plans to get a complex activity done, as long as:
2. They are not too far in the process of dementia (assumption: early and mid stage of the illness);
3. The steps are presented through at least video and sound;
4. The steps are clear and well chosen (feel logical).
5. Most unusual interactions (not what people are used to do), are not suited for people with dementia. Normal buttons seem to be the most intuitive to use.
6. The most phone-like shape was preferred by the participants in the group.

These insights confirmed that such a device would indeed increase capacity to perform the activities. This means that there is a definite opportunity for such a product to support people with dementia in the future.

Figure 4
Infographic about QR prototype



How to use **GUIDEMENTIA?**



Figure 5
First Prototype with QR Scanner

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The Start of GUIDEmentia
Since providing proper step-by-step instructions would require audio and video, using a smartphone within the concept would make rapid prototyping easier. Furthermore, the shape and interface matched the user's preference based on the user test. The concept included the ability of scanning multiple activities, thus requiring a way of scanning and selecting them. In order to come up with a quick prototype, QR scanning was considered the best option, as smartphones already have cameras.

Prototype
A quick prototype was created to test the concept as a whole (figure 5): size, form and way of presenting the information. The prototype was able to scan a single activity at once using a QR code scanner and the casing was printed in the material at hand. When scanning an activity, the first step automatically played. The product used video to get the information across. The video would automatically repeat itself as long as the user didn't press one of the two buttons displayed on the screen (go back or next step).

Insights & decisions
This first prototype generated a few new insights:

- Scanning an activity with QR code did not work well. It was difficult to scan the activity and it created a few glitches in the application, e.g. the application could only scan once after opening it. Each small glitch in the system would result in confusion for the end user and should be avoided, in order to test the concept effectively;
- The device needs a proper button and good contrast relative to the cover.

Before going into a real user test, these obvious problems had to be solved in a new iteration, in order to get more valuable feedback from the possible users.

New Scanning Methods for GUIDEmentia
The quick prototype was mainly used for presenting and discussing the chosen concept. Although the concept proved interesting, there was plenty to improve regarding user interface, appearance and scanning method. The next step focused on the latter. QR code scanning requires a line of sight between camera and tag and can malfunction in different lighting conditions, both aspects can be confusing for people suffering from dementia.

A brainstorm led to some alternatives, all of which satisfied the requirement of being inexpensive.

Automatic
By placing beacons at the different activities in the house, the distance between a device and the GUIDEmentia product can be calculated. An activity could automatically start when the user comes near a beacon. The system would be slightly more expensive and more complex to build, but could lead to a more pleasant user experience.

Matching shape
Another option would be to place connection stations on each activity. The user would place or hang his/her product in a shape that matches the product, like placing a cup in a cup holder. This would make the system a lot bulkier but the different activities, as well as the scanning method, could be easily recognized.

NFC scanning
Inexpensive NFC tags would be placed near each activity, the user holds the device near a tag and the activity will start. The tags could be shaped to be recognizable and, due to their small size, easily be added to a home environment.



Prototype

Due to the complexity of the target group, the next step was making a prototype for user testing (figure 6), in order to test the concept. The main difference in the next prototype was the feature for NFC scanning. NFC technology was chosen as it could easily be implemented in the current concept, thus allowing short-term user testing. In this version, rectangular NFC cards were chosen, and a card slot was added to the back of the prototype.

The prototype was 3D printed in a neutral color, namely white. The power button was printed in blue, to achieve sufficient contrast [7]. Pressing the button turns on the device, leading to an instruction screen, explaining how activities can be scanned. Once a card is placed in the slot, the activity will start and continue similar to the first prototype.

User Test

For the first user test, family Doesburg was selected (figure 7). The couple still lives at home and the husband is diagnosed with an early stage of Alzheimer's. Despite the early stage, certain activities cannot be completed anymore. For this user test one of these activities was selected, in this case playing a DVD.

H. Doesburg was filmed while performing the process, guided by his wife's instructions. These videos were then implemented in the prototype, combined with separately recorded audio instructions. The prototype, along with a matching NFC card were given to test for one week. H. Doesburg was asked to use the prototype once during the first meeting as well as during the last meeting to check the differences and thus the progress. Furthermore, both were asked to use the prototype a few times during the test period.

