

Report

**Developing and applying a conceptual framework
to translate and embed '*the curriculum*' into an
existing e-health application**



Tom Oostewechel

Master Thesis Industrial Design Engineering

UNIVERSITY OF TWENTE.

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Preface

This report is the result of the graduation project which has been conducted to obtain the Master of Science (MSc) degree in Industrial Design Engineering at the University of Twente in the Netherlands. The research project described in this report has been executed within the organisation Jouw Omgeving, and in co-creation with the Quality of Life Centre, both located in Utrecht. Jouw Omgeving supplies an e-health application as a Software as a Service (SaaS) to healthcare providers in the Netherlands, while the Quality of Life Centre provides coherent and integrated products and services focused on persons with complex intensive support needs (CISN).

This research project has pursued the translation and embedding of the curriculum - a blueprint for delivering optimal care to persons with CISN - created by the Quality of Life Centre, into the existing e-health application of Jouw Omgeving. While writing this thesis, I experienced first-hand how complex and sometimes even 'contradictory' healthcare is organised in the Netherlands, especially if an individual has multiple complex support questions. The most demanding challenge in this research was to find ways to describe this complexity concisely without wandering off and losing sight of the primary purpose. This study achieved this goal through conducting extensive analysis, re-framing large parts of this report, learning to apply new knowledge, and above all, staying persistent throughout this iterative process. Eventually, it was very liberating when all the individual pieces coalesced into one coherent solution in the last chapter. Working on this thesis has been a gratifying experience since it contributed to the development of a solution for a group of individuals where many large problems and obstacles occur and so far, no suitable and structural solutions exist. Helping to develop a product that could substantially advance the lives of others has kept me highly motivated throughout the project. However, the fundamentals laid out in this thesis should not be interpreted as final, but rather as dynamic and constantly evolving alongside the changes that are happening in the Dutch healthcare field.

Finally, I wish to thank those who have been involved in the execution of this research project. Without their valuable and imperative knowledge, critical feedback, and guidance it would not have been possible to reach such results. Robbert Slotman, my mentor and co-owner of Jouw Omgeving, for providing me with the opportunity to perform my thesis at Jouw Omgeving and giving me all the freedom during the process. Mia Nijland, owner of the Quality of Life Centre, for conveying extensive background information and critical knowledge of the target group that helped me substantiate important design choices throughout this report. And Roy Damgrave, my mentor from the University of Twente, for providing professional guidance during our meaningful discussions. Special thanks go out to all my colleagues at Jouw Omgeving for the open and friendly work atmosphere and all the after-work activities!

I hope you enjoy reading!

Tom Oostewechel
Utrecht, January 8, 2018

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Summary

Delivering care to people with complex intensive support questions (CISN) is complicated. Both parents, relatives and professionals face complex challenges while providing care services to this group. Parents entangle in a web of bureaucracy, professionals are forced to do more tasks in less time, and the cooperation between formal and informal networks is not optimal. Recent digital developments attempt to make it easier to organise care around a person, family and other stakeholders. The Dutch government and patient federation assume that a personal health record (PHR) provides citizens with more insight, freedom, and control over their health. A PHR is an information platform, through which individuals can access, manage and share their health information, and that of others from whom they are authorised, in a private and secure environment. However, the concrete applications and their added value for people with CISN are still unknown.

Jouw Omgeving, a developer of an e-health application, intends to use its online platform as PHR. However, as elaborated, there is still insufficient knowledge and insight into what is needed to facilitate this for persons with CISN. Thus, to acquire more insight into this group, contact was made with the Quality of Life Centre, developer and provider of services and products aimed at achieving a 'good life' for the target group. One of their products is a curriculum 'Flourish and Stimulate' which is a blueprint for delivering optimal care to persons with CISN. As a result of a meeting, the researcher drafted a research proposal to jointly collaborate on the development of a PHR for this specific target group. The proposal suggested that their curriculum, based on an evidence-based support program, should be translated into an e-health application and embedded in the existing platform of Jouw Omgeving. Both parties commissioned the execution of the proposal after chapter one provided insight into the consequences and strategic advantages for those directly involved. Hereafter, the report followed a four-part layout: an analysis of the Dutch healthcare landscape and the e-health domain, the design of a conceptual framework for the development of e-health applications, the application of this framework to the curriculum, and finally, to determine the conditions for embedding the curriculum in the platform of Jouw Omgeving.

Chapter two describes the analysis of the Dutch healthcare system. Products and services naturally belong to a broader context. In this research, it became clear that the curriculum is part of the extensive Dutch healthcare system. Inside this system it needs to function to be successful. By analysing this context, more insight has been gained into how the curriculum relates to this system, and in particular, to the e-health domain. This exploration phase resulted in four concrete results: an overview of trends that led to the reform of the Dutch healthcare system in 2015, an explanation of essential mechanisms that determine the functioning of this new healthcare system, a definition of the e-health concept, and finally, a list of common factors that influence the adoption of e-health applications. In doing so, system-level implications, as well as possible opportunities for the design of the curriculum inside the healthcare system, were made insightful.

Since it is intended to translate the curriculum into an e-health application, the e-health domain has been studied. It turned out that the healthcare sector lacks a structural integration of new technological applications. Thus, to unearth the causes of why so many applications fail to be sustainable, the second part of chapter two executed a literature study. Common obstacles for the adoption of e-health applications have been identified, classified, and coupled to relevant concepts (frameworks, methods, tools), which are mentioned in literature as possible solutions to these problems. Based on those results, chapter three developed a conceptual framework which can guide the development of e-health applications in general, and that of the curriculum in particular. The framework is based on value creation for both end users and stakeholders and can be considered as the foundation for the development and implementation of sustainable e-health applications.

In chapter four, five and six, the conceptual framework is applied to the curriculum. In chapter four the added value of the curriculum becomes clear from the perspective of the end users. The curriculum has three end-user groups, but since these are not uniform, two segmentation strategies are applied. Through applying value proposition design, the most critical needs were mapped out for each end user group and subsequently, it was elaborated in which way the curriculum can meet those needs. The end use of the curriculum has been mapped through applying workflow analysis. This detailed analysis reveals which processes are carried out by the end users on the one hand while providing insight into the information they need during actual use on the other.

Chapter five describes the added value of the curriculum from the perspective of stakeholders. During the arrangement of care for a person with CISN, parents come in contact with each of the four core healthcare acts. Since each healthcare act has different procedures and stakeholders, four stakeholder networks have been designed which illustrate who the involved stakeholders are and how they exchange value with each other. Based on the results from chapter four, multiple leverage points were identified where the application of the curriculum was expected to be of added value. Besides, network structures also provide a visual overview of how stakeholders might be affected in the case of implementation.

Chapter six takes both viewpoints of chapter four and five and integrate and translate these into functional requirements for the design of an e-health application. Based on these requirements, it was concluded that the platform of Jouw Omgeving offers sufficient opportunities for embedding the curriculum. After that, the design principles and existing components of the Jouw Omgeving platform have been used to convert the requirements into visual representations. In this way, the results of chapter six generated a holistic understanding of what is needed to embed the curriculum in the platform of Jouw Omgeving. The results should be viewed as a rudimentary version of a PHR for the target group. This research concludes with an elaboration of how the results of this research relate to: the current healthcare system, a possible future healthcare system, and finally, to a worst-case scenario.

Samenvatting

De zorg voor personen met intensieve ondersteuningsvragen is complex. Zowel ouders, verwanten als professionals ervaren veel problemen die de zorg voor deze groep met zich meebrengt. Ouders raken verstrikt in een web van bureaucratie, professionals moeten steeds meer doen in minder tijd en de samenwerking tussen formeel en informeel netwerk verloopt moeizaam. Recente ontwikkelingen op digitaal gebied proberen het beter mogelijk te maken om zorg rondom een persoon, gezin en andere betrokkenen te organiseren. De overheid en de patiëntenfederatie veronderstellen dat een persoonlijke gezondheids omgeving (PGO) burgers meer inzicht, vrijheid en regie kan geven over de eigen gezondheid. Een PGO is een digitaal hulpmiddel, in beheer van de persoon zelf, waarmee de gebruiker in een besloten, beveiligde omgeving gezondheidsinformatie kan openen, beheren en delen met anderen die hiervoor geautoriseerd zijn. De concrete toepassingen en de toegevoegde waarde hiervan zijn echter nog onbekend voor personen met intensieve ondersteuningsvragen.

Jouw Omgeving, een ontwikkelaar van een e-health applicatie, heeft de intentie om haar online platform in te zetten als PGO. Zoals gezegd, is er nog onvoldoende kennis en inzicht om dit te kunnen faciliteren voor personen met intensieve ondersteuningsvragen. Voor meer inzicht op dit gebied, is er contact gelegd met het Quality of Life Centre, ontwikkelaar en aanbieder van diensten en producten gericht op een mooi leven voor deze doelgroep. Eén van hun producten is het curriculum 'Floreren en Stimuleren', een blauwdruk voor het proces van goede zorg en leermogelijkheden voor de doelgroep. Naar aanleiding van dit contact is er een onderzoeksvoorstel opgesteld om gezamenlijk op te trekken in de ontwikkeling van een PGO voor deze specifieke doelgroep. Dit voorstel opperde om het curriculum, gebaseerd op een *evidence-based* ondersteuningsprogramma, te vertalen naar een e-health applicatie en in te bedden in het bestaande platform van Jouw Omgeving. Nadat in hoofdstuk een de consequenties en strategische voordelen voor beide partijen inzichtelijk waren gemaakt, gaven zij akkoord voor de concrete uitvoering van het voorstel. Het uitgevoerde onderzoek kent hierna een vierledige indeling: de analyse van het Nederlandse zorglandschap en e-health domein, het opstellen van een conceptueel framework voor de ontwikkeling van e-health applicaties in het algemeen, de toepassing van dit framework op het curriculum, en ten slotte, het vaststellen van de voorwaarden voor het inbedden van het curriculum in het platform van Jouw Omgeving. Dit rapport volgt deze indeling.

Hoofdstuk twee beschrijft de analyse van het Nederlandse zorgsysteem. Producten zijn immers altijd ingebed in een bredere context en het curriculum maakt onderdeel uit van het Nederlandse zorgsysteem. Door deze te analyseren is er meer inzicht verkregen in hoe het curriculum zich verhoudt tot dit systeem, en in het bijzonder, tot het e-health domein. De analyse levert vier concrete resultaten op: een overzicht van trends die aanleiding gaven tot de hervorming van het Nederlandse zorgsysteem in 2015, een toelichting van belangrijke mechanismes die het functioneren van het nieuwe zorgsysteem bepalen, een definitie van het begrip e-health, en ten slotte, een lijst van factoren die invloed kunnen hebben op de adoptie van e-health toepassingen in het algemeen. Hierbij zijn ook de implicaties en kansen voor de ontwikkeling van het curriculum binnen het zorgsysteem in kaart gebracht.

Aangezien het de bedoeling is dat het curriculum wordt vertaald naar een e-health applicatie, is ook het e-health domein onderzocht. Het bleek dat de zorgsector achterblijft bij het duurzaam en structureel integreren van nieuwe technologische toepassingen. Om te achterhalen waarom dit het geval is, werd een literatuurstudie uitgevoerd. Obstakels voor de adoptie van e-health applicaties in het algemeen, zijn geïdentificeerd, geclassificeerd en gekoppeld aan relevante concepten (frameworks, methoden, tools), die in de literatuur worden aangedragen als oplossingen voor deze belemmeringen. Naar aanleiding hiervan is in hoofdstuk drie een conceptueel framework ontwikkeld dat richting kan geven aan de ontwikkeling van e-health applicaties in het algemeen, en het curriculum in het bijzonder. Het framework gaat uit van waarde creatie voor zowel eindgebruikers als stakeholders van een e-health applicatie. De resultaten kunnen als fundament worden beschouwd voor de ontwikkeling en implementatie van duurzame e-health applicaties.

In hoofdstuk vier, vijf en zes wordt het conceptueel framework toegepast op het curriculum. In hoofdstuk vier wordt de meerwaarde van het curriculum inzichtelijk vanuit het perspectief van de eindgebruikers. Het curriculum heeft drie eindgebruikersgroepen. Aangezien deze niet uniform zijn, worden twee segmentatie strategieën toegepast. Door de toepassing van *'value proposition design'* is voor elke groep in kaart gebracht wat de belangrijkste behoeften zijn en is vervolgens bepaald op welke manier het curriculum hieraan kan voldoen. Het eindgebruik van het curriculum is in kaart gebracht met behulp van *'workflow analysis'*. Deze gedetailleerde analyse maakt enerzijds inzichtelijk welke processen worden uitgevoerd door eindgebruikers en anderzijds welke informatie zij nodig hebben tijdens het daadwerkelijke gebruik.

Hoofdstuk vijf beschrijft de meerwaarde van het curriculum vanuit het perspectief van stakeholders. Aangezien ouders van personen met intensieve ondersteuningsvragen te maken krijgen met vier zorgwetten, en deze zorgwetten allemaal eigen procedures en stakeholders kennen, is er voor elke zorgwet een 'stakeholder netwerk' opgesteld met betrokkenen en de onderlinge interacties die ze hebben. Op basis van de resultaten uit hoofdstuk vier zijn in elk netwerk specifieke interacties geïdentificeerd waar naar verwachting de toepassing van het curriculum waarde toevoegt. Tevens geeft het in een visueel overzicht weer hoe stakeholders beïnvloed worden bij een mogelijke implementatie.

In hoofdstuk zes zijn de inzichten uit hoofdstuk vier en vijf samengebracht en vertaald naar functionele eisen voor een e-health applicatie. Op basis van deze eisen is geconcludeerd dat het platform van Jouw Omgeving mogelijkheden biedt voor het integreren van het curriculum. Hierna zijn de ontwerpprincipes en bestaande componenten van het Jouw Omgeving platform gebruikt om de eisen om te zetten in visuele weergaven. Op deze manier is voor zowel Jouw Omgeving als het Quality of Life Centre tastbaar gemaakt wat er ontwikkeld moet worden tijdens de technische realisatie om te komen tot een basis PGO voor de doelgroep. Dit onderzoek sluit af met een beschrijving die inzicht geeft op welke manier de resultaten uit dit rapport zich verhouden tot het huidige Nederlandse zorgsysteem, een mogelijk toekomstig systeem, en ten slotte, tot een *'worst-case'* scenario.

Glossary of terms

CISN	Complex intensive support needs is a generic term for all in Netherlands existing subgroups within the (disabled) care. CISN specifically emphasizes on questions of people instead of their limitations or disabilities
Conceptual framework	Written or visual representation that explains the key factors, concepts or variables that will be studied and sequentially depicts the relationships between them
Curriculum	Roadmap that enables parents and professionals to offer support tailored to the needs and wishes of persons with profound and multiple disabilities
Decentralisation	Process of redistributing or dispersing functions, powers, people or things away from a central location or authority
E-health	The use of information and communication technologies for health, commonly referred to as e-health applications
Entitlement	Persons are covered by law for the costs to a certain extent of curative and high level and intensive care
Healthcare provider	Organisations, institutions and individual healthcare providers who offer healthcare, assistance, and support.
Healthcare purchaser	Organisations or institutions that are responsible for buying care from healthcare providers
ICF	International Classification of Functioning, Disability and Health (ICF) is a classification of the health components of functioning and disability
Information object	An unit of information that is relevant from the perspective of the company or user of a product
Integral	Necessary and important as a part of a whole
Jouw Omgeving	Jouw Omgeving is an organisation that provide innovative, compelling, and interactive online treatments through a secure web-based platform and an expanding collection of mobile applications

Minimal Viable Product (MVP)	A product with just enough features to satisfy early customers, and to provide feedback for future product development
Personal Health Record (PHR)	Information platform, through which individuals can access, manage and share their health information, and that of others from whom they are authorised, in a secure environment.
Prevalence	The fact of something existing or happening often
Private individual	Persons that consume healthcare services (also referred to as care recipients, healthcare consumers, patients or clients)
Quality of Life Centre	The Quality of Life Centre is a company that supplies coherent and integrated products and services to the healthcare sector in the Netherlands. The services are focused on enhancing and enabling quality of life for persons with CISON
Reverse engineering	Process of extracting knowledge or design information out of anything man made and reproducing something based on that extracted information
Social domain	Includes all the efforts of municipalities (local authorities) carried out in work, care and youth
Software as a Service (SaaS)	Software licensing and delivery model in which software is licensed on a subscription basis and is centrally hosted
Tacit knowledge	Unwritten, unspoken, and hidden knowledge held by practically every normal human being, based on his or her emotions, experiences, insights, intuition, observations and internalised information
Transcending domains	No relation to legislation, type of care or living environment
'Trial run'	A small project or research that is meant to try out new innovations that are situated in the development stage
Value proposition	The collection of products and services a business offers to meet the needs of its customers

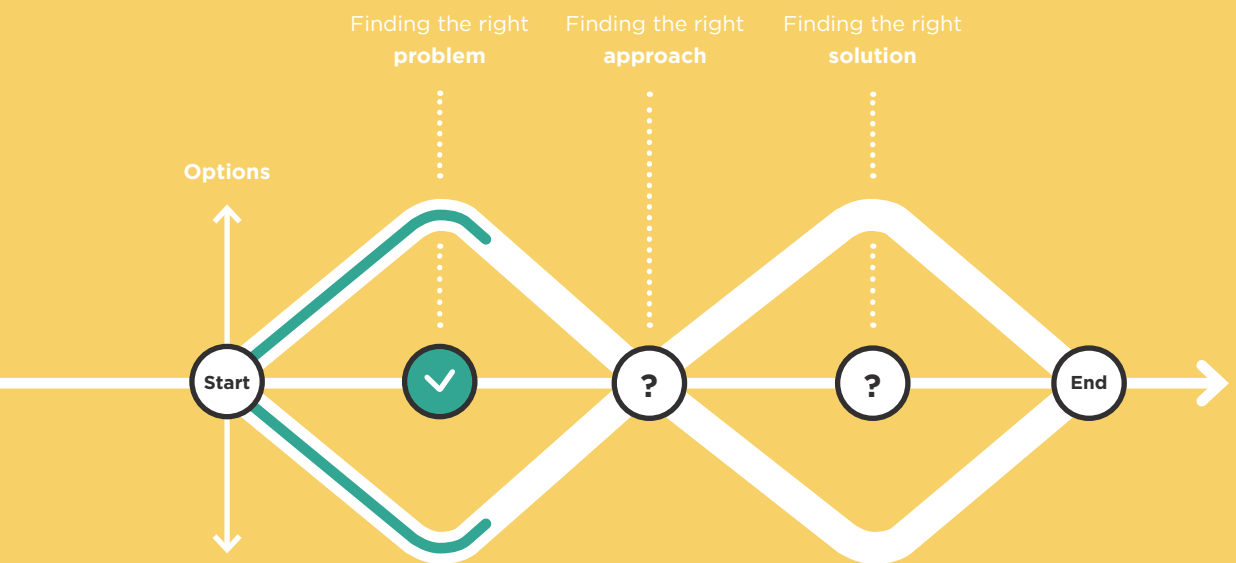
Chapter

01

Formulating strategic intent

Determine on a strategic level why a partnership between the Quality of Life Centre and Jouw Omgeving is beneficial, define the core problem that will be addressed, and establish an appropriate research approach.