Insights & Decisions

Feedback was gathered through observations during the meetings and notes from the user. Overall, the product proved helpful in supporting the user to complete steps he wasn't able to complete before. However, there were certain flaws as well:

- Problems occurred from the quality of the videos, leading to unclarity in different remotes and buttons;
- After scanning and looking to the product on a table, the screen was difficult to see when the user was standing;
- In certain steps, the user performed the step as indicated in the video and continued to the next step without checking if he succeeded.

The test led to opportunities as well. The couple seemed interested in using the product for more than just performing activities, e.g. scanning photos or paintings to get information about them. Another insight regarded the importance of creating clear instruction videos. The videos used in this test proved not to be perfect, and the concept would be strong if users could make their own videos.

New User Interface for GUIDEMENTIA

Most of the issues could be solved with some simple adjustments to the video, but the case and user interface required a bit more attention. Focus for the next iteration was on the latter as it did not require a new prototype.

Since the goal of the authors was to come up with a feasible solution, the solution should be inexpensive. Checking whether an action has been performed would require either adjusted machines or many added sensors, neither would be cheap. Furthermore, the informal caregiver should not be burdened with added tasks such as checking whether a button is pressed correctly. Therefore, the decision was made to have the user check that him- or herself.

Prototype

Firstly, adjustments were made to a few steps and videos, as well as the order they were in. Furthermore, a check was added. Instead of having each video continuously repeating itself, the video would now run once and move to the following screen. The user is asked if the step was completed successful and gets the option to either rewatch the video or continue to the next step (figure 8). In accordance with feedback, an option was added to stop an activity at any time.

User Test

After finishing the next version, the prototype was returned for a new test with Family Doesburg, to see if the check system and new UI worked better. The test setup was similar to the previous one, consisting of observations during the presentation and retrieving of the prototype, and notes from the couple. The couple was first made aware of changes in the prototype and video instructions, which was retrieved after a week and a half.

Insights & Decisions

The observations and feedback showed that most issues had been resolved, apart from the viewing angle (since hardware improvements had not yet been made). However, the user test only involved one activity, with one NFC card that would always remain in the prototype. Validating whether scanning with multiple activities would work wasn't possible. Since the card is not physically connected to the activity it is meant for, this setup didn't make a strong case.

Apart from the functionality of the product, telling apart different remotes and buttons still proved challenging. For future implementation, clear instructions on creating proper quality videos is essential, which could be improved by using colored stickers on different buttons and devices.



Figure 8
Changes in the User Interface

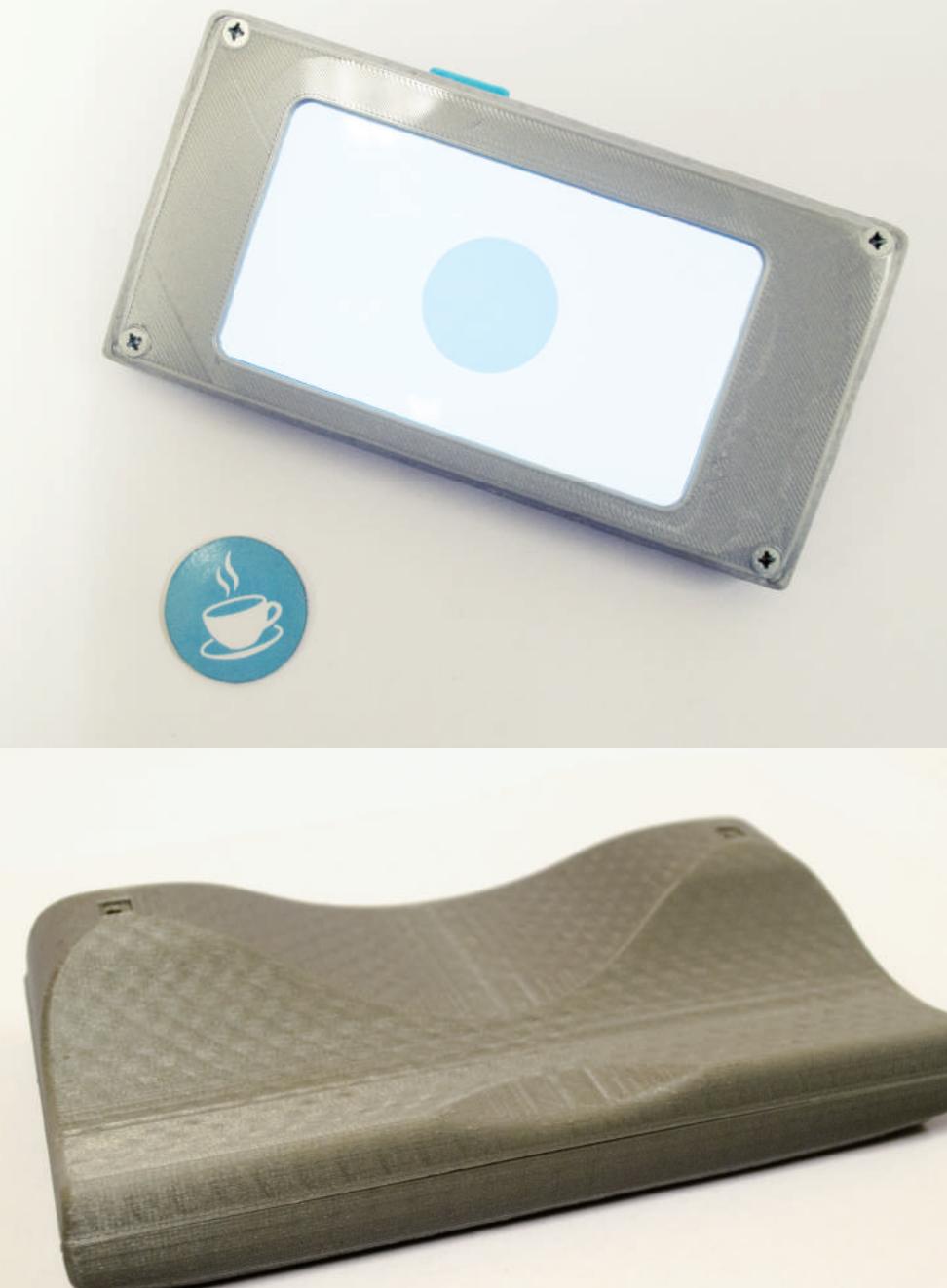


Figure 9
Improved Shape of GUIDEMENTIA

New NFC technique and shape for GUIDEMENTIA

Since the NFC cards would have to be picked up and placed into the prototype, they would be placed near the associated product. Since the card is not truly connected to that product, it is difficult to understand its meaning. However, from the different scanning technologies, NFC still proved best fitting for the current stage of the project. Therefore, research was performed on NFC in different shapes and sizes. A solution was found in small round NFC stickers. The stickers are small enough to be directly applied to different devices, including slim devices like DVD players.

Furthermore, attention was paid to the phone case, since discarding NFC cards made a card tray unnecessary. In a new iteration, the viewing angle would be addressed as well.

Prototype

The NFC cards were replaced by NFC stickers, which could be pasted directly onto the intended product. The stickers are easy to identify and associate to the **GUIDEMENTIA** concept, as each one features the same blue background, with a white icon on top, matching the colors in the product's UI. A new starting screen on the device was designed as well. It featured a bouncing ball to attract attention, its shape matching the new NFC tags.

For the next prototype, the phone case was redesigned. The stickers can be scanned simply by holding the **GUIDEMENTIA** product next to them, removing the need of a card tray. After scanning, the product can remain on the sticker or be placed anywhere else, depending on the context and user preference. Furthermore, the viewing angle was improved and comfortable grips were added (figure 9).

User Test

For the next user test, another couple was selected; family Vos. F. Vos has been diagnosed with Alzheimer's for a longer time and is noticeably further along in the degenerative process. First, similar to the previous version, videos were recorded, in this case regarding making coffee. F. Vos used to be able to do his himself, which stopped after the purchase of a new machine. After implementing the videos in the prototype, it was left for testing for a duration of two weeks (figure 10).