Time



1.1 Introduction

Since the twentieth century, the Netherlands experienced a steep increase in economic welfare and continuous technological advancements which resulted in better access to healthcare services and highly improved treatments. Overall, these improvements have manifested in, for example, a rising life expectancy and in more people with a chronic disease. Presently, these consequences give rise to pressing concerns about the ability of the Dutch healthcare system to deliver the best possible care on the one hand while keeping healthcare affordable and accessible to all citizens on the other. It is these kinds of challenges that are forcing organisations operating in the healthcare sector to innovate and renew their services and products to meet the new requirements and possibilities that technological innovations, society, and government impose on them. For example, they are continually seeking for innovative measures to reduce cost, increase quality, stimulate prevention, facilitate a more responsible and influential role for the client, or any other development that helps towards improving health or healthcare in general.

However, this is not regarded as an easy task as healthcare is strongly regulated, which results in a high interdependency between actors. As a consequence, there are few organisations and providers that can achieve better-quality or more affordable care solitary. Especially at a time where disruptive changes follow each other in rapid succession and technology will be increasingly intertwined with our daily lives, effective collaboration between healthcare actors is assumed to be crucial. Healthcare should not be a zero-sum game where some established organisations make profits off the backs of others. In the coming years, actors in the healthcare sector will all face major challenges which they have to solve together, one way or another. Hence, it is believed that only through adopting a win-win mindset, actors can achieve solutions that are mutually beneficial and satisfying for everyone involved. Through efficient collaboration, they can minimise time, money, and resources during the development of solutions and maximise positive outcomes for everyone involved in healthcare. From this belief system, the starting point of this research project was a proposition for collaboration between Jouw Omgeving and the Quality of Life Centre, both operating inside the healthcare sector. The primary aim of the proposal and further content of this chapter was threefold: to determine on a strategic level why a partnership might be beneficial, to define the core problem that will be addressed, and to establish an appropriate research approach.

This introductory chapter elaborates the starting point of this research. First, a brief intermezzo provides the reader with a summary of the rationale behind the selection of a definitive research direction. Resulting from this selection phase the definite and the further topic of this chapter, was the proposition for collaboration. Section 1.2 presents a more elaborate description of both companies on primary business characteristics. To show why a partnership might be beneficial, section 1.3 provides preliminary insight into drivers that motivate the need for such a collaboration. Subsequently, the problem statement in section 1.4 will provide detailed background information on the core issue that will be addressed in this research. Finally, section 1.5 captures the essence of this research through the formulation of the primary research question and provides insight into the global structure of this report.

Intermezzo

Selecting a final research direction

This brief intermezzo provides the reader with the rationale behind the selection of a definitive research direction. At the start of this research project, no defined problems were present within Jouw Omgeving. However, they had the desire to explore various topics that could potentially add value to their existing services. Therefore, an extensive initiation phase was executed (Appendix A). The objective of this phase was twofold: elaborate which topic could deliver the most value to Jouw Omgeving on the one hand while investigating if the issue was comprehensive enough for a graduation project on the other. Below a summary of the initiation phase is given:



Research directions that were not selected

Virtual reality

Virtual reality is quickly maturing, and the equipment is cheaper to acquire and better accessible due to the continued shift from desktop to mobile devices. Moreover, Jouw Omgeving collaborates with several healthcare providers that are increasingly interested in deploying virtual reality through the platform of Jouw Omgeving as an interactive tool for the treatment of specific conditions. Most of those organisations already have, to some extent, access to the equipment and have been moderately experimenting with virtual reality based treatments. Nevertheless, there are still some fundamental challenges with the use of virtual reality in healthcare practice. A significant obstacle is that it remains challenging to convert evidence-based protocols directly into virtual reality based treatments since this conversion creates a whole range of new barriers. At this point, the fundamental problem is the lack of an underlying framework that indicates what parameters (e.g. the color of a spider) are most relevant for each condition or disease and subsequently, in which way these parameters should be used in the design of virtual reality treatments. Besides, researchers and healthcare professionals should concur on which hardware and software are best suited to represent those parameters. Finally, there are many practical (e.g. quality of equipment) and safety barriers (e.g. unattended treatment) that need to be tackled. While the mentioned challenges are extensive enough to be addressed in a possible graduation project, it was concluded that pursuing virtual reality does not fit well within the context of Jouw Omgeving. The bottom line is that virtual reality has currently too many downsides inside a healthcare setting. Therefore, pursuing virtual reality will be neither financially nor strategically attractive for Jouw Omgeving at this point.

Data collection and visualisation

One of the fundamental challenges of data collection in healthcare is the ability to leverage the gathered data to gain a better understanding of the patient's needs and the course of the treatment. In this sense, Jouw Omgeving can contemplate on two possible objectives with data collection and visualisation. On the one hand, they could utilise data to improve the user experience of their platform while on the other, they could provide healthcare organisations with valuable insights into

the progress of treatment, which eventually could empower them to improve their care services. However, there is a limitation in tracking users due to strict privacy and confidentiality restrictions. These constraints make it troublesome for Jouw Omgeving to collect data that could be used to optimise the functionality and user experience of the platform. Furthermore, Jouw Omgeving already analyses, to some extent, the behaviour of clients and professionals by applying various analytical tools. Nevertheless, it is debatable whether the platform, in its current structure, can gather enough relevant data and subsequently, present it to healthcare organisations and clients in such a way that could incite activities which could improve, for example, the current treatment. Mainly, the concern is the limitation in tracking users which limit the opportunities for both improving the user experience of the platform as well as providing valuable insights into the progress of treatment. Hence, it was concluded that the solution space in this direction is too narrow which makes it not worthwhile for a graduation project to pursue data collection and visualisation.

Implementation

For healthcare providers, the implementation of an e-health application has a tremendous impact on the primary care processes and business operations in general. Hence, Jouw Omgeving has implementation experts who are actively involved in the implementation of the platform in healthcare organisations. To support the complicated process, they developed a method which offers guidance to organisations in systematically adopting the platform. It became evident that Jouw Omgeving is already putting a lot of effort into the implementation process. They developed implementation tools and have experienced implementation managers that guide the implementation process in healthcare organisations. Hence, it was concluded that there were currently no real opportunities present within this direction that provide sufficient cause to start a research project.

Selected research direction

Collaboration between Jouw Omgeving and Quality of Life Centre

At the end of the initiation phase, it was a collaboration between two parties that was identified as the direction that could add the most value to Jouw Omgeving. Briefly put, the reasons for a collaboration were fourfold; both parties operate in the same Dutch healthcare system, focus both on the disability sector but on another target group, have complementary business needs, and finally, a partnership enables the exchange of existing infrastructure and target group knowledge. Section 1.2 to 1.5 will present a general description of both companies, address why a partnership might be beneficial, elaborate the core issue that will be addressed in this research, and capture the essence of this research through formulating a primary research question.

1.2 Company profiles

This section presents a general description of both Jouw Omgeving (●) and the Quality of Life Centre (▲) to provide an overview of the corporate context of this project. It shortly describes both companies on primary business area's such as the perspective of the company, vision and goals, and the method they apply during daily business operations:

1

Perspective companies

●

Innovative and effective online help trough collaboration

Jouw Omgeving supplies an online e-health platform to healthcare providers in the healthcare sector in the Netherlands. The providers apply the platform as an aid for the treatment and guidance of clients from a variety of target groups. Since their foundation seven years, their main aim is to provide innovative, compelling, and interactive online treatments through a secure web-based platform and an expanding collection of mobile applications. A unique characteristic is that their platform is designed from a client point of view instead of the healthcare professional's perspective. Core objectives of Jouw Omgeving revolve around the visual layout, user experience, and active collaboration with healthcare providers. The platform is low-threshold and suitable for children over eight years old.

▲

A worthy life for persons with CISN

The Quality of Life Centre is a company that supplies coherent and integrated products and services to the healthcare sector in the Netherlands. Those services should enhance and enable quality of life for persons with CISN. Reasons for the foundation were trends in the healthcare sector. According to the Quality of Life Centre, the sector necessitates better custom made services, especially for persons with complex disabilities. Since their foundation one year ago, their main aim is creating conditions for a 'good life' for individuals with CISN. They believe this can be achieved by providing them, their parents, professionals and social network with products and services that prioritise the common interest, give mutual contact more meaning and ensure that the necessary cooperation runs more smoothly.

2

Vision and goals

●

Achieve a leading position in the disability sector

Jouw Omgeving positions itself as market leader in e-health for youth care and persons with a minor mental disability. Most of the clients of Jouw Omgeving are situated in the disability sector. Within this division, more suppliers of e-health technology are active with all their slightly different strategy and approaches. Moreover, once healthcare providers join a specific platform they do not intend to switch supplier since the implementation of e-health has a profound impact on their primary healthcare processes. Thus, Jouw Omgeving wants to appeal new healthcare providers to maintain and strengthen their position. On the short term, their objective is to achieve a leading position in the disability sector, which they regard as a potential growth market. On the long term, they want to gradually work towards a platform that is suitable to use as a personal health environment (PHR).

Focus on a universal and integral curriculum

The Quality of Life Centre positions itself as expertise and resource centre in the knowledge landscape of persons with CISON. The Quality of Life Centre bundled their products and services in an integrated one-stop support shop which contains all resources that are needed for a good life of people with CISON. In the Netherlands, more research centres are active, but all have a different focus. In contrast to other centres, the Quality of Life Centre is the only one that focusses on a universally applicable and integral curriculum (see section 1.4) for both the supporting and learning needs of persons with CISON. On the short term, their objective is to disclose the curriculum in an efficient manner that fits the current technology driven society. The initial focus solely lays on persons with severe and complex support needs. After validation during a controlled and restricted trial run, the intention is to 'scale' the curriculum to individuals with less complex support needs. On the long term, they aim to become market leader regarding a standardised curriculum for health and education for the entire disability sector.

Method and expertise

Expertise in development, design, training and implementation

Jouw Omgeving applies a process-oriented method, where it attempts to work as closely as possible with development partners, healthcare professionals, and clients. Their team of twenty members consists of user interface designers, developers, marketing and implementation managers, and experts in the field of online help. Their expertise spans across different areas, from the design of specific treatment plan, training of healthcare professionals, clients and their social network to supervising and accompanying the implementation of the platform in healthcare organisations.

Expertise in care and education, training, support and advising

The Quality of Life Centre applies a process-orientated method. They attempt to work as closely as possible with different stakeholders to make optimal use of their available knowledge and experience and to strengthen each other in favour of the end users. Their team of ten members consists of behavioral specialists, paramedics, teachers, ambulant facilitators and general project members and assistants. Their expertise spans across different areas; from extensive knowledge on care and education, training of professionals and parents, supporting children and their family to advising stakeholders.

Conclusion

This section provided an overview of the corporate context of this project and a general description of both Jouw Omgeving and the Quality of Life Centre. By describing both companies according to the same construct, it was possible to compare them on key business areas which, in turn, made it possible to describe why a partnership might be beneficial. A more elaborate analysis of both companies can be found in appendix A. Based on this analysis, the next section provides preliminary insight into drivers that motivated the need for a collaboration.

1.3 Research motive

The Dutch healthcare landscape is regarded as an incredibly complex system with a lot of interdependencies between a plethora of actors. A transcending challenge for everyone in the healthcare sector is to collectively keep healthcare affordable and accessible to all citizens without compromising on the quality of care. However, there are no ‘silver bullet’ solutions that can ensure continuous and accessible high-quality care. Consequently, no organisation can achieve this goal solitary. Effective collaboration between actors is assumed to be essential. It can minimise waste during the development of efficient solutions and in the process of healthcare delivery while maximising positive outcomes for patients, and society in general. Moreover, the starting point of this research project was a proposition for collaboration between two actors from the healthcare sector, namely Jouw Omgeving and the Quality of Life Centre. Briefly put, the reasons for collaboration were fourfold; both parties operate in the same Dutch healthcare system, focus both on the disability sector, have complementary business needs, and finally, it enables the exchange of existing infrastructure and knowledge. An essential part of any form of collaboration is to make involved parties co-owner of a problem or conversely, by making clear what each other’s roles are in a partnership. In this way, they should become equally committed and involved in solving that problem. However, to achieve this state, concerned parties need to gain insight into why a partnership might be beneficial. Figure 1.1 depicts the drivers for collaboration and the expected synergy advantages for each company.

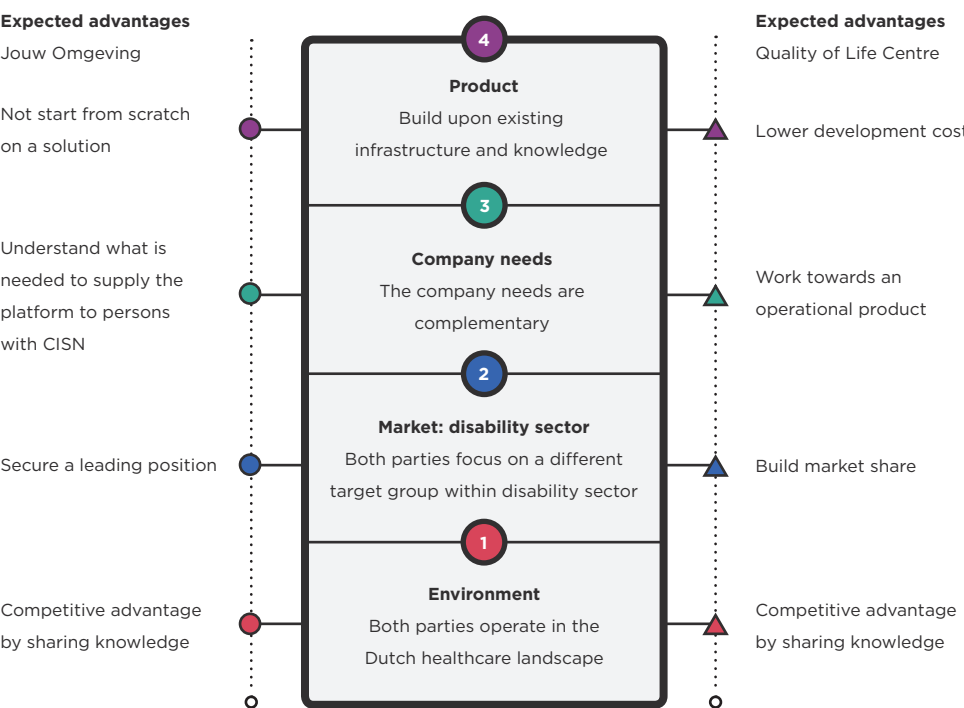


Figure 1.1 Drivers for collaboration and expected synergy advantages for each company

Key drivers for collaboration

Through providing preliminary insight into drivers for collaboration, it should create commitment and clarity among Jouw Omgeving and the Quality of Life Centre, and more importantly, ensure continuity after the completion of this research project. The drivers were uncovered through analysing both actors via the same construct. Below, a summary of the essential drivers is provided:

- **Government legislation and landscape trends**

All the current developments indicate that the citizens will move to the centre of the healthcare landscape. This prediction is already partly initiated by the Dutch government through the deployed decentralisation, the focus on participation, and the new laws that aim at prevention of diseases, self-reliance, and the self-management of citizens. Meanwhile, the rapid technological developments in the healthcare sector are providing persons with new opportunities for performing self-diagnosis and self-treatment. These new possibilities could radically change the current delivery of healthcare. Since both Jouw Omgeving and the Quality of Life Centre operate within the healthcare sector, it will be crucial for them to adjust their services to those recent developments actively. Through collaboration, they can expand their network and gain a competitive advantage over competitors.

- **Complementary needs**

The bottom line is that through cooperating on an equal basis, both parties can create circumstances in which they could reach significant synergy advantages. Simply put, complementary needs are needs of two different parties that, when combined, make another thing better or more whole. Through extensive research, it became evident that both companies have a probable fit at four levels. On an environmental level, both parties operate in the same landscape and can gain a competitive advantage by sharing knowledge. On a market level, both organisations can expand their market share since they both address a different target group within the disability sector. On a company need level, the Quality of Life Centre wishes to make their existing product, a curriculum focused on persons with CISON, operational through a 'digital infrastructure'. The need of Jouw Omgeving is to gain insight into what is required to make their online e-health platform suitable for persons with CISON. Lastly, on a product level, the current hypothesis is that both products will have various cross-over functionalities. In this way, Jouw Omgeving does not have to start from scratch with a solution for the target group, but rather expand on what the Quality of Life Centre has developed.