Insights & Decisions

From the couple's feedback, it became clear that scanning proved to be an issue, mainly because it was new to F. Vos. His wife did notice a learning pattern while using the device, allowing him to eventually be able to complete the process of coffee making. Whenever F. Vos did not succeed in scanning the activity, she would do this for him, which she did not mind as it still resulted in less required effort from her side and a sense of meaningfulness for F. Vos.

Figure 10
Usertest with F. Vos

**Final Design of GUIDEMENTIA**

After accomplishing the iterative design process, the authors came up with the final concept of **GUIDEMENTIA** (figure 11), a service consisting of the device for the person with dementia and an application for the caregiver. **GUIDEMENTIA** supports the person with dementia by completing multistep activities and thereby unburdens the caregiver.

Device for the person with dementia

The device of **GUIDEMENTIA** is designed to independently guide a person with dementia through the process of an activity by showing small instruction videos, e.g. making coffee, setting the table or getting ready for bed. To start an instruction video, the user simply holds the device against a NFC sticker, attached to the activity. All activities that are added to the device consist of short videos, visualizing the different steps required to complete an activity. After playing a video, the user can either indicate (s)he is ready for the next step, or wants to rewatch the video. When all steps are completed, the device is ready for a new activity.

Figure 11
GUIDEMENTIA Final Version

Design

The final version of the prototype is made out of CNC machined wood, and finished through sanding and oil. This will make the product more appealing for a living room product (figure 12). The product features comfortable gripping on the back, making it easy to move it around within the home environment. After scanning an activity, the product can be placed on a table or counter. The viewing angle of the display will fit most standing and sitting body positions.

Technology

The product features an android smartphone with a custom designed application. The design of the case limits functions, exposing only the display and a power button, thus making it easier to use. Multiple activities can be transferred to the device, each one linked to a NFC tag. When the device is turned on, and is held near a tag, it will initiate the matching activity, starting with the first step. After the video has played, a menu will show up, allowing the user to go to the next step, rewatch the current step or stop the activity.

Extra Feature

To improve ease of use, a docking station was designed. The docking station satisfies two important aspects of the concept:

- The docking station will remain in one spot. Based on the previously mentioned learning capabilities, users will learn where the product is, thus helping with implementing the product in their daily routine;
- The dock will function as a charger. The shape matches the product's shape, making it easy to connect them. Once placed in the dock, it will start to charge. This allowed for an even simpler product, leaving only the screen and the button on top visible.



Figure 12
Design of the Device of **GUIDEMENTIA**



Figure 13
Design of the Application of **GUIDEMENTIA**

Application for the caregiver

The application of **GUIDEMENTIA** allows the caregiver (family or friends) to add and manage instructions videos to the device, according to the user's personal needs (figure 13). This informal caregivers play important roles in products designed for people with dementia.

A caregiver app was designed to fulfil the purpose of making own instructions. In this concept, the video instructions work best when recorded in the environment the product will be used in. In order to maintain the low cost of this solution, it would be best to have these videos made by relatives or friends. Next to the advantage in price, they will know how to transfer the required information as clear and efficient as possible.

The application can be downloaded on any smartphone, and linked to the **GUIDEMENTIA** product. The application makes it easy to create and manage step by step videos. The user starts by naming an activity, filming the first step and then adding audio to the video. This process can be repeated until the activity is completed. The caregivers can adjust, add or delete steps when activities become too difficult or easy. Another function is controlling sound, volume and brightness.

For an actual product launch, it would be interesting to involve companies in the **GUIDEMENTIA** concept. The app includes a database which can be filled with pre-recorded activities, for example by companies making videos for their products, who then contribute to a dementia-friendly society. Although context-specific videos would work better in some cases, device-specific instructions could be used regardless of the surroundings of the product.

See appendix B for the full application.

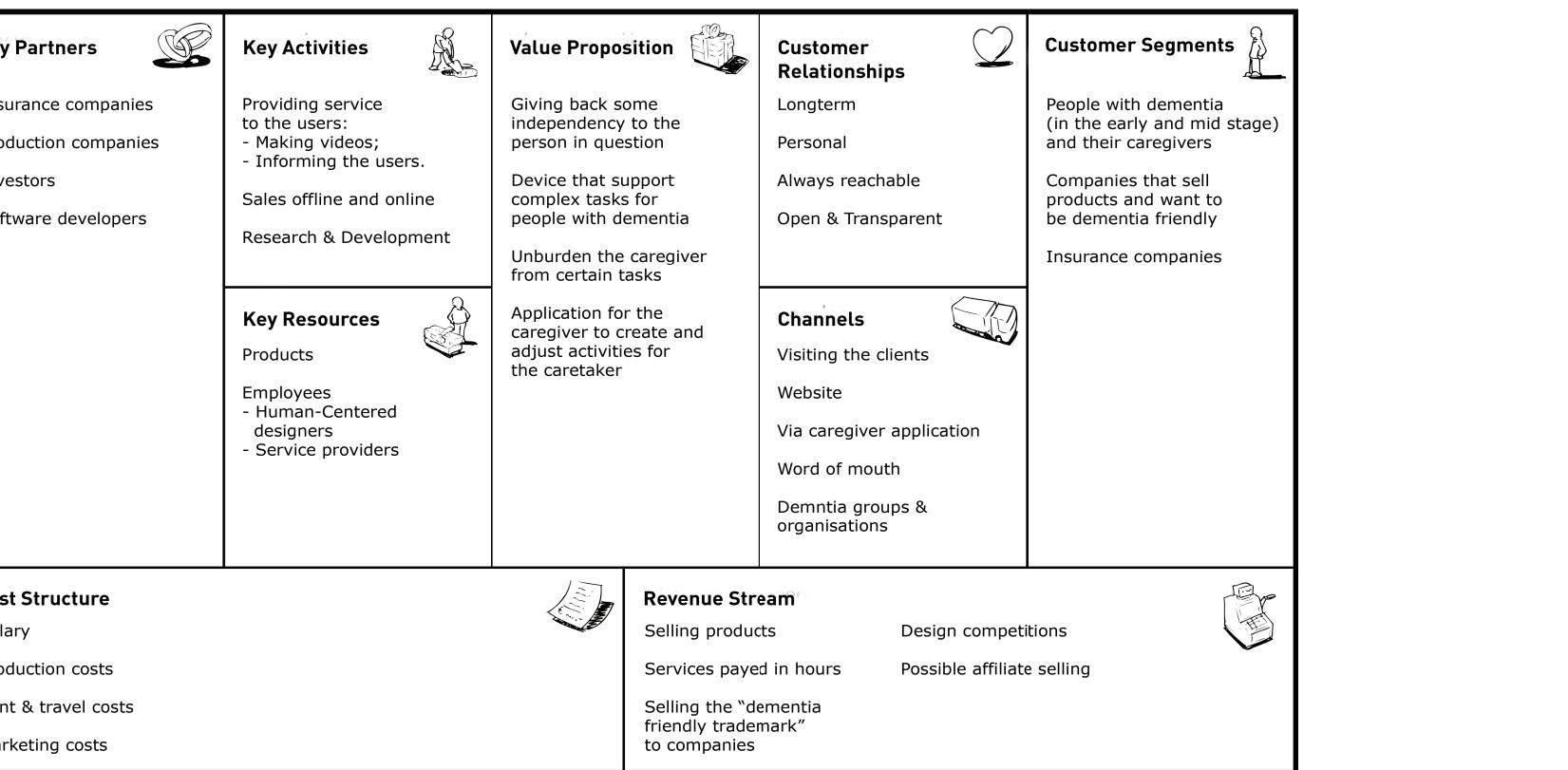


Figure 14
Business Model Canvas

Business Model of GUIDEMENTIA

In order to make this product become a reality, a business model is needed to make the opportunity more concrete. An elaborate business plan is not yet valuable for this stage of the business development. Many factors in the process of establishing a startup are not yet stable and cannot be predicted. Therefore, a business model canvas (figure 14) seemed sufficient in this stage.