- **Build upon existing infrastructure and knowledge**

Both parties can benefit from each other's expertise. The Quality of Life Centre has the universal and specialistic knowledge on the target group where Jouw Omgeving has the technical know-how and an existing online infrastructure. Concerning cost, the main expected advantage of collaboration is that (part of) the present digital infrastructure of Jouw Omgeving could be leveraged during the development. The product of the Quality of Life Centre should ideally integrate into the existing infrastructure of Jouw Omgeving and utilise existing technical components, modules and functionalities to reduce cost drastically and eventually aid a smoother and faster development. However, during this process, it will be important not to lose sight of or compromise the underlying vision of the curriculum.

1.4 Problem statement

In the Netherlands, at least 200.000 persons live with CISON according to the 'Vereniging Gehandicaptenzorg Nederland' (VGN, 2017). The term CISON is a generic term for existing subgroups¹⁾ within the disabled care and explicitly emphasises on questions of people instead of their limitations or disabilities (Figure 1.2). In their daily lives, these individuals are incredibly 'care intensive'. Compared to 'normal peers', they have additional support questions, are permanently dependent on the help and support of others, and often have a combination of physical and mental disorders which vary from mild to very severe (Maes et al., 2011). Consequently, this group consist of individuals that form a heterogeneous population, which makes everyone's functioning differently. Moreover, the necessity of offering lifelong, complex care, is inevitable. It is this complexity and permanent character that asks for much commitment of all those involved. So, the vitality, well-being, and happiness of individuals with CISON are therefore mainly determined by the attitude and dedication of those involved. The initial focus of the Quality of Life Centre will lay on the most complex and dependent subgroup (CISON-C). They reason that once you can solve the key issues for this group, it will be possible to 'scale' a solution to the other, less complicated subgroups. Hence, to avoid confusion, in the remainder of this report the term CISON is referred to the 15.000 persons out of the most complex group.

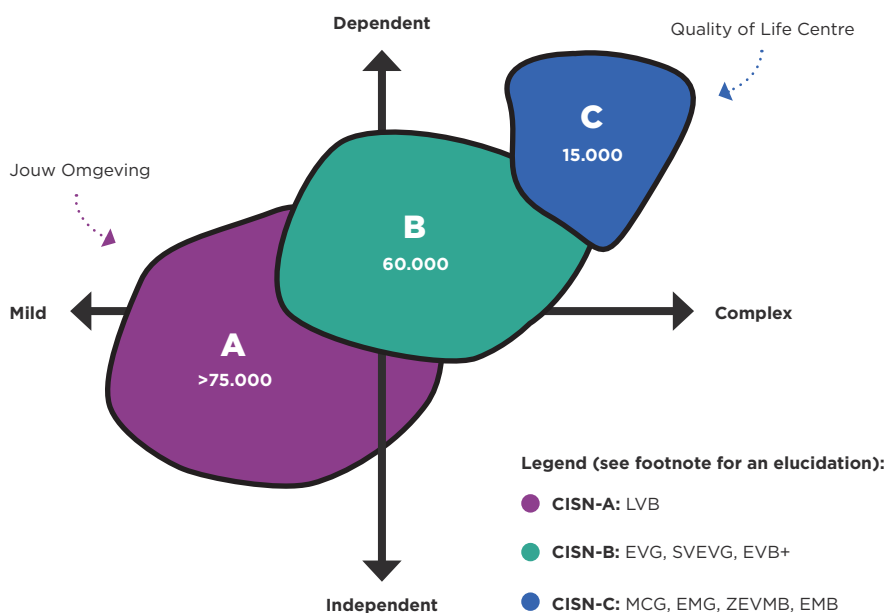


Figure 1.2 Abstract representation of the subgroups within the disability sector in the Netherlands

- 1 Within the mental disability sector in the Netherlands, a distinction is made between different subgroups: this includes people with profound intellectual and multiple disabilities (MCG, EMG, ZEVM, EMB), with severe mental disabilities without (EVG) or with severe behavioral problems (SVEVG), and finally, persons with a mild mental disability (LVB).

The characteristics of people with CISN

In order to establish a clear understanding of the group CISN, this section will describe, on the basis of key characteristics, what it means for an individual to live with CISN. Appendix B provides a more detailed description of this subgroup. Below a summary is provided:

C

Key characteristics of individuals with CISN

Communication on a different level

Persons often do not possess an active or passive understanding of a language (speech, gestures or use of symbols). Frequently, they communicate through body language and use different movements that alter in frequency, intensity, and direction. Even the most basal facial expressions such as raising eyebrows or making eye contact are a means of communication. It is evident that persons with CISN have communication possibilities, but the signals are often so subtle that they require a lot of observational ability to recognise.

Health and behavior

Overall, persons are vulnerable and have a substantially increased risk of health problems. Diagnosis and treatment are difficult since a person cannot verbally express and indicate what is wrong with him or her. There is often a question of epilepsy, obstipation, and sleep problems. With the advancement in age, more health problems might come to the surface or develop. There is a chance that due to growth, abnormalities occur in the skeleton or that existing problems grow in intensity. Besides the physical limitations, there are often various behavioural problems.

Small differences, major implications

Persons with CISN differ from each other in physical condition, motorial skills, and visual and communicative possibilities. Some of them can point out things, grab objects or even say a few basic words. They can make their intentions clear, while others are not able to communicate. Some people can move independently, while other persons depend on caregivers to move. Other people have a short attention span regarding things in their immediate environment, which makes it difficult to establish contact or learn new things. These differences might seem small and irrelevant at first but often have significant consequences for direct interaction.

Small social network

Persons with CISN that live at home or in an institution often have a small social network. Their social system primarily consists of members of the family, grandparents, and the professional network that is built around the family. They have few connections and are not able to enter individually into new ones. Besides, a family member with CISN heavily influences the whole dynamic within a family. The intensity of care has a tremendous impact on the life of the members of a family since their daily tasks and activities mainly revolve around addressing the care needs of the person with CISN. Other, also important family duties and events, are often organised around the care needs, postponed, or even neglected.

An ideal situation

In an ideal situation, actors involved in the care and education of persons with CISN should acknowledge the lifelong and complex questions that arise and facilitate opportunities for personal development. They should minimise bureaucratic processes, enhance an equal cooperation, and support parents and family as much as possible. Above all, parents should feel understood by others and experience self-government and flexibility so they can entirely focus on their well-being and that of their child.

The problem with complex care: a web of bureaucracy

Unfortunately, parents of children with CISN get astray in a web of bureaucracy (NOS, 2017) and encounter many problems during the arrangement of fitting care and education where most of the children are not even going to school. Primarily, they must deal with all sorts of troublesome 'non-essential' issues. There is often a case of long queues, lingering uncertainty among parents, a lack of expert knowledge and expertise at organisations, fragmented care and education, inefficient cooperation between formal and informal network, disappearing facilities, and a surplus of paperwork (Houthuijs, 2017). At this moment, even the most basic forms of care for persons with complex support needs are under severe pressure and extra care, which could improve their quality of life, is barely delivered due to a shortage of financial resources (VGN, 2017). Meanwhile, parents experience little freedom and flexibility due to exhausting bureaucratic matters and the intensive care tasks they perform every day. The amount of care has a tremendous impact on the life of the members of a family since almost all their daily tasks and activities revolve around addressing those care needs. Other, also important family duties and activities, are often organised around the care needs, postponed, or even neglected. As a result, parents are usually physically, practical, and emotionally burdened (Dautzenberg, Moonen & Wagemans, 2015).

But how does one address all these issues and realise and organise a good life for care intensive persons and their families?

Since their foundation two years ago, the Quality of Life Centre attempts to answer this question through the development of several (integrated) products and services. Moreover, the central and key pillar of the Quality of Life Centres offering is their curriculum, which is also the central topic in this research project.

Development curriculum: towards a holistic approach

The Quality of Life Centre identified an existing fragmentation in the field of care and education for people with CISN. They regard the present curricula as incomplete since they are not integrally applicable and not capable of transcending domains. Most of the existing curricula were not sufficient in holistically answering the complex individual questions of persons with CISN. As a result, people with CISN do not receive care and education tailored to their needs. Currently, the Quality of Life Centre partly solved this problem. They combined the current healthcare and educational curricula into one coherent curriculum that is assumed to be both integrally applicable and capable of transcending domains. In simpler words, the curriculum is not related to legislation, type of care or living environment. Furthermore, the Quality of Life Centre based the development

on an underlying knowledge framework which revolves around the Capability Approach (Nussbaum, 2011), the intervention 'Floreren' (Beernink, 2015), the Quality of Life Concepts (Schalock et al., 2002), the International ICF framework (WHO, 2002), and the principles of the UN Treaty (WHO, 2002). However, the foundation of the curriculum was the evidence-based methodological framework of Vlaskamp (Vlaskamp, 1993). This method describes a roadmap that enables parents and professionals to offer support tailored to the needs and wishes of persons with profound and multiple disabilities. The Quality of Life Centre supplemented this method with additional (sub)steps and filled it with knowledge products. Presently, these products are mainly deployed isolated and used in the care and educational practices whether appropriate or not. Therefore, the Quality of Life Centre organised and classified those products through utilising the systematic steps which were embedded in the Vlaskamp method. This process further detailed the curriculum and intends to make the Vlaskamp program more user-friendly and better accessible to parents and professionals from the care and educational field.

Intended users

As a result, the curriculum should provide parents and family with a personal guidance system which supports them in finding their way in arranging care and education for their child. Additionally, it should offer professionals in care and education with a founded prescriptive advisory and work-system. Chapter four will further detail the end user groups and elaborate which benefits they might expect during use. Subsequently, it describes how end users will use the curriculum in practice.

The missing link

The problem that the Quality of Life Centre faces, even though they already developed the curriculum, is that they are currently not able to provide it in an efficient, widespread, and convenient manner to its intended users. Presently, there is a lack of a suitable 'medium' that can facilitate the envisioned use. The hypothesis is that the digital infrastructure of Jouw Omgeving might be appropriate for the curriculum's intended use. Chapter six will validate this hypothesis. In this sense, the curriculum needs to be translated from an 'offline variant' into an 'online variant'. However, it is already evident that this translation process requires additional product and process development. Moreover, it is still unclear which approach this translation process should adopt to ensure that the vision and intended purpose of the curriculum is not lost in translation. Section 1.5 will address those concerns through elaborating the approach this research will adopt.

Expected results research

So, the translation process of the curriculum becomes the central notion in this thesis. By systematically researching the curriculum, and in particular the translation process, its results will have an expected impact on multiple levels. On a global scale, this research will contribute to the development of a solution for a group where many extensive problems occur and so far, no suitable and structural solutions exist. On an organisational level, it will allow both the Quality of Life Centre and Jouw Omgeving to benefit from each other's knowledge and resources and fulfil their needs more efficient against lower cost. On a social level, and most importantly, it will help enable the realisation and organisation of a 'good life' for persons with CISON and their families.

1.5 Research approach

The underlying rationale of this research project is the notion it can build upon an already developed product. However, the development of the curriculum was primarily based on tacit knowledge. Tacit knowledge is difficult to assess and transfer to other persons through writing or verbalising (Chugh, 2015) since it 'lives inside' the head of individuals. This observation inherently creates boundaries for the proposed translation. Moreover, as seen from a design perspective, this fact makes it a challenge to convey the added value of the curriculum to involved stakeholders on the one hand and to ground choices on what to develop on the other. So, the fundamental question resulting from this is:

How does one translate tacit knowledge that is embedded in the curriculum into explicit, structured, and actionable insights?

For this research project, it is argued that adopting the concept 'reverse engineering' can embody this concern. Essentially, reverse engineering is the process of extracting knowledge or design information out of anything human-made and reproducing something based on that extracted information (Eilam, 2005). This project intends to address the stated problem through applying reverse engineering to the curriculum. To facilitate this process, this research leveraged different concepts to structure the unknowns consequently. Eventually, it should enable the 'reconstruction' of the different components of the curriculum in a meaningful way (Figure 1.3). The insights resulting from this process provided the foundation for the design of a comprehensive, actionable design document that should support both the Quality of Life Centre and Jouw Omgeving during the design and operationalisation of the curriculum. More briefly put, the core of this research is captured by the following primary research question:

Primary research question

How can the curriculum of the Quality of Life Centre be translated into an e-health application to aid a sustainable implementation in the Dutch healthcare system?

The primary research question is further specified into three supporting research questions to maintain a clear and coherent structure throughout this report. Each question addresses vital sub-areas, and its results should contribute to answering the main research question:

Sub research questions

1. How does the Dutch healthcare system function and what is its relation to e-health?
2. How should the principles of e-health development be applied to the translation process of the curriculum?
3. How should the results of the translation process be embedded in the existing infrastructure of Jouw Omgeving?

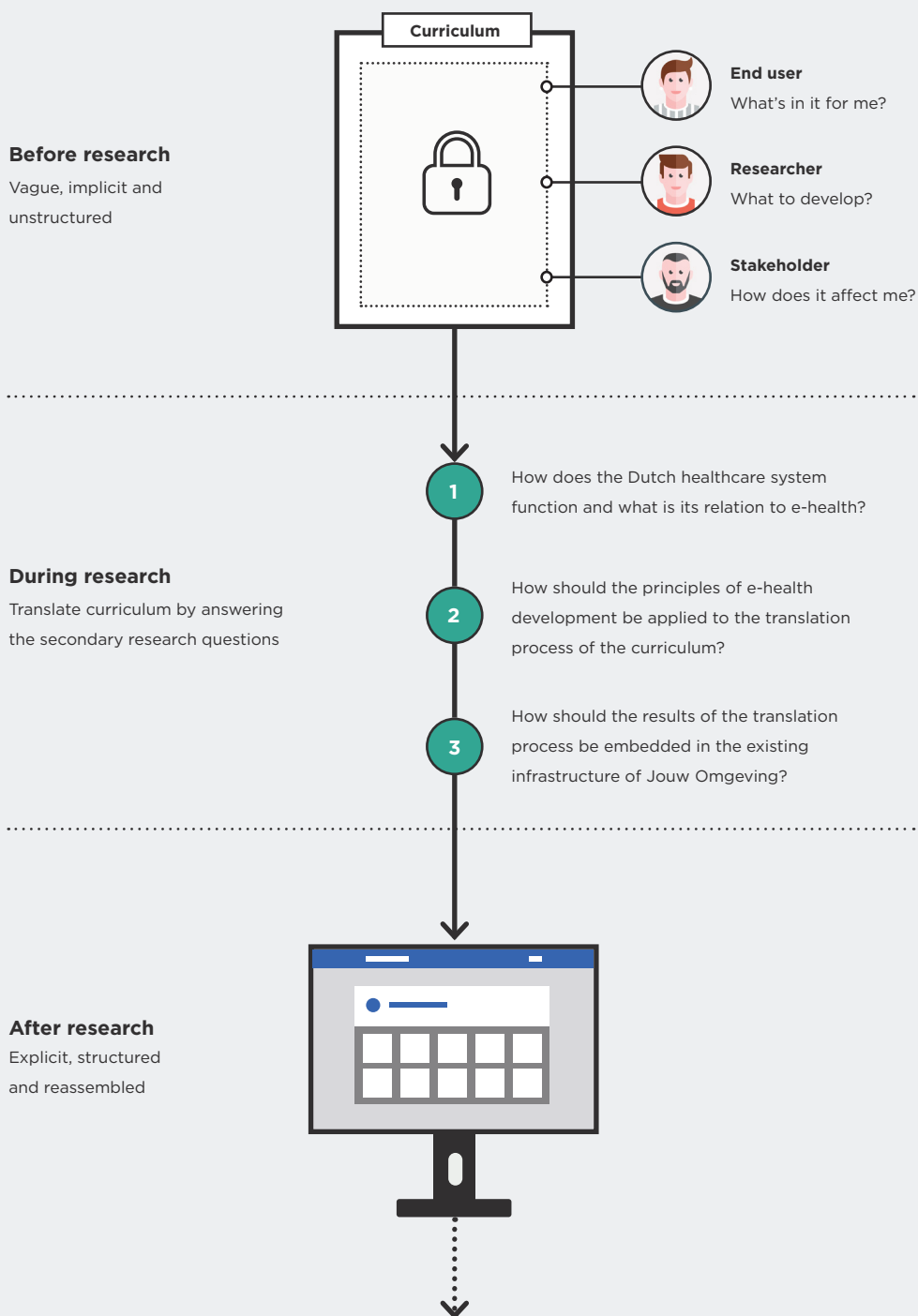


Figure 1.3 High-level overview of the research approach

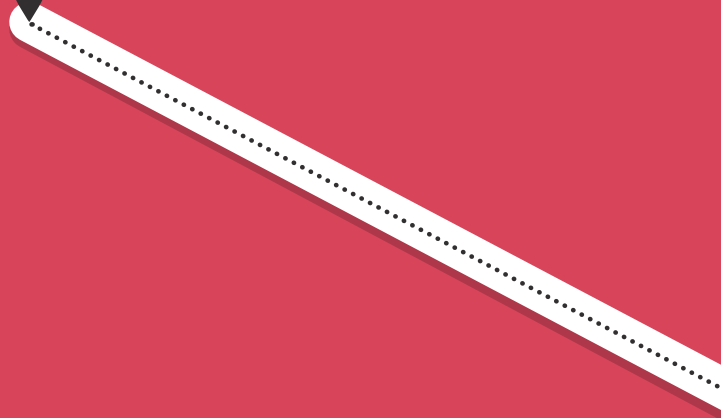
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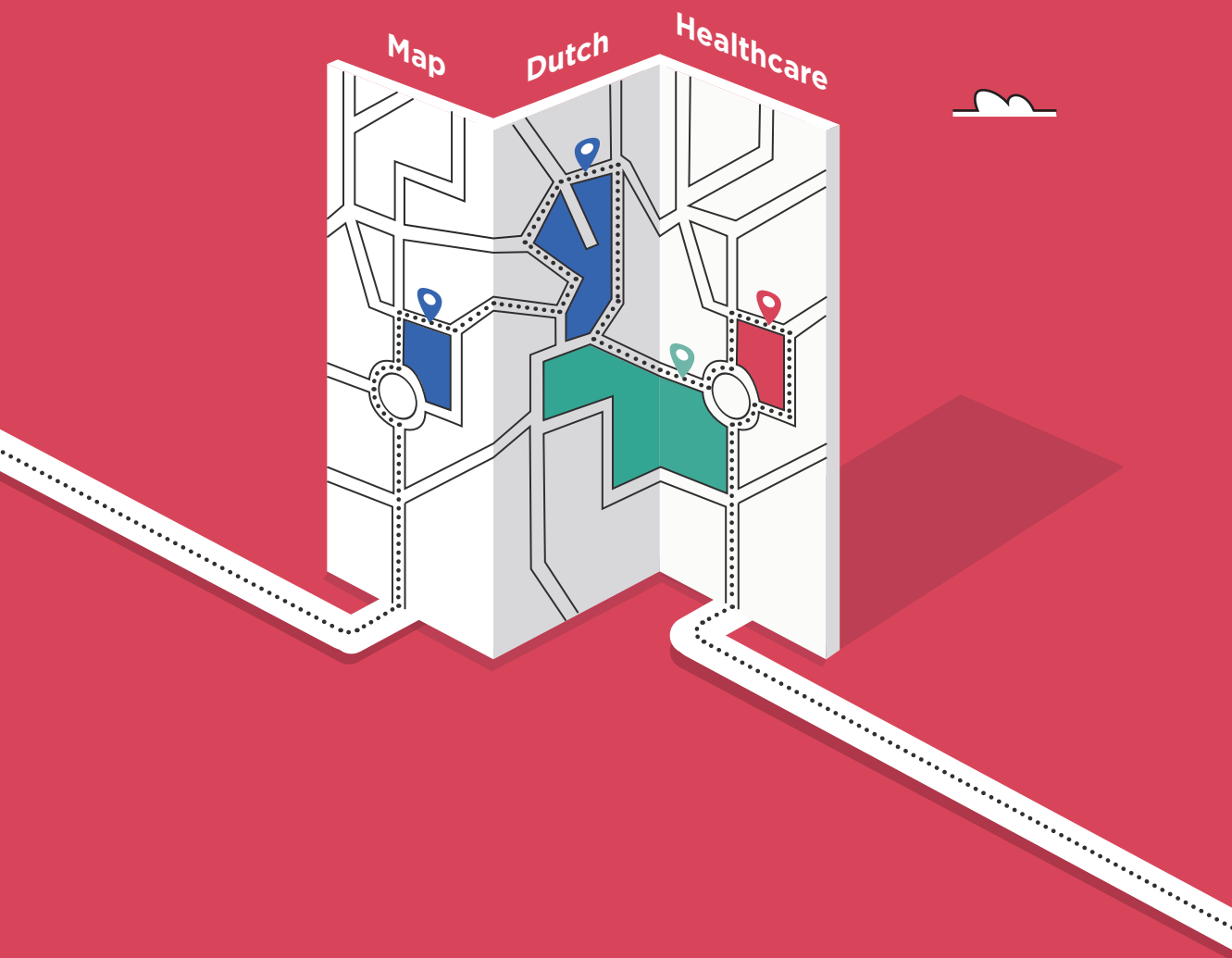
02

Mapping the research environment

Mapping the context of this research project to reach a more profound understanding of the Dutch healthcare system

Start





Naturally, products aren't developed and used in a vacuum but inherently belong to a broader ecosystem. Within this environment, there will be multiple forces at play that all interact, shape the rules of what will be possible and credible, and naturally set preconditions for a successful product. For example, it is logical that products in the car industry should comply with different regulations than products in the food industry. Failing to understand these rules will lead to undesirable outcomes, even if the 'product' in itself is of exceptional quality. Accordingly, it is debated that it will be important to uncover changes that are happening in the field that might influence and affect this research. In this case, the environment in question is the Dutch healthcare system where the curriculum, in the form of an e-health application, will be embedded. However, without meaningful context, the relations that will form between the environment and the curriculum will be difficult to comprehend and interpret. There is a need to assess and construct the environment where this research project 'moves through'. By placing the curriculum into the context of the Dutch healthcare system, it becomes possible to develop a greater understanding of the value of the product considering other components of the system (Kumar, 2013). In this sense, the primary aim of this chapter is to generate a certain level of understanding of the context which, in turn, enables more grounded decisions throughout this research. The gained knowledge will not only help to recognise possible opportunities and constraints but also aid in understanding system-level implications for the intended reverse-engineering process of the curriculum.

But achieving a profound understanding seems no easy task since the Dutch healthcare system is regarded as a complex system with a lot of interdependencies and a plethora of actors. For example, how does one distinguish beforehand what is valuable and non-valuable information? How does one determine what the most significant actors and concepts are? Finding answers to those questions is like walking a fine line between drowning in too much information and oversimplifying the situation. Only through exploring and processing the new information it becomes possible to question previously held assumptions and re-frame situations. However, without a defined route guiding this exploration process, it will be very easy to get astray in healthcare ever-shifting web of interacting factors. Hence, this section constructed a map (Figure 2.1) which symbolises the taken route in this chapter towards reaching a more profound understanding.

The map: a chapter overview

Universally, a map is only useful when it shows the current location, the destination, and a defined path between the two which provides enough detail so someone does not get lost along the way. In this case, our current location and beginning of this chapter is the outer border of the healthcare system where things still seem unclear and uncorrelated. Moving down the path, and into the healthcare system, our path is crossing four stops where a question represents each stop. Through systematically answering each question it should make things more understandable, reveal relationships, and bring us closer to our intended destination: a clearly constructed overview of the healthcare system and profound insight in its main building blocks. Once arrived at the destination and end of this chapter, the journey resulted in a sound knowledge foundation that enabled the selection of essential principles for e-health development in chapter three.

Map Dutch healthcare system

As metaphor for reaching a more profound understanding

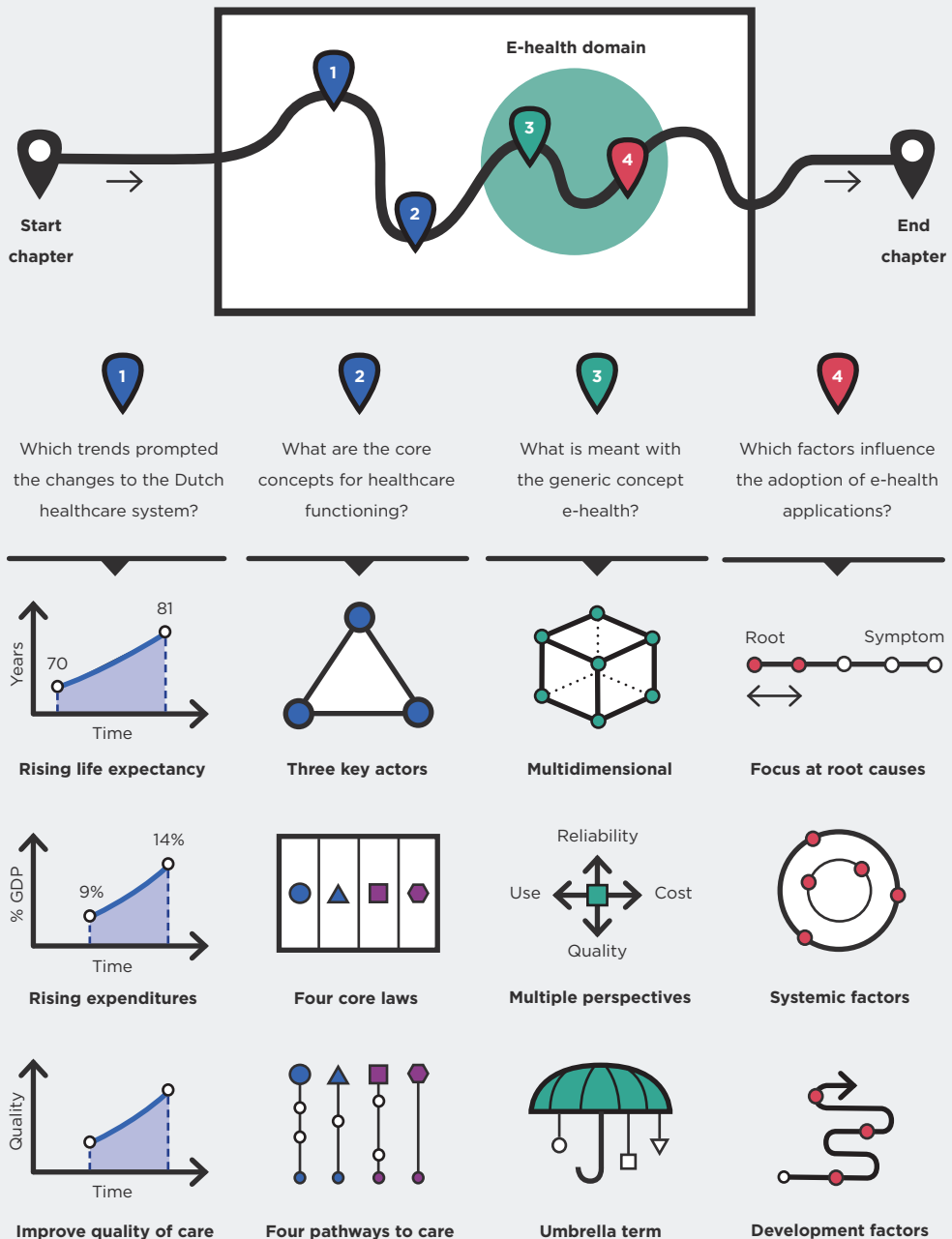


Figure 2.1 The overall structure and main conclusions of chapter two

2.1 Dutch healthcare system - The need for change

A certainty is that everyone will, at some point in their lives, encounter healthcare. In the role of caregiver for their children and parents, or as 'receiver' for an own disease or limitation. Some are privileged enough to live a relatively long and healthy life where others are less fortunate and are, or become (entirely) dependent on the healthcare system for the rest of their lives. Once this happens, people expect that they receive the best support and care possible. However, the composition and preferences of the society are changing, and with it the ability of the healthcare system to deliver the best possible care on the one hand while keeping healthcare accessible to citizens on the other. For example, the overall life expectancy is rising, and more people develop chronic diseases. Mainly fuelled by these trends, there is a growing awareness that the organisation of the Dutch healthcare should change since healthcare expenditure is rising too steeply. According to Edith Schippers (2014), [...] *'Care ought to be delivered in or near the home, with a full range of online services and the use of smart technologies. If we can transform health care in ways like these, we will both further improve it and make it more affordable'*.

However, without further background information, it will be difficult to anticipate on past and future developments and trends within the healthcare system. By researching what caused the government to change the healthcare system and how it realised those changes, more insight is gained into its functioning. Furthermore, the goal of this research project is to develop a sustainable e-health application that 'exists in and interacts with' this system. Hence, in-depth insight is required to create a sound understanding of the implications the healthcare system might have during the development process. Chapter five provides a visual network structure that provides a detailed overview how the curriculum interacts with the current healthcare system. But before this was possible, it was important to understand the basic 'structural' components of this same system. The healthcare system is regarded as a dynamic, complex and evolving field where difficulties are often composed of many interacting factors, persons and organisations. Thus, the concepts presented in this section are not assumed to be comprehensive nor meant to characterise all the interrelated components of the healthcare system. Instead, the main aim is to capture its principal actors and concepts. Eventually, this should result in an understandable overview of the structure of the Dutch healthcare system and a sound comprehension of how it functions the way it does.

2.1.1 Trends as drivers of change

The continuous trends and developments in the social domain have led to rising concerns of keeping healthcare affordable and accessible to all Dutch citizens. In 2015, the Dutch government anticipated on those concerns by implementing a significant reform in the healthcare system. On the one hand, they wanted to improve the financial sustainability of the healthcare system while increasing the quality of care on the other. This section describes the most important results of an elaborate analysis of the Dutch healthcare system (Appendix C), which is the landscape both the Quality of Life Centre and Jouw Omgeving operate in. The primary aim of this analysis was to uncover changes in the field that might influence and shape the research environment. This section will put the rising concerns into a perspective of significant historical and future developments and elaborate what prompted the changes to the Dutch healthcare system.

Rising life expectancy and chronic diseases endanger financial sustainability

In 1950, the average life expectancy was close to seventy-one years. In the following decades, society experienced a steep increase in economic welfare and technological advancements which resulted in better overall access to healthcare services, highly improved treatments, and more emphasis of policymakers on preventive measures. Over a sixty-year period, this has led to an increase in average life expectancy by nearly eleven years, to eighty-one years in 2014 (Figure 2.2). According to recent scenarios, the life expectancy will continue to rise, but less steeply than over the last decades (Hoeymans et al., 2014). However, despite the fact people are living longer, they are also developing chronic diseases at an earlier age, and consequently, cause a relative decrease of years people live in 'good health'. This growth is partly attributable to the ageing population but also to the improvements made to medicine and diagnostics. Diseases that were once untreatable became treatable, and besides, an early detection of a chronic illness implies that people will live longer with their condition. As with the life expectancy, the prevalence rate of chronic diseases is expected to increase.

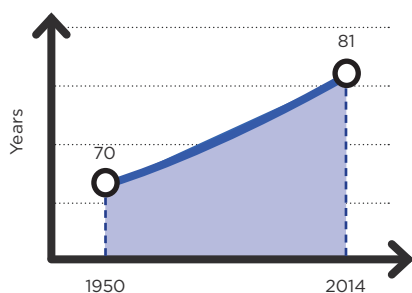


Figure 2.2 Rising life expectancy

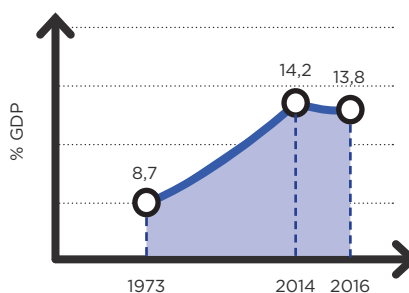


Figure 2.3 Rising expenditures

As a result, healthcare expenditure (Figure 2.3) grew alongside the rise in life expectancy and the number of people with a chronic disease. However, it is important to note that other demographic trends in the social domain, such as the amount of wealth and technical advances also contribute to growing cost. It is a fact that wealthier countries spent more on healthcare due to higher living standards. Furthermore, technological advancements have caused improved treatment options resulting in more accessible treatments and a lower mortality rate for diseases that were once fatal (De Vries & Kossen, 2015). In general, healthcare expenditure can be expressed in absolute terms, per capita, or as a percentage of the gross domestic product (GDP), where the latter is preferred since it factors in inflation. Between 1973 and 2014, before the policy changes, healthcare expenditures grew from 8,7% to 14,2% of GDP (CBS, 2017). More recent numbers illustrate signs of stabilisation and even a slight decline in healthcare expenditure to 13,8% of GDP in 2016 (CBS, 2017). A preliminary and cautious conclusion might be that the recent policy measures are indeed dampening the growing rate of healthcare expenditure. However, the significant dependency on a lot of unpredictable and interrelated factors make a long-term prediction of healthcare expenditures difficult. Measures meant to reverse one trend may have positive or negative effects on others. Hence, the exact scale of savings and its impact on public health challenges should become more apparent in the coming years (Hoeymans et al., 2014).

Structural changes to improve ‘quality of care’

As a second reason for the reform, politicians and policymakers believed that the quality of healthcare could be further increased by, literally, bringing it closer to the people (De Vries & Kossen, 2015). However, according to Hoeymans et al. (2014), defining the notion quality of care is challenging since it can be described from four different perspectives. In this sense, quality of care is multidimensional and its interpretation dependent on societal values, norms and context of use. For the government, improving the quality of care is about better answering the individual care questions of its citizens. They attempt to achieve this through transferring functions and responsibilities from the central government to the local authorities, also known as decentralisation (Figure 2.4). In doing so, the government assumes that local authorities can offer more targeted care and better meet the individual needs against lower cost and with less bureaucracy (Rijksoverheid, 2013). The rationale is that local authorities know the different communities, its facilities, and many of its citizens much better than the government ever will.