The Business model canvas points out the most important aspects of such a startup. It is estimated that the total market is 74.7 million people living with dementia in 2030 and 131.5 million in 2050 [13]. The Serviceable Available Market is the same as the Total Available Market, if the product starts selling in 2022. This is because each of the individuals suffering from the illness passes the phases in

which the product is useful. According to the alzheimer's organisation, people age 65 and older can live for an average of four to eight years after a diagnosis [3]. This means that on average, the people who suffer from dementia in 2030 will have had their first symptoms in 2022 at the earliest. By having reached 10 percent of this market in 2030, there is a Serviceable Obtainable Market of approximately 7.47 million people. If the price of the product will be approximately 250 euro, a total revenue of the product at that year could be approximately 1.867.500.000 euro. If five percent of this revenue will be left after costs and taxation, the company will have a (roughly estimated) profit of about 93.4 million euro. The market for the product is huge, and will only increase in the years after 2030. Whether this model is best suited for the service will become more clear when the cost price of the product is more carefully investigated.

Discussion & Conclusion

The term "*Final design*" in this pictorial does only implicate the state of the design until this point in time. The design has many positive aspects, but also many possible improvements for the future. To reflect on the current state of the project, we have to evaluate it against the initial vision. To what extend is this vision achieved, and how could it be elaborated?

The main vision was to give back independency, to the extent that can be handled by the person in question. With the current capacity of people with dementia, too much independency can result in high stress levels because they cannot handle the situation. On the other hand, if you give the same person too little independency, (s)he will quickly feel useless and lose a sense of purpose. Through GUIDEMENTIA, we discovered that it is possible to give back a part of this independency through step-by-step instructions to complete multistep activities. The regain of independency was clearly visible during the user tests when the participants showed a great amount of satisfaction and joy after finishing tasks that were previously out of reach. However, even though this is a great achievement, the product is not yet at a state that can easily be used.

Another important aspect to consider is that the final prototype has only been tested with two people with dementia. This allowed for a deeper connection with the participants and helped to create a service that is specifically useful for them. However, this also means that we cannot claim to have a solution for every person with dementia in the early and mid stage. Though it is very reasonable in the case of GUIDEMENTIA, as it can adjust to the needs of the user.

An often asked question within our process is whether people who cannot make coffee on their own can still use GUIDEMENTIA. During the user tests and conversations with future users, we discovered that they were able to learn how to work with new devices as long as they were introduced to it in an early stage of the disease and are used repeatedly.

For example, F. Vos (one of the participants who suffer from dementia) uses a tracker whenever he goes outside the house. Through this device, his wife can track and find him. F. Vos learned to use the button on the device when he is lost in order to receive help. He is still able to use the device, even though he has coped with the illness for a longer period of time. Other studies also suggest a capacity to learn in an early stage of dementia [6, 12, 15]. Using these sources we assume that when introducing GUIDEMENTIA in an early stage, the person in question is able to learn how to use the product and is therefore able to use the device, just like the tracker used by F. Vos. Furthermore, the caregivers of the participants made clear that, even if the caretakers would not be able to learn how to setup the product, they would not mind setting it up for them. This makes a big part of the capacity for learning irrelevant.

From this, we can draw the conclusion that the product could have a big impact on the independency or perceived independency of people with dementia in the early and mid stage of the disease. In order to further elaborate the service and make the product fulfil its purpose even better, we would like to suggest a few recommendations for future work. These recommendation are described within the next chapter.

Recommendations for Future Work

In order to make this product really work, more careful research has to be done in several aspects of the current design. We propose to find a few principles of conveying the information of the steps in a way that allows various people (with a range of different stages and forms of dementia) to go through the process of following the steps all by themselves.

This research can be done through the following question: What is a good* dementia friendly step-by-step plan? From this question different subquestions occur: What are the principles of making a good video? How to make the different steps of an activity intuitive? How to adjust the plan to the stages of dementia?

What follows from these questions is also: How to minimize caregiver effort in the process while remaining a very accurate service for the person with dementia? Should the company make the videos or should the caregivers do that themselves? If caregivers make the videos themselves, how can we guarantee the effectiveness of the device?

Another interesting perspective to take towards the product is the exact interaction with it and how people with dementia are actually going to use the product in daily life. This might require a more long term study in which it might be interesting to look at what should be measured by the device, in order to improve its service. For instance, should the device be able to warn family when it is not used for a certain amount of time by a person with dementia who lives alone?