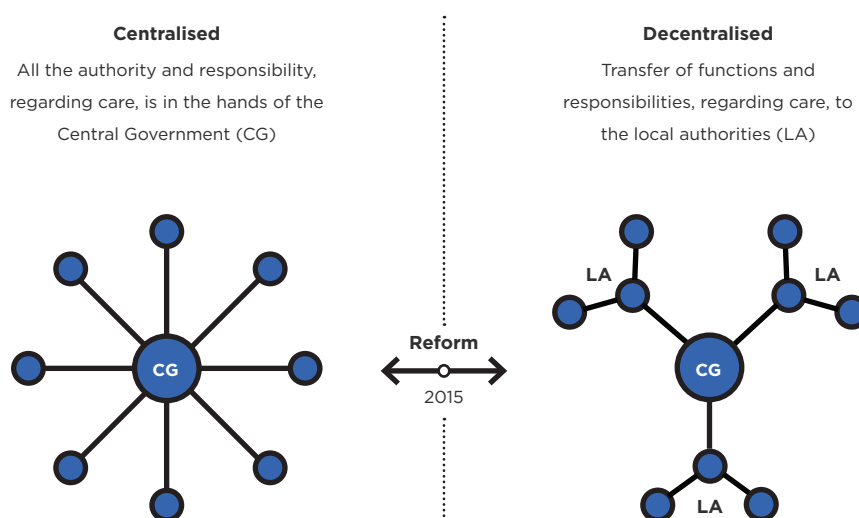


Figure 2.4 Simplified network structure before (left) and after (right) the reform

Also, the decentralisation encourages citizens to rely more on their network and less on publicly provided care. In this context, decentralisation is considered as bilateral: there is currently a debate that decentralisation is more correlated to budget cuts than as an ‘ideological concept’ to bring care closer to the people. There is raising concern that it might cause too many regional differences resulting in situations that are contradictory to the democratic principles of justice, accessibility and solidarity (De Jong, 2016). This project will not take a stance on whether decentralisation is the right means to improve the quality of care or that it was merely implemented as a disguised budget cut. It resulted, however, in significant structural changes to the system and imposed a lot of responsibilities on local authorities generating a whole new system that delivers social services to citizens.

Long-term effects of the reform remain difficult to predict

Due to improvements made in prevention, treatments, medicine, technology and diagnostics the average life expectancy of a Dutch citizen has increased by nearly eleven years and is expected to rise even further in the future. Simply put, people are living longer while developing a chronic disease at a younger age. Alongside those trends, healthcare expenditure increased to rates that are higher than in many other European countries. As a response to these financial and demographic trends, the government reformed the Dutch healthcare system in 2015. Briefly put, the goal of the reform was twofold: ensure that healthcare remains sustainable for future generations while increasing the quality of care through helping people in a way that better meets their individual needs. The government believed to achieve those goals through new laws and decentralisation, which resulted in fundamental structural changes to the healthcare system as further illustrated in section 2.1.2. Now, two years after the measures were executed, its long-term effects on public health, quality of care, and expenditures remain difficult to predict. What is clear, is that the transcending societal challenge will be, despite all occurring trends and results, to collectively keep healthcare affordable and accessible to all Dutch citizens.

Future prospect: citizens moving to the centre of the healthcare system

Besides the trends that led to the reform, the elaborate business environment analysis (Appendix C) uncovered a variety of other trends, industry forces, and specific characteristics of the Dutch healthcare system. However, there was a common topic discovered, where multiple trends focus explicitly on the role of the private individual. These trends imply that the private individual will get a more important and influential role in receiving and choosing care. The concerned trends are summarised below:

- **Legislation and initiatives shift towards autonomy and freedom of choice**
Individuals with health problems are more engaged in managing their own care and reinforced with technological resources resulting in more personally tailored care, more self-management and self-reliance. It is expected that future generations will prefer and demand more shared decision-making.
- **A stronger voice for the individual and more empowerment**
The patients right act gives patients, clients and their representatives a stronger voice in their treatment. Because of this, citizens are better informed before they first enter the healthcare chain.
- **Changing relation private individual – healthcare provider**
Delivery of care will be increasingly independent of the time and place. Care will be more and more delivered remotely or at the home of a person. Persons will gain access to opportunities for performing self-diagnosis and self-treatment where healthcare providers will probably shift their focus to complex diagnostics and joint decision-making, in which personal considerations are decisive.
- **Fast technological developments might increase autonomy**
Fast rise of new e-health resources, that enable self-management, such as applications for smartphones and wearables, health platforms, and personalised health records. Future technological developments such as artificial intelligence, sensors and robotics will allow decision-support, self-diagnosis and self-treatment.

2.1.2 The fundamental concepts of healthcare functioning

It is evident that when only the basics of a complex system are of importance, the fundamental hurdle will be figuring out what not to look at. Consequently, trying to get a sound understanding of the Dutch healthcare landscape is like walking a fine line between what is essential and contrary to that, unimportant as viewed from the context of this research project. Where section 2.1.1 briefly described why the reform of the healthcare system was necessary, this section attempts to further enhance the understanding of how the government realised those structural changes and what its implications were for its overall functioning. This objective is achieved through uncovering its key players, describing the core acts that govern healthcare and dictate the care pathway, illustrating how individuals can get access to healthcare, and finally, examining who determines the coverage of care.

The triangle of key players

Due to the vast complexity of the healthcare system, it's will be very easy to get astray in its ever-shifting web of interacting factors such as policies, laws, financial incentives, technological innovations, stakeholders, and business models. Hence, to better understand the fundamental functioning of healthcare, and not be put off by its many details, a simplified abstraction of the system is necessary (Kaplan & Babad, 2011). The abstraction of the core functioning of healthcare system is partly embodied by a triangle of three 'connected' actors (De Vries & Kossen, 2015).

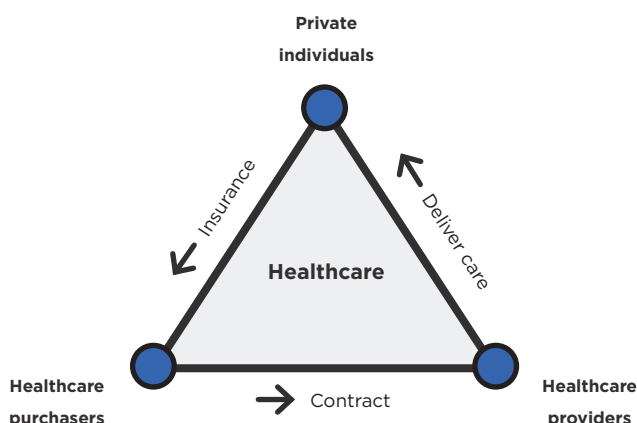


Figure 2.5 The healthcare triangle

Figure 2.5 depicts a triangle with at each end a key actor, all fulfilling a distinct role. On top are the private individuals who are required by law to insure themselves against medical expenses and are the final consumers of healthcare services. On the right are the healthcare providers, which are institutions, organisations and individuals that offer healthcare services in the form of products, assistance and support. Lastly, healthcare purchasers close the loop and buy care from the healthcare providers. Depending on the associated healthcare acts, they are represented by three different parties; health insurance companies, healthcare administration offices, and local authorities.

Besides these three key actors, there are several other significant players involved in the healthcare system such as the government, regulators, implementing bodies, advisory boards, and health funds (De Vries & Kossen, 2015). This section does not further address these parties in detail because they fall outside the scope and intended purpose of this chapter. However, they are important to mention, since the full spectrum of actors eventually defines healthcare. They form mutual relationships, interact and exchange value, and jointly represent the Dutch healthcare system. In this sense, healthcare is defined as the full range of actors, resources, activities and supporting activities designed to maintain and improve people's health and self-reliance to reduce, end, compensate for and prevent any shortcomings in this respect (Hoeymans et al., 2014). More briefly put:

Healthcare refers to anything and anyone contributing to health and autonomy

An overview: the four core acts that govern healthcare

As of January 2015, the Dutch government has implemented a major reform in the healthcare system with the introduction of three new acts and the reallocation of responsibilities and tasks to local authorities, often municipalities. The overall philosophy of those measures is that they should encourage prevention and emphasise the importance of the network and autonomy of citizens. Primarily, the measures were designed to ensure that people receive the minimum of assistance, care and support that is possible and, at the same time, as much as they need (De Vries & Kossen, 2015). Essentially, each act focuses on a different area of healthcare (Table 2.1). Appendix D provides a more elaborate overview of each act.





Symbol	Act	Brief description	Year
	Healthcare Insurance Act	Providing curative care with an emphasis on serving to cure or heal.	2006
	Long-Term Care Act	Government of high level care and intensive (24/7) forms of support	2015
	Social Support Act	Support private individuals to live at home for as long as possible.	2015
	Youth Care Act	Government of all health services for people under eighteen in the Netherlands	2015

Table 2.1 The four core acts that govern healthcare

Four pathways to access healthcare services

Where the previous section defined the players that are necessary for the healthcare system to function, it is the four core acts together that govern the underlying rules of this 'functioning'. Fundamentally, their working is twofold: they jointly determine what type of care is covered by law on the one hand, while establishing procedures which path an individual should follow from initial request to receiving care on the other. In this regard, there is causal link between those two functions, as the type of care covered in each act dictates which path a person should take towards receiving the appropriate care. Thus, since there are four core healthcare acts, there are likewise four distinct care pathways a private individual might take. Figure 2.6 shows a simplified model of the four paths to receiving care.

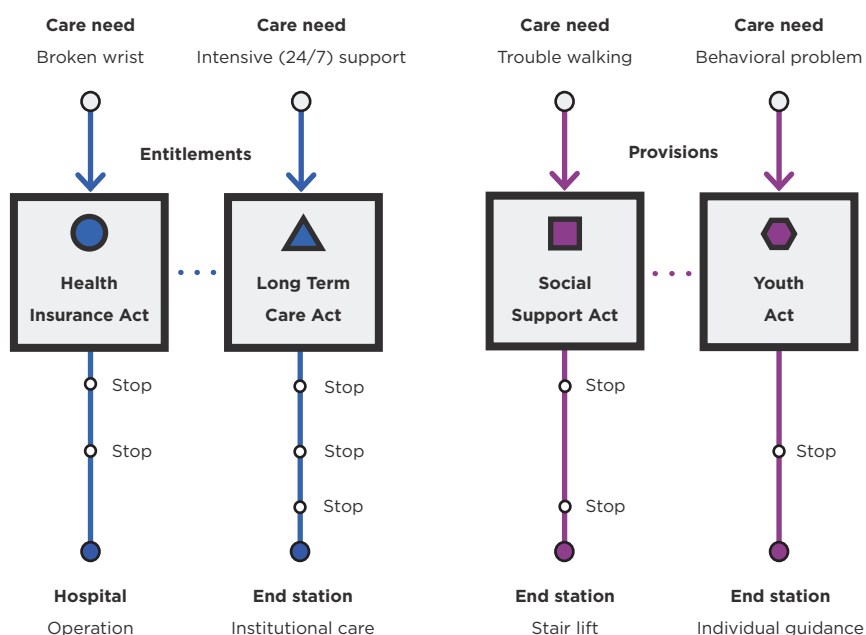


Figure 2.6 Simplified model of the four care pathways

In the event of emergencies, the procedures for receiving care are very explicit. If a situation is life threatening, people are taken by ambulance or other transportation to the hospital's emergency department. If this is not the case, there are numerous possibilities, and the procedures vary depending on which of the core healthcare acts applies. In general, a person might have various reasons to enter the healthcare chain. However, it's the gravity and complexity of the private individuals need that will eventually determine what care, the place, and from which healthcare provider(s) someone will receive care. Describing all four pathways in detail would fall outside the scope and intended purpose of this section. Hence, for the sake of clarity, the following part illustrates the care pathway covered under the Health Insurance Act.

Care pathway Health Insurance Act

The overall philosophy of the Dutch government is that it expects its citizens to be self-reliant. This philosophy includes being able to perform all the daily activities without the assistance from others. If this is not possible, people are first required to invoke support of those in their immediate environment, for example asking help in doing groceries. Normally, a person only enters the healthcare chain if the direct environment is no longer able to meet the care need(s) of the person. In the case of the health insurance act, private individuals can schedule an appointment with primary healthcare providers (e.g. doctor) without requiring a referral. These providers usually give advice, carry out examinations, treat, or refer the private individual to secondary healthcare providers such as hospitals in the case of more complex specialistic care. If the primary healthcare provider has provided a referral, the private individual moves on to the selection procedure. The private individual has the right to choose between different healthcare providers. The healthcare insurance company, with which a private individual has entered a contract, often mediates in this decision-making process. A precondition for full compensation is that the selected healthcare provider(s) signed a contract with the health insurance company. After the selection procedure, the healthcare provider and private individual establish a treatment plan. Hereafter, the private individual receives the appropriate care. Summarised, the total pathway under the Health Insurance Act is illustrated in figure 2.7.

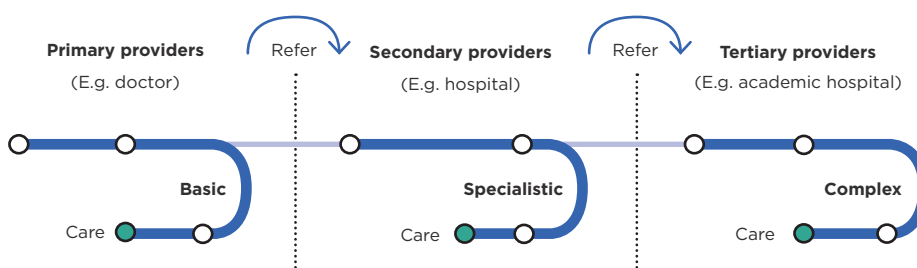


Figure 2.7 Pathway under the Health Insurance Act

Government determines coverage of care

In the Netherlands, a private individual is either 'entitled' to care or able to claim 'provisions' needed for their additional care needs. In the case of entitlements, for example a doctors visit, persons are covered by law through an insurance policy for the cost to a certain extent of curative and high-level and intensive care. Every year, the ministry of public health determines, based on the recommendations from the National Healthcare Institute (NHI), the final package. In case of provision (e.g. wheelchair), private individuals do not have the opportunity to insure themselves. Every year, the central government sets quality standards and other requirements by which local authorities must comply. The local authorities determine themselves how to ensure this quality and are free to decide which type of care they purchase from which (local) healthcare providers. They often assess together with the individual in question, which type of care, assistance or support is most appropriate.

2.1.3 Conclusion

The main aim of section 2.1 was to understand why the reform of the Dutch healthcare system was necessary while further enhancing the understanding of how the government realised the reform and what its implications were for its functioning. Figure 2.8 summarises and visualises the main building blocks of the Dutch healthcare system.

Why the reform was necessary

People are living longer while developing a chronic disease at a younger age. As a result, healthcare expenditure increased and the government responded by means of a major reform in 2015. The goal of the reform was twofold: ensure that healthcare remains sustainable for future generations while increasing the quality of care through helping people in a way that better meets their individual needs. The government believed to achieve those goals through three new laws and decentralisation, which resulted in fundamental structural changes to the healthcare system. Now, two years after the measures were executed, its long-term effects still remain difficult to predict.

How the reform influenced the functioning

Briefly put, the functioning of the Dutch healthcare system is embodied by a triangle of three actors that interact and exchange value with each other. In this way, its functioning could be captured in one sentence: *“Private individuals buy a policy or request a personal budget from a healthcare purchaser who, in turn, grant them access to care or provisions from healthcare providers who, individually, sign a delivery contract with the concerned healthcare purchaser.”* It is obvious that without rules the triangle would collapse, so the government outlined and implemented four core acts which govern the underlying rules of its functioning. Correspondingly, the four core acts serve two different purposes to support its functioning. On the one hand, they regulate what ‘entitlements’ and ‘provisions’ are covered by law, while establishing a distinct pathway an individual should follow from initial need to receiving care on the other. Every year, the ministry of public health determines the ‘package of entitlements’. For provisions, the central government sets quality standards and other requirements by which local authorities must comply. Eventually, all these structural elements resulted in four distinct pathways which will guide a person from initial need to actually receiving the appropriate care. It became evident that each pathway is related to one of four acts and therefore, has its own specific procedures and network structure of stakeholders. In the case of complex needs, it is possible that an individual moves alongside multiple paths simultaneously. As chapter five will illustrate, this will also be the case for the parents of persons with CISN.

The healthcare system is dynamic and susceptible to change

During the analysis, it became clear that demographic trends strongly influence the way the government organises the healthcare system. Unexpected trends, financial setbacks, or even a changing composition of the government may cause the introduction of new laws and regulations. This will inherently influence and change the system in minor or big ways. Hence, it will be important to leverage future trends and anticipate on possible changes that might influence the development of the curriculum. This will be done through constructing a future scenario in chapter six.

The main 'building blocks' of healthcare

An overview of the relation between the different parts

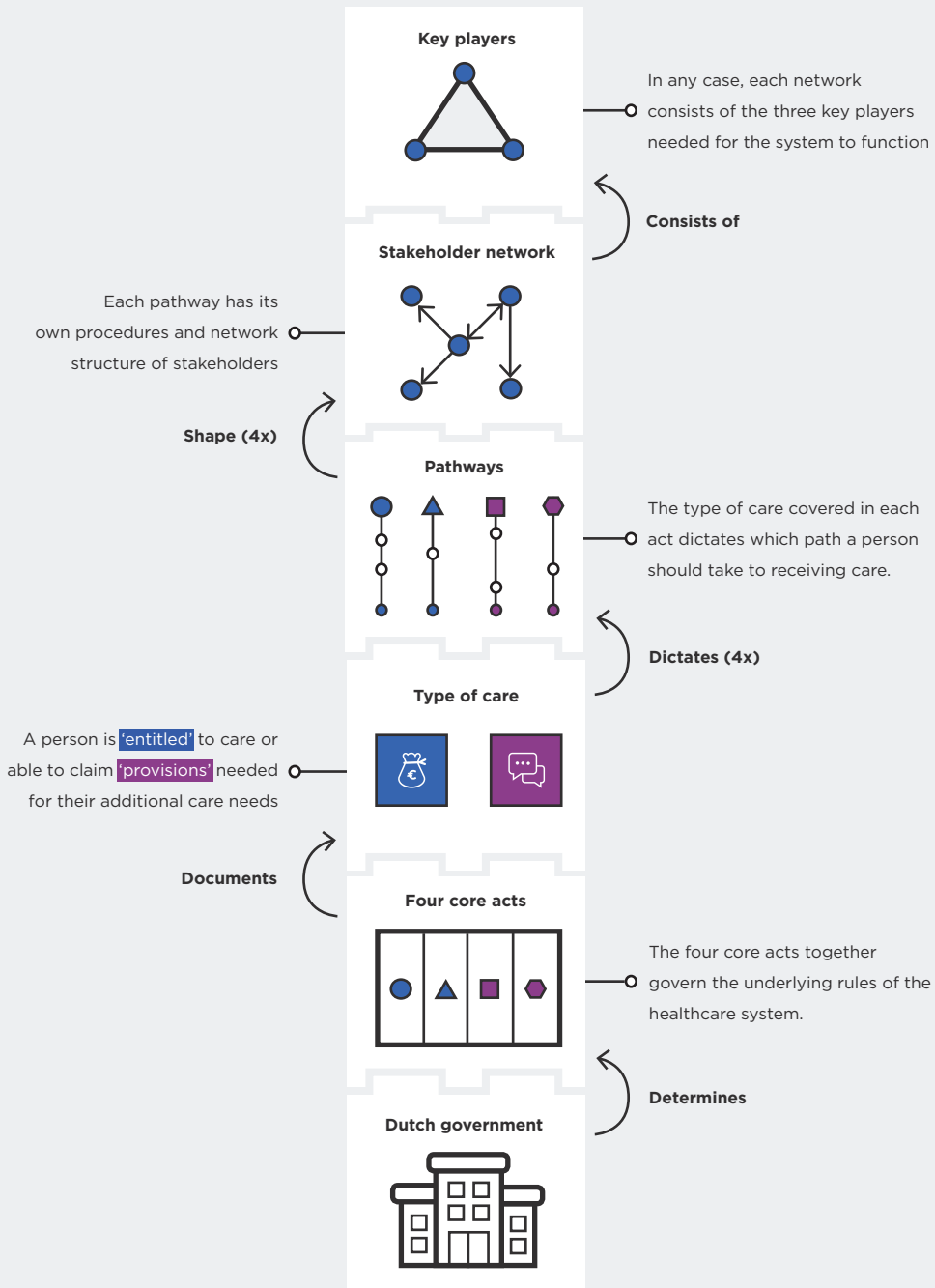


Figure 2.8 Main building block of the Dutch healthcare system

2.2 E-health - A broad domain within healthcare

Today technology is all around us and deeply rooted within our society. Historically, new disruptive technologies have brought affordability and convenience to society in a variety of industries, but also new challenges. Likewise, in the healthcare industry there has been an increase in the application of information and communication technologies, commonly referred to as e-health applications (WHO, 2016). In the recent years, the applications of e-health have grown exponentially, and researchers and governments from all over the world recognised its potential to make healthcare more affordable and efficient (Scott & Mars, 2013). This increase is probably best illustrated by the steep rise in the availability of smartphone applications related to health. Disregarding their overall quality, safety and effectivity, it perfectly forecast an underlying trend where medical information will become continuously available to the customer at any given time, device or place. According to Lucien Engelen (2016), [...] *“Medical technology is getting smaller, evolves from portable to implementable, moves from organisations into the environment of clients, and takes the shape of a consumable item.”*

It is evident that such trends have the potential to change and disrupt the healthcare industry on a large scale. Currently, healthcare providers operating in the Dutch healthcare sector intent to renew their products and services to meet the new requirements and possibilities that technological innovations, society, and government impose on them. They are seeking for innovative measures to reduce cost, increase quality, stimulate prevention or to facilitate a more responsible and influential role for the client (RVS, 2017). To achieve those varying goals, the providers are progressively making use of e-health applications to support, streamline or replace current treatment services (Eysenbach, 2008). However, compared to other industries where new technologies are broadly adopted, the healthcare sector seems to lack a swift adoption of promising e-health incentives. As will be illustrated by section 2.2.2, this slow adoption seems attributable to different obstacles that can be subdivided into system, developmental, organisational, and individual barriers. As a result, e-health technologies often face adoption problems, and as soon as initial funding stops, few of them achieve a truly sustainable and structural implementation. From a system thinking perspective, it appears that most of the e-health applications are, in fact, superficial solutions that attempt to solve symptoms rather than the more fundamental root causes of the problems they're addressing (M. Senge, 1990).

The observed obstacles with implementation emphasise the importance of getting preliminary insight into the general e-health concept. It is apparent that when these obstacles are overlooked or ignored, all the consecutive research activities might, sooner or later, result in an irreversible path to failure. In its core, the ultimate intention of this research project is to lay a funded basis for the development of a sustainable e-health application. However, developing sustainable e-health applications requires a sound understanding of why so much applications fail to be sustainable in the first place. Hence, as was done in section 2.1, the main aim is to lay a theoretical foundation through elaborating the generic term e-health, how it is classified, and what its obstacles are for implementation. In chapter three, this knowledge enabled a founded selection of approaches, methods and tools which can support to overcome the observed obstacles.

2.2.1 The notion e-health explained

Within healthcare, the term e-health is a common notice but is often used without a clear explanation of its meaning. The term literally implicates the use of information and communication technologies for health (WHO, 2016). However, since the term is not limited to specific technologies, user groups, or type of healthcare it leaves a lot of room for interpretation. This broadness has led to many different understandings and definitions of e-health (Pagliari et al., 2005). Since this research is mostly about the design of an e-health application, it is fundamental to adopt a clear understanding of what is meant with the generic e-health concept and which factors influence the adoption of e-health applications. Briefly put, this section will illustrate that e-health has no clearly defined meaning, that a lack of classification hinders decision making, and that developing e-health applications is about reducing uncertainty among the involved actors.

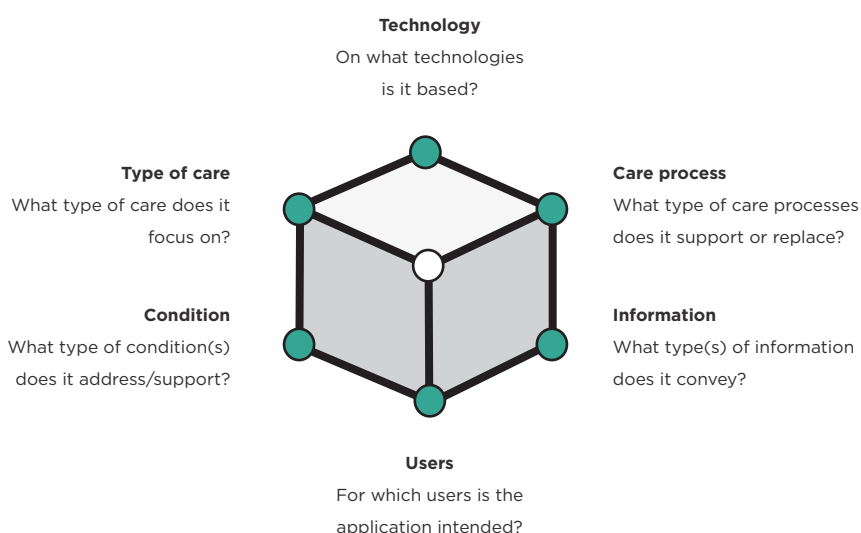


Figure 2.9 The multidimensionality of e-health (based on the researchers interpretation)

E-health has no a clearly defined meaning

E-health is a complex term to define since it's multidimensional (Figure 2.9). In a broader sense, the term not only embodies the technical aspect, but also revolves around improving the flow of information, a new way of working and attitude, and commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide (Pagliari et al., 2005). Over the last years, many definitions have been developed and adopted, but all illustrate that e-health is a concept without a clearly defined meaning. Moreover, the definitions implicate that the context and network of stakeholders are crucial elements for describing e-health more holistically, as a health insurance company will view e-health from an entirely different perspective than general practitioners. Consequently, these different perspectives raise distinct questions when an actor decides to develop or start to work with an e-health application (Figure 2.10). To clarify,

patients want to gain insight in the ease of use, general practitioners are concerned with the reliability of measurement data, healthcare purchasers want an overview of long-term returns, and policy makers want to know if those new possibilities don't lead to unnecessary treatment (Ossenbaard et al., 2017). So, it is evident that without a clear understanding of the e-health application in question, a discussion among stakeholders might rapidly lead to contradictory values and different truths, eventually resulting in uncertainty. Thus, to knowingly choose an e-health application there is a need for reducing uncertainty. However, this seems to be no easy task as illustrated by an experienced healthcare consultant (Van Rouwendaal, 2016), [...] *"The flood of available innovations and the versatility of areas where those innovations are needed or possible, make consciously choosing incredibly complicated."*

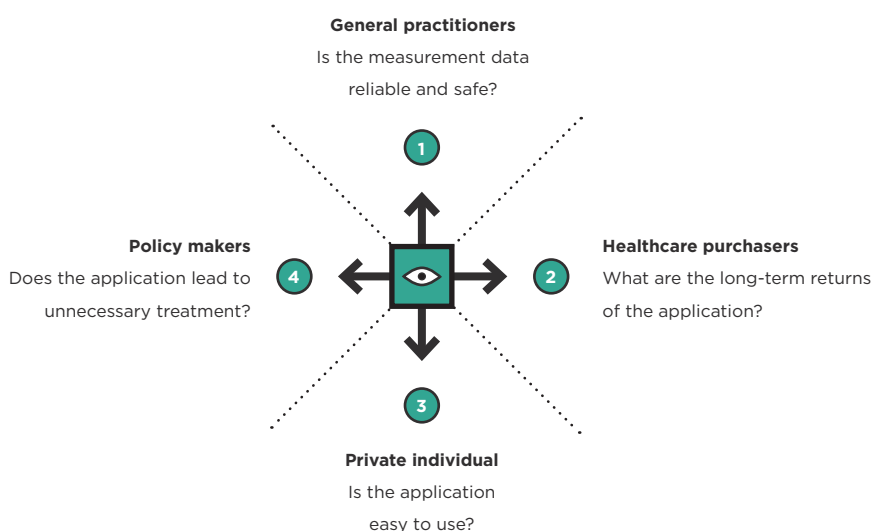


Figure 2.10 The various perspectives on an e-health application

Lack of unified classification hinders decision making

The previous section illustrated that the notion e-health is not generally applicable and in sole use meaningless without additional context. Throughout the years, e-health became a concept that is used to cover a broad spectrum of things rather than a single distinct item and can, therefore, be associated with an 'umbrella term'. In other words, all the applications that provide new solutions using information and communication technologies in healthcare could be attributed to the term e-health. Essentially, a logical structure is needed to understand and clarify how those various e-health solutions are structured and related to each other. In general, this structure can be achieved through applying classification. Simply put, classification is the process of systematic arrangement of events, processes or objects in specific categories. Often a fixed system is used, such as the widely known periodic table in the chemical sector. However, for e-health, there is currently no unified classification system in place (Figure 2.11). There are multiple classification schemes in circulation which all serve a different need (Akkersdijk, Kelders

& Van Gemert-Pijnen, 2016). While they might create a general overview they are not able to deal with all the different dimensions of e-health. Subsequently, the fragmented use of classification leads to a biased comparison, non-standardised evaluation and an overall lack of scientific evidence on efficiency and quality (Ossenbaard et al., 2017; Akkersdijk et al., 2016). In practice this leads to situations where decisions on e-health applications are often based on - *“what we think makes sense, what we can afford, what vendors recommend”* - rather than scientific evidence (Ammenwerth, 2015).

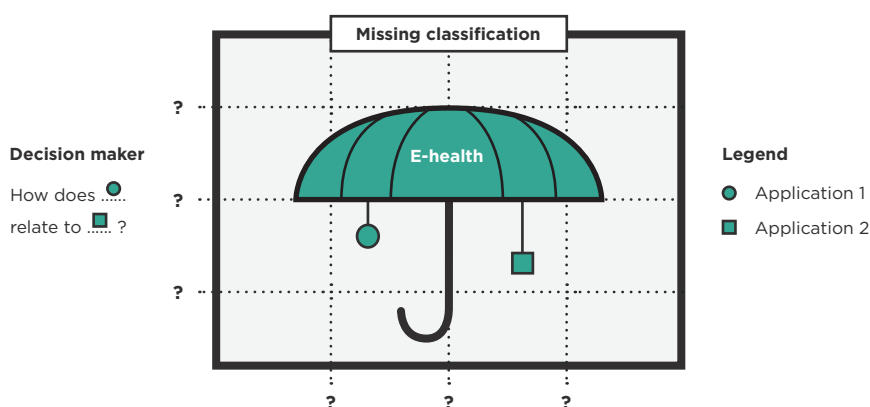


Figure 2.11 Missing classification system for e-health applications

Conclusion: development of e-health applications should reduce uncertainty

It became clear that the notion e-health is an umbrella term without a clearly defined meaning. It has multiple definitions, is multidimensional, and the numerous perspectives and interests of involved actors consequently raise different questions. Moreover, the fragmented use of classification results in decisions on e-health applications that are often not based on scientific evidence. Consequently, without a clear understanding of the e-health application in question, decision makers are less likely to choose that specific e-health application, users will express more change resistance, healthcare purchasers will doubt future affordability, and healthcare providers question its safety. It is this uncertainty among the involved actors that hinders consciously choosing and eventually, reduces the probability of a successful implementation. It stresses the importance for this research to actively reduce ambiguity to increase the chances of success of the curriculum. In this view, reducing uncertainty becomes one of the main goals this research should pursue. The first step towards this goal is put in motion by section 2.2.2 which attempt to uncover the failure and success factors for e-health applications.

2.2.2 Factors that influence the adoption of e-health applications

Ever since e-health became a means of delivering health information and services more efficiently, researchers, companies, and governments worldwide have developed strategies to discuss its potential and to measure its distinct effects on healthcare delivery. Currently, it remains a work in progress since there is still a broadly varying success in the implementation of e-health applications into health practice. It appears that e-health

applications cannot be properly coupled to the healthcare system. They often face multiple obstacles, and as soon as initial funding stops, few of them achieve a sustainable and structural implementation (RVS, 2017; Van Limburg et al., 2011). These obstacles emphasise the need to understand factors that influence implementation to be able to address those factors in chapter four and five. Similarly, as seen from a design perspective, it is not only important to highlight obstacles, but also to identify concepts that have been mentioned to be successful in the past. Building this research upon successful concepts that can address or bypass a failure factor, provides a solid foundation for further analysis and allows application of information that is already substantiated. Briefly put, this section will elaborate the importance of focusing on fundamental causes. Hereafter, a founded list of failure factors and successful concepts was assembled by following four successive steps (Figure 2.12). Eventually, the founded list, and output of the process steps, served as input for chapter three where a conceptual framework has been constructed.

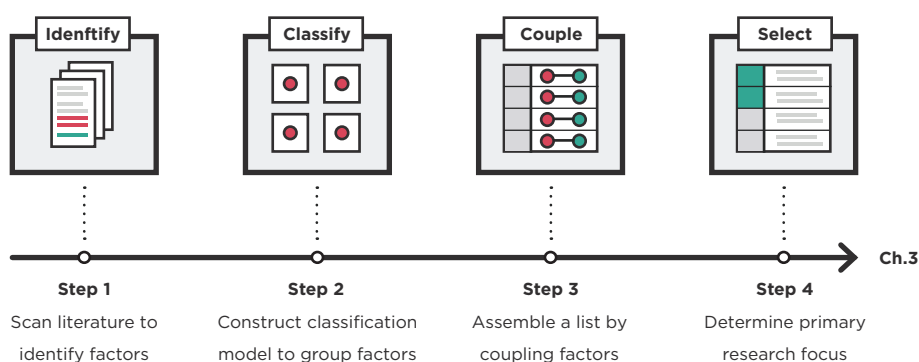


Fig 2.12: The followed process to determine a founded list of concepts

Strategic mindset: focus on fundamental causes

Think of an e-health application as a diagnose for a disease. When no or an incorrect diagnose is made, the wrong treatment will be prescribed. While it might suppress the existent symptoms, the underlying disease will still be present. Likewise, if an e-health application focuses too strongly on solving symptoms rather than the fundamental causes of a problem, the solution could be desirable at first sight, but might never achieve a sustainable implementation in the future since the underlying problems are still present. In general, all problems have a path of influence running from noticeable symptoms to concealed root causes. As a problem solver, the closer one gets to the root causes, the better the overall solution will be (Thwink, 2017). In perspective of this research, it is essential to uncover and differentiate between fundamental causes that have a high impact on the adoption of e-health applications and consequently, symptoms that have little impact. By deliberately targeting the research activities to solve factors that have a large impact, the assumption is that the design of the curriculum will better meet the conditions for a sustainable implementation.

Step 1: Research and identify factors

Based on an extensive literature study, including a review study by Ross et al. (2016) and a recent advisory letter of the RVS (2017), failure factors and successful concepts for e-health were identified. While it has been attempted to consider a wide scope, it is also important to acknowledge that several failure factors are inherently a consequence of the context where an e-health application is applied. For example, e-health applications used in the United Kingdom are logically influenced by other contextual factors than those used in the Netherlands. In this view, 'foreign' literature that described system barriers might be less useful since it assumes a different environment than this research project has adopted. Therefore, the emphasis of the literature study was mainly concentrated on literature that mentioned the Dutch healthcare system as context. A complete overview of the results of the literature study is provided by appendix E.

Step 2: Construct classification model to group factors

Where the introduction section elaborated the importance of focusing on fundamental causes, this section aims to make this mindset tangible by classifying the uncovered factors into a logical division. In this research, a classification model is constructed based on the amount of impact a failure factor has on the adoption of an e-health application. Essentially, the model consists of four classes which each represent a different set of problems and subsequently, are ranked from large to little impact based on a system thinking perspective. Starting with the highest impact, the systemic class represents problems that arise from the specific structure of the Dutch healthcare system. A step lower is the development class, which embodies problems that stem from the various considerations that are made throughout the design phase of an e-health application. Next, the organisational class represents problems that are determined by the distinctive characteristics of an individual organisation. Lastly, the lowest impact is embodied by the individual class, where its problems mostly arise from individual characteristics. Below the four classes are further explained where the letter stands for the amount of impact the class has on the adoption of e-health applications (H = High, M = Medium, L = Low).