From a business perspective, it is also very important to figure out: What are the production costs of such a product? How can we cut costs while maintaining the same value?

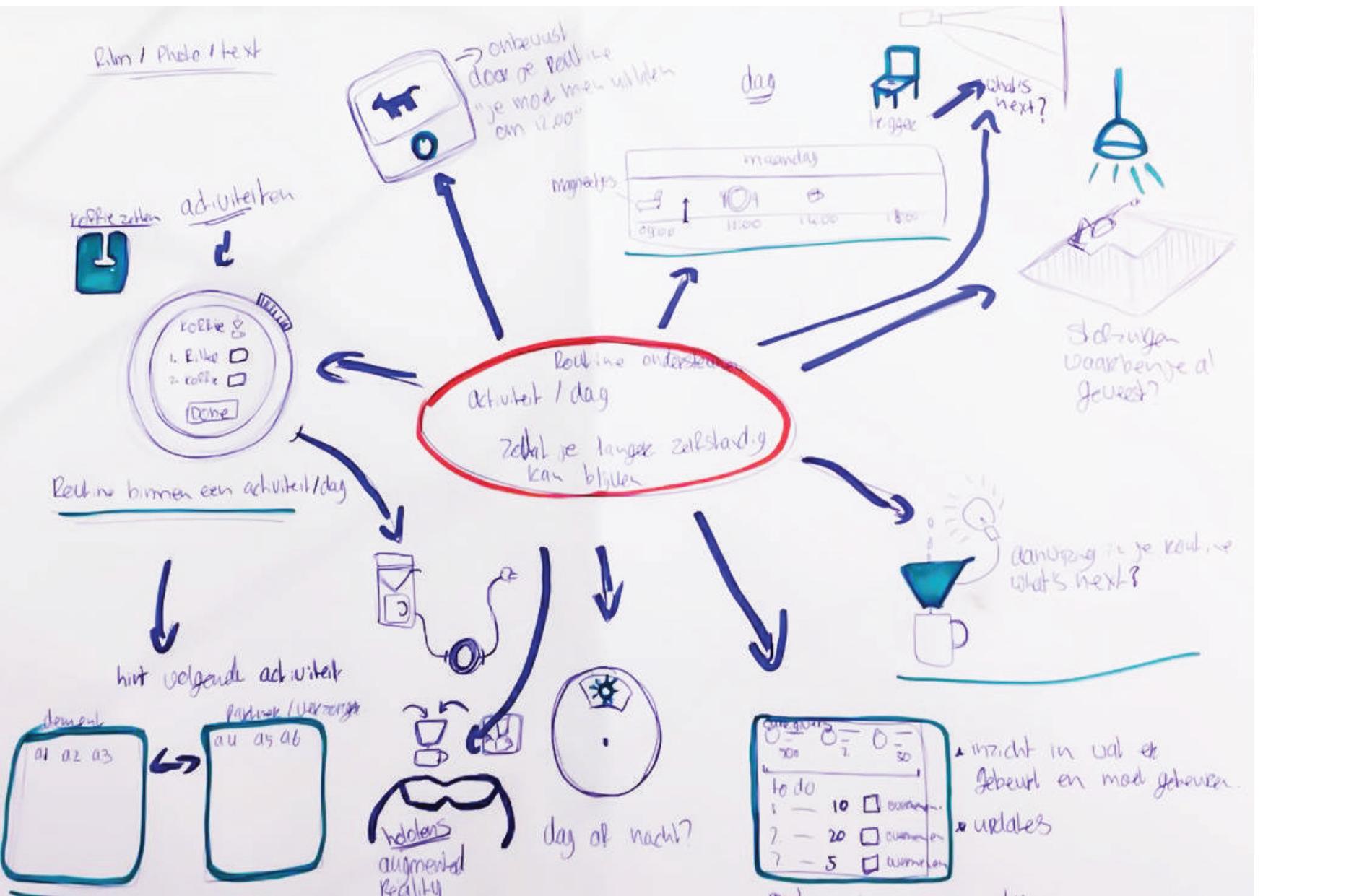
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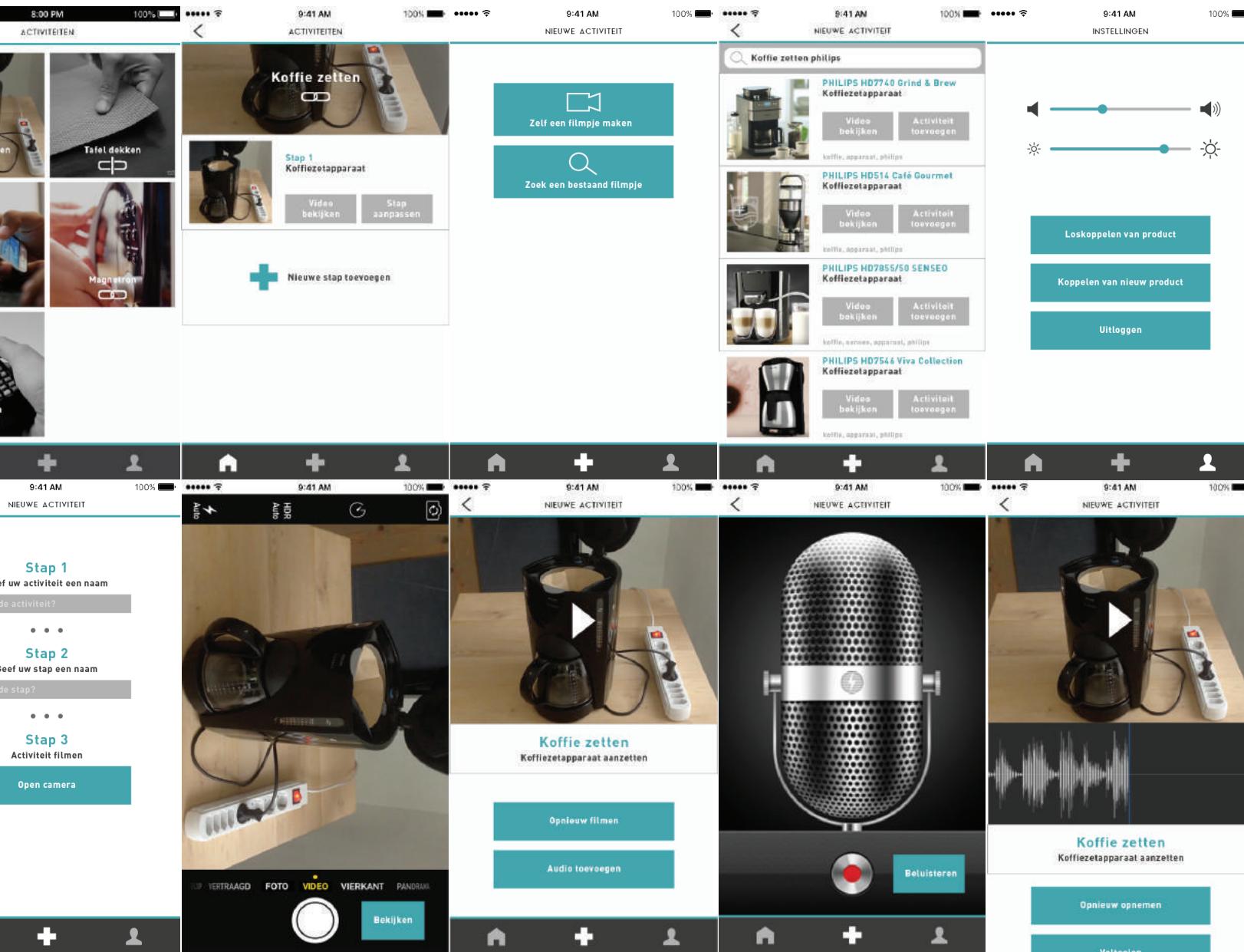
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* (Good in the question means, people with dementia should be able to complete the whole step-by-step plan all by themselves without having the capacity to perform the activity without such a plan)



Appendix A
First Idea Generation



Appendix B
Design of the Application



GUIDEMENTIA