H

Systemic: Problems that are systemic are affecting most of or a whole system rather than only a small part of it (Thwink, 2017). Usually, these problems arise from the distinct mechanisms and structure of a system. Likewise, different systems will generate other distinctive problems. In this view, every organisation or individual that is developing, supplying, implementing, or using an e-health application are subject to the same problems produced by the larger healthcare system. Since the Dutch healthcare system outlines the context of this research project, the goal becomes to find the systemic problems that arise from this particular system. While systemic problems have the most influence on the adoption of e-health applications, they are difficult to overcome since a problem solver is only capable of applying a limited amount of force onto the larger system. Solutions that are systemic change the fundamental way a system works through changing its structure. Thus, it will be complicated to influence these problems as it will be impossible to change, for example, the financial payment structure of the healthcare system. However, although they can't be influenced directly, by making them visible, it becomes possible to intentionally respond to or even move around them.

- H Development:** Problems that are classified into the development class stem from considerations made throughout the design phase of an e-health application. As with systemic problems, development problems also have a relatively large impact on the adoption. This is because all the fundamental characteristics (e.g. technology, users, interface) of an e-health application are defined in this phase. Ideally, the design phase should acknowledge the complex relationships between involved actors, technology, human characteristics, and the socioeconomic environment. Disregarding those factors during development will eventually result in technology that has a lower adoption in healthcare practice. However, compared to the other three classes, the problem solver has a high influence on problems in the development class. For example, by adopting the right approach during development, it will be possible to address and overcome the uncovered barriers through applying proper design activities.
- M Organisational:** The problems in the organisational class often arise from the mechanisms and structure of an individual organisation. In simpler words, what might be a problem with the adoption of an e-health application in one organisation might not be the case for another. These inner differences often result in a varying compatibility between the e-health applications and the existing systems and workflow of the organisation. Due to these inner differences, organisational problems have little influence on the adoption of e-health applications and are therefore regarded as symptoms. For example, measures aimed to address a problem in healthcare organisation A must be carried out again in healthcare organisation B or even have a conflicting effect.
- L Individual:** Problems that are classified in the individual class arise from personal characteristics such as the knowledge, beliefs, and skill level. As with the organisational class, the problems vary between persons and one might exercise a positive attitude towards e-health applications whereas another might have negative perceptions. Moreover, as they are often the end-users of an e-health application in practice, they are often not the ones that decide to use it or pay for the purchase of an e-health application. In this sense, individuals have the lowest influence on the adoption of e-health applications.

Step 3: Assemble a list by coupling factors

After that the failure factors were classified into four distinct classes and ranked based on the amount of impact they have on the adoption of an e-health application, the sequential step is to couple successful concepts to the uncovered failure factors. In this research, a successful concept is broadly interpreted and understood as a framework, approach, method or tool that is mentioned in literature and regarded capable of overcoming or addressing a failure factor. Eventually, the process resulted in a founded list of failure factors coupled to successful concepts and provides a solid foundation for further analysis (Appendix F). It is important to note that the compiled list does not provide a complete overview of the whole e-health domain. The main aim of the list was to specifically emphasise the Dutch healthcare system and might therefore be less useful in another context. However, it is assumed that the list represents a sufficient scope of factors that influence the adoption of e-health applications.

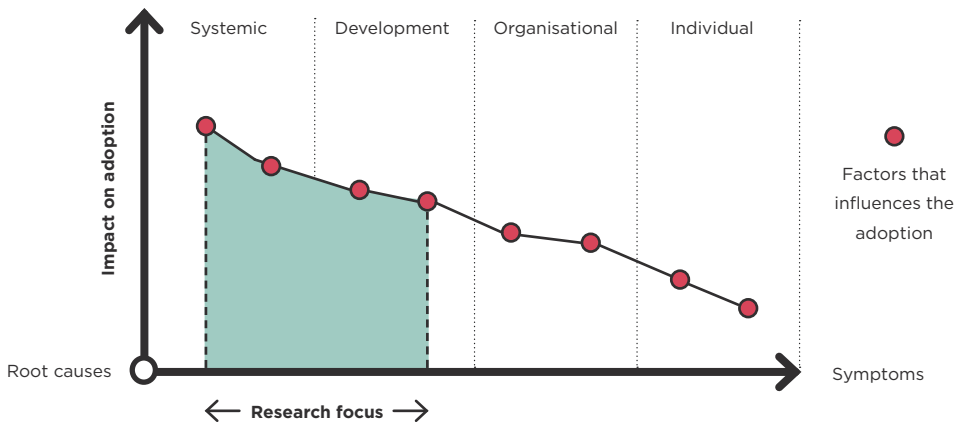


Figure 2.13 Primary research focus

Step 4: Determine the research focus

Now that the list is composed, the final step is to determine on which specific concepts this research should focus (Figure 2.13). It is apparent that it will not be valuable nor feasible to apply all the identified concepts in this research without a clear rationale driving that application. By intentionally leveraging the research activities at addressing the factors that have a high impact on the adoption of e-health applications, it is assumed that the design of the curriculum will better meet the conditions for a successful implementation. Since the systemic and development class have the highest impact on the adoption, the concepts classified in those groups logically become the focus of this research project.

2.2.3 Conclusion: leverage high impact concepts

All problems have a path of influence running from symptoms to root causes. As problem solver, the closer one gets to the root causes, the better the overall solution will be. Therefore, this section adopted a mindset that focused on uncovering and differentiating between fundamental causes that have a high impact on the adoption of e-health applications and consequently, symptoms that have less or little impact. This mindset was made tangible by adopting a four-step process where failure factors and successful concepts for e-health were identified, a classification model was constructed to classify and couple them to successful concepts. Eventually, the concepts in the systemic and development class became the focus of this research since they have the highest impact on the adoption of e-health applications. However, as this decision provides some direction and narrows the scope of this research, it still doesn't elaborate how the concepts from both classes should be applied in this specific research project. Essentially, there is a need for an approach that can connect and organise the concepts into one coherent whole while simultaneously considering the context of this research project. Chapter three will address this concern through constructing a conceptual framework which will provide further guidance throughout the remainder of this research.

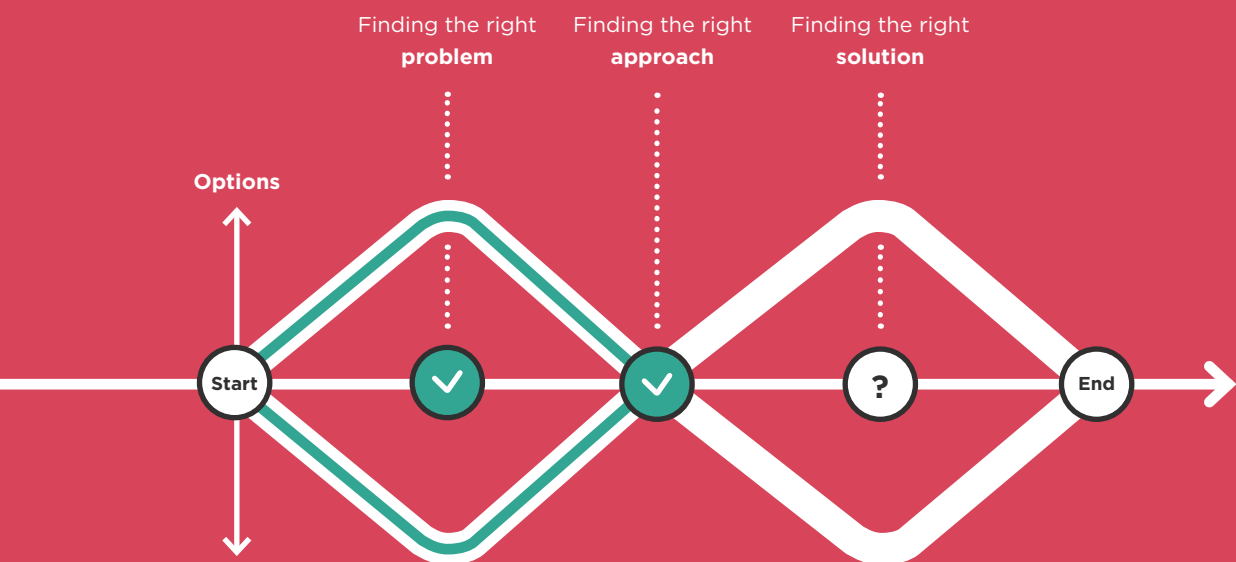
Chapter

03

Conceptual framework

Developing a conceptual framework that can provide direction and govern the further application of the selected principles for e-health development

Time



So far, the Dutch healthcare system was broken down into key concepts to gain a better understanding of its functioning. The generic term e-health was elaborated, and a fundamental goal of this research became reducing uncertainty among the involved actors. A funded list was compiled with concepts that are considered to be capable of overcoming one or more of the identified problems. While this list already provides some direction, it doesn't elaborate how the concepts from both the systemic as well as the development class should be applied in this research. Essentially, there is a need for an approach that can connect and organise the concepts into one coherent structure while simultaneously considering the context of this research project. Hence, this chapter aims to develop a conceptual framework that can provide guidance on the one hand while facilitating the organisation and selection of the concepts on the other. In this way, the conceptual framework becomes the foundation for the application of the selected concepts in chapter four, five and six.

Chapter two illustrated that the Dutch healthcare system highly influences e-health applications. In fact, it is assumed to be a dynamic system where underlying demographic trends result in continuous changes to laws, regulations and financial budgets. Consequently, these modifications influence the system and all the elements inside in a certain way. The various interdependencies, the numerous perspectives, interests of involved actors, and the multidimensionality of e-health applications implies the need for an integrated approach. For instance, while one might develop a technologically feasible and desirable e-health application, it might not be financially attractive for some influential stakeholders. By disregarding certain relations and patterns that occur in the larger system, it will generally lead to less successful products. In the case of e-health development, adopting a single perspective will likely be inadequate. By only assuming a product perspective, it will be difficult to discover the impact of an e-health application on the larger system it is embedded in. Likewise, by only embracing a systemic worldview, it will inherently lack critical feedback from the intended end users. Thus, the crux of this research project is the need for an adequate framework that can simultaneously consider different perspectives. By incorporating more than one perspective into the development process, it is assumed that this research can create a more holistic understanding of end-users and stakeholders needs while generating a more profound insight in which places the curriculum could be accurately coupled to the larger Dutch healthcare system.

A binocular as metaphor for incorporating two perspectives

The acquired knowledge in chapter two provides detailed insight in the Dutch healthcare system and the e-health domain. However, this information represents a high level of abstraction and doesn't elaborate how this knowledge should be applied. In the remainder of this research, there is a need to explore the lower levels of the map to connect and organise this knowledge into a coherent whole. Briefly put, a binocular can symbolise this exploration process through inspecting the Dutch healthcare system more closely (Figure 3.1). Essentially, each side of the binocular represents one perspective. The left lens embodies the product view and zooms in all the way to the specific interactions that take place between the end-users and the curriculum. While the right lens symbolises the system view and zooms in less far, thus, enabling it to discover the impact the curriculum has on the system it is to be embedded in.

Incorporating two perspectives

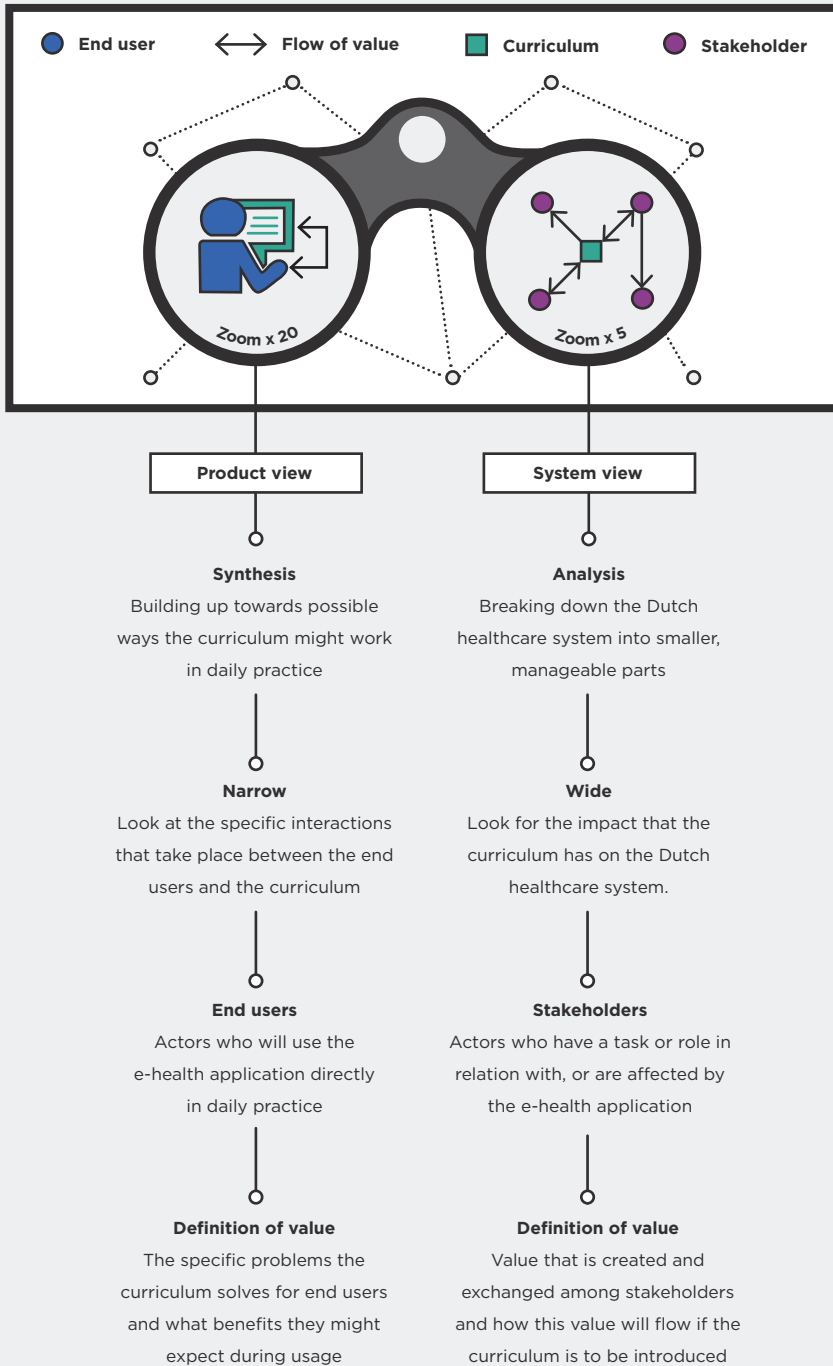


Figure 3.1 Incorporating two different perspectives

3.1 Conceptual framework

A conceptual framework is a written or visual representation that explains the key factors, concepts or variables that will be studied and sequentially depicts the relationships between them (Miles & Huberman, 1994). In simpler words, a conceptual framework provides the structure and contents for further study. Chapter two concluded that this research should leverage concepts which have a high impact on the adoption of e-health applications. However, in the literature those identified concepts often lack a clear explanation as to why, how and in which order they should be applied during the development of e-health applications. Therefore, the main aim of the conceptual framework is to organise, select, describe and connect the concepts into one coherent structure. In doing so, the framework can govern the application of those concepts in the upcoming chapters and facilitate the intended translation of the curriculum into an e-health application.

The validity of the conceptual framework

The proposed conceptual framework in this section is constructed from the perspective of e-health development. In addition, it assumes a unique situation where there was already an existing product as well as a technical infrastructure present. Alongside the personal experiences of the researcher, this specific situation has been influential in determining the structure and final selection of the concepts presented inside the framework. However, it is believed that this will not limit its use for other developers of e-health applications. The conceptual framework is built upon an extensive literature study and revolves around value creation. Due to its structure, concepts might be easily added or supplemented with other ones to tailor it to the specific setting of another e-health application development project or in the case when new insights around e-health development arise in the future.

3.1.1 Underlying rationale conceptual framework

The starting point for the construction of the conceptual framework was the founded list with multiple concepts that were classified into the systemic and development class. By analysing those concepts more closely, a common denominator was extracted. Most of the literature sources argue that activities revolving e-health development should uncover and assess the added value of an e-health application. Moreover, it became evident that the concepts should be capable of creating value for both the involved end users as well as the stakeholders. By making the value of an e-health application insightful and transparent for the affected actors, it is expected that this will reduce uncertainty for them. However, what is meant with the term value in the context of this research project, and what is its relation to the terms end users and stakeholders? Without further clarification, the relations between those terms will be difficult to comprehend. Therefore, this section will elaborate and map the relationships between end users, stakeholders, and value and illustrate that the term value is bilateral depending on whether someone is regarded as end user or stakeholder. As a result, the uncovered structure is mapped in figure 3.2 which visualises the underlying rationale of the conceptual framework. The underlying rationale of the framework is built upon the need for incorporating two perspectives, and proposes that e-health development should create value for end users and stakeholders through applying high impact concepts to reduce uncertainty among them, which in turn, could increase the adoption in practice.

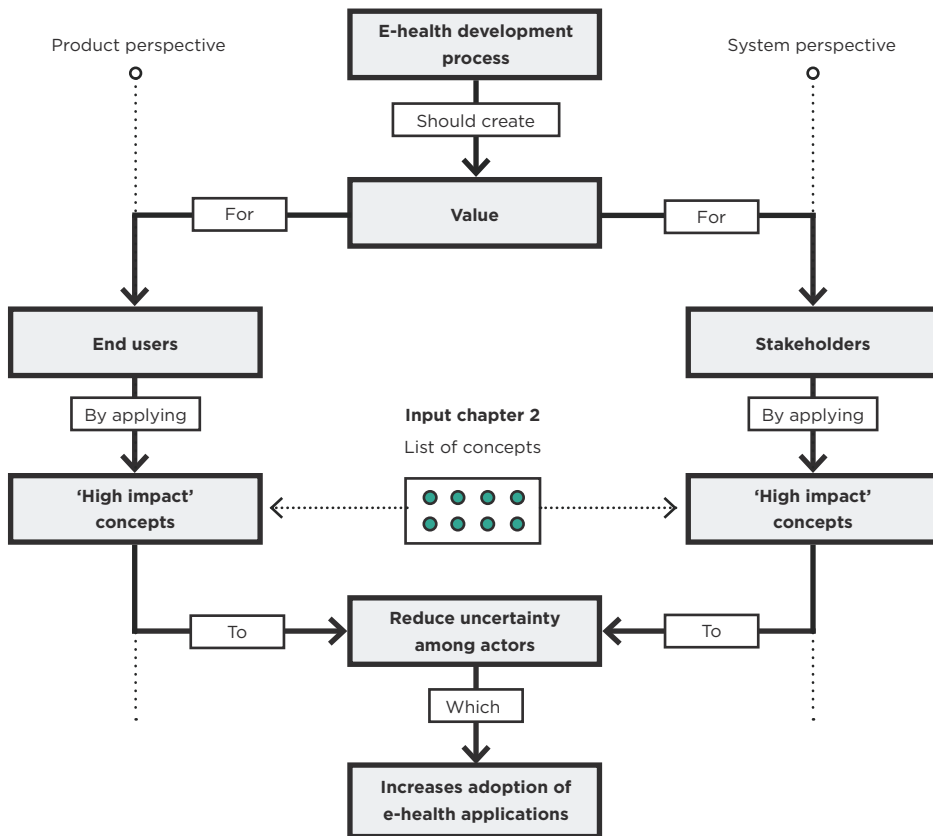


Figure 3.2 Underlying rationale of the conceptual framework

End users and stakeholders

In an idealistic scenario, where a company develops a new e-health application for just one individual, this person will then be the only end user and consumer, and the only stakeholder and customer of the product. It will fulfil all the possible roles, from decision maker and buyer to the ultimate user. In this case, only the needs and priorities of this individual will be of importance during the development process. However, the real situation is more complicated due to the specific way the healthcare system functions. As already illustrated in section 2.2.1, e-health applications often have a complex network of actors, where each involved person or organisation will have its role and set of priorities that are not always apparent. By disregarding (some of) these priorities during development, it is assumed that the product will end up less successful. Uncovering and incorporating those multiple viewpoints might help enable more informed decisions during both the development as well as in the implementation phase. So, to deal with the different priorities of the involved actors, this research distinguishes between the terms end user, stakeholder and their marketing synonyms consumer and customer. This distinction is made because the primary interests of end users are essentially of a different order than those of stakeholders. This statement can be explained by comparing

both definitions. In general, end users and consumers are the persons who are the final users of an e-health applications where stakeholders and customers are all the persons and organisations that have a task or role in relation with or are affected in the broadest sense by the e-health application (Van Velzen et al., 2013). Due to strong regulations and the payment structure of healthcare, end users and consumers are in most scenario's, not the ones that execute the purchase or have an influential say in choosing an e-health application. So, while the end users are concerned with the daily interaction of the e-health application, stakeholders are either invested in the decision-making process of buying or in a certain way affected by the e-health application. In other words, end users will need other types of information regarding the e-health application than stakeholders to determine if it will be aligned to their personal viewpoint. This research assumes that this information can be made insightful through uncovering and describing the added value the curriculum is expected to have for both end users and its stakeholders.

Pursuing value

Generally, the term value is related to the importance, worth, or usefulness of something (Oxford Dictionaries, 2017). In its core, every business begins with value creation and attempts to deliver value in such a way that it will generate profit after cost. In a broad sense, a set of related work activities produce value, such as the design of a business website. In a similar way, it is assumed that the development process of e-health applications will generate value. Essentially, each activity in the development process will add a certain amount of value to the final solution. However, the question arises which types of value creation this research should pursue? Based on the perspective one embraces, the value is understood in two distinct ways in this research. From a product and end user point of view, the value is essentially about what specific problems the curriculum can solve for them and what benefits they might expect during usage. Whereas from a systemic and stakeholder viewpoint, the value is about analysing which type of value is created and exchanged among stakeholders in the Dutch healthcare system and secondly, how this value will flow if a new concept, and in this case, the curriculum is to be introduced in this system. Put simply, the definition of value is dependent on whether someone is classified as an end user or as a stakeholder. Section 3.1.2 will explain how value is used as means to classify the different concepts.

3.1.2 Organising concepts into three maps

The previous section stated that the value of an e-health application is understood differently by end users than by stakeholders. In this way, the value becomes a means to select and classify the uncovered concepts. In the conceptual framework, concepts that can create value for end users will be organised in an end user value map where concepts that can create value for stakeholders can be structured in a stakeholder value map. The results generated in both maps will come together in the solution map. In this research, each map represents a connected set of concepts, where for each concept an explanation is provided as to why they are selected, how they might be applied, and what the results of that application will be. Together, it is expected that the application of the three maps will provide the required holistic insights of what is needed to translate the curriculum into an e-health application. Figure 3.3 provides an complete overview of all the selected concepts and depicts the relations between them.

Conceptual framework

For the development of e-health applications

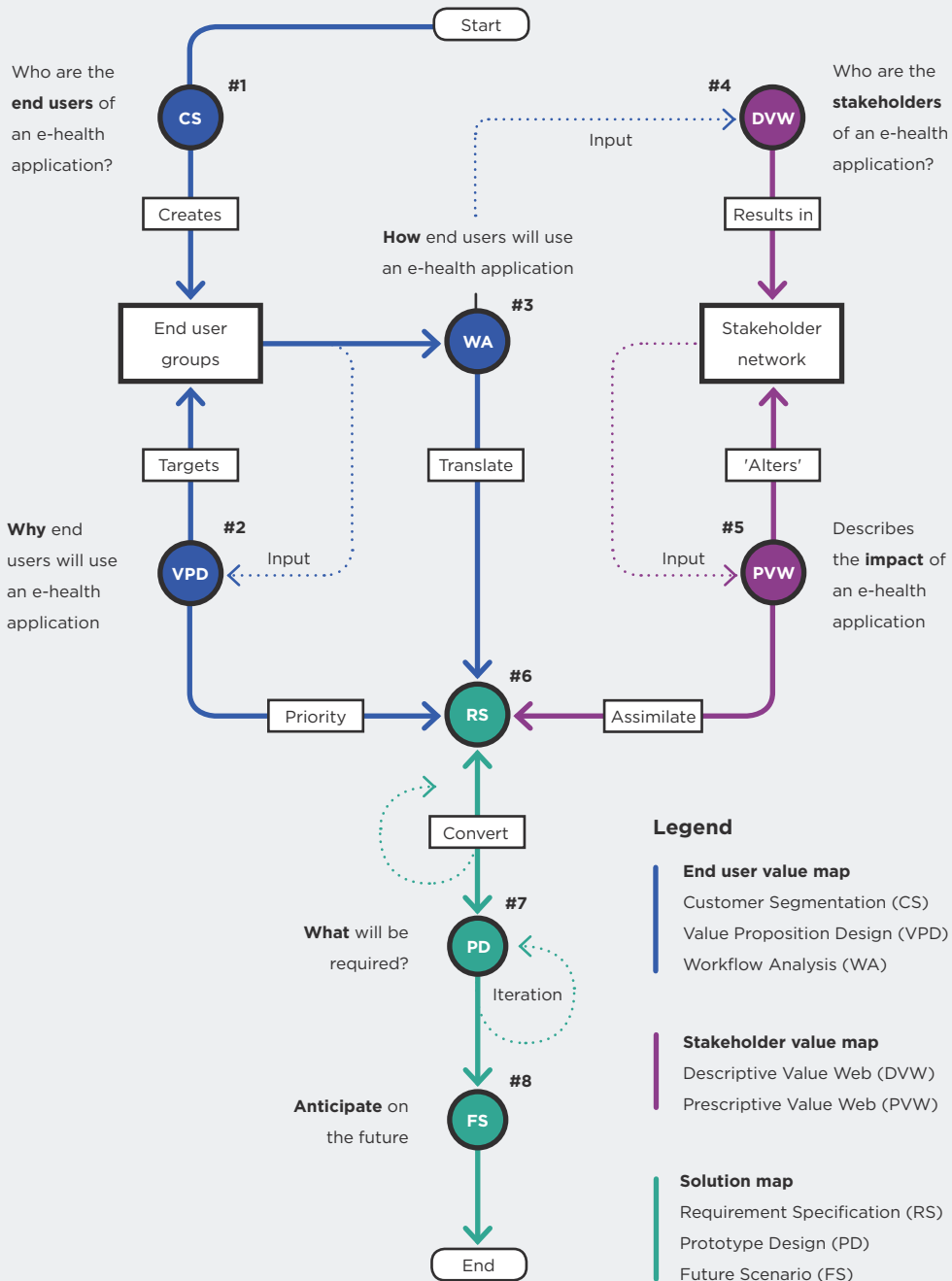


Figure 3.3 Conceptual framework for the development of e-health applications

End user value map

The end user value map consists of concepts that can help uncover who the end users are, define what specific problems the curriculum can solve for them, and what benefits they might expect during usage. Chapter four describes the application of the concepts.



Customer segmentation

Why

Without any prior knowledge of how a target market is segmented, it will be challenging to develop and market a product efficiently. In general, the development of a new product should be built on a thorough understanding of the consumers it attempts to serve since they are not all the same. At its core, customer segmentation (Figure 3.4) is the process of dividing a population into distinct groups (Hague & Harrison, 2017). This division is often based on a set of characteristics and ranges from publicly available geographic or demographic data to some more demanding approaches which assume needs or economic value. In this research, the goal of applying customer segmentation is to define on which distinct end user groups within the disability sector the curriculum should focus. Based on these insights, the different end user groups can then be targeted efficiently by a value proposition which states why someone should buy or use a service (Osterwalder et al., 2014). In this way, customer segmentation will scope the further research activities and ensures that the development process incorporates the motivations of the right end user groups.

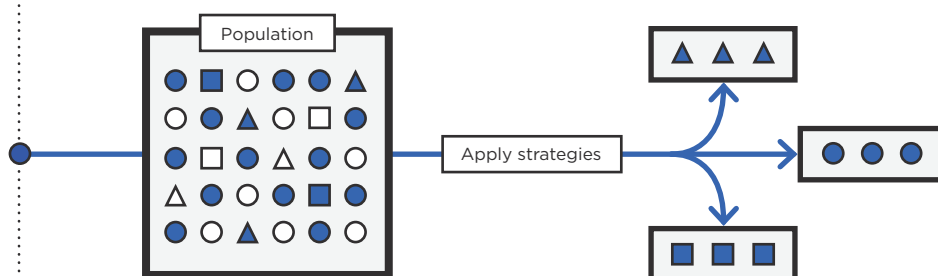


Figure 3.4 Customer segmentation

How

By applying an approach or strategy, distinct customer segments can be determined. In the literature, multiple procedures are mentioned that could be applied, all with their specific opportunities and disadvantages (Hague & Harrison, 2017). However, a selection is often dependent on the market a company operates in or the complexity of a product or service. This research will firstly analyse these different approaches and then select one or more strategies that will fit within the context of this research project.

What

Customer segmentation activities result in a target market that is divided into one or more distinct end user groups. Moreover, these groups will serve as input for both the value proposition design as well as the workflow analysis.



Value Proposition Design

Why

Where customer segmentation established the different end user groups, the next step is to target them with a distinct offering. Necessarily, each defined group requires a different offering. This offering, also often referred to as a value proposition, should be noticeably different for each of the end user groups. Otherwise, a segmentation would not have been necessary in the first place. Simply put, a value proposition is a clear statement which explains, for each group, how a product or services solves problems, improves a situation, or which benefits it might have (Osterwalder et al., 2014). By applying value proposition design activities, it becomes conceivable to make the added value of the curriculum explicit to the different end users in an understandable language. In doing so, value drivers are uncovered and listed in order of their importance which, in turn, can ground choices of what features to develop (Van Gemert-Pijnen et al., 2011) and, if applicable, in which specific order.

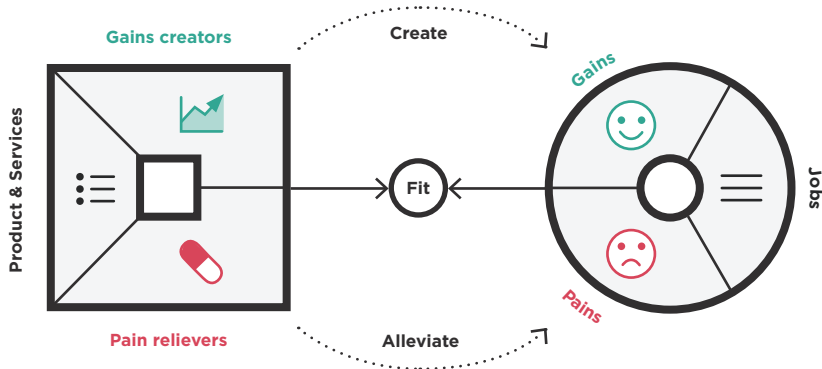


Figure 3.5 Value Proposition Design

How

The most promoted and convenient framework for designing value propositions is the one described by Osterwalder et al. (2014). Thus, this research project will adopt this approach. Briefly put, this framework (Figure 3.5) proposes a three-step process which results in a set of value propositions for the different end user groups. First, the customer profile describes the identified customer segments in a structured and detailed manner. Next, the value map elaborates the benefits customers can expect from a product. Finally, a hypothetical problem-solution fit is achieved when the customer profile meets the value map. Overall, fit means that you know at least who your customer is, why your customers need your product, that your solution can solve the problem effectively, and finally, that there is evidence to back up those claims (Osterwalder et al., 2014).

What

The value proposition design activities result in the first tangible and validated evidence that there exist multiple problems for the different end user groups. A list of prioritised value propositions is generated which specify how the curriculum can address those problems. In addition, the priority score serves as input for the requirement specification.



Workflow Analysis

Why

Where value proposition design provides the rationale why the different end user groups should use the curriculum, it does not provide how they will use the curriculum and what sort of information they need during that use. This information can be made insightful by incorporating workflow analysis (Figure 3.6) in the development process. In this research, the goal of workflow analysis will be twofold. On the one hand, it is to understand which processes are executed by the end users and what information objects they produce or need during the use of the curriculum. Based on this understanding, it becomes possible to derive the desired functionalities for the curriculum. On the other hand, it might help in identifying in which way the e-health application might disrupt or alters the existing workflows of the different users in a current state, without the curriculum (Ross et al., 2016). It is important to make this insightful since when a fit is perceived between the e-health application and an existing workflow it might facilitate use, and thus, improve implementation.

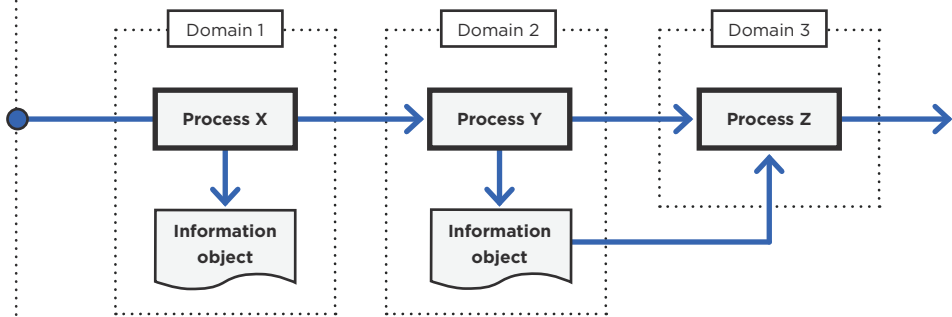


Figure 3.6 Workflow Analysis

How

The workflow analysis will be primarily supported by using the available documentation of the Quality of Life Centre. This documentation already describes, to some extent, which processes are executed during the use of the curriculum, only not in such a way that these can be directly utilised in this research. Therefore, this material will firstly be analysed, interpreted and translated in convenient process descriptions by leveraging a reference domain model care (Nictiz, 2017). Briefly put, this instrument consists of a set of generic processes and information objects divided into domains that are specific for the care sector. Since the information inside this method is generic, it is generally applicable for all care institutions in the Netherlands. In this research, this instrument is (partly) used to design the information architecture that is required for the curriculum to function.

What

The result of the workflow analysis will be an overview of processes and information objects that embody how the curriculum is used by the end users. These information objects describe what type of information end users need during use and serve as input for the requirements specification.

Stakeholder value map

The stakeholder value map consists of concepts that can help uncover who the stakeholders are, define how value is created by stakeholders in a current state, and display what value the curriculum adds to stakeholders in a future state. Chapter five describes the application of the concepts in the stakeholder value map.



Descriptive Value Web

Why

Before it is possible to explain what impact the curriculum will have on stakeholders, it is necessary to determine who the stakeholders are and what type of relationships they have with each other. Naturally, each e-health application will have its specific context. Inside this setting, there will be different stakeholders involved with all their own interests. By mapping all the stakeholders in this environment, it will be possible to understand the relationships between them. In this research, the goal of the descriptive value web is to visualise the existing set of relationships among stakeholders in the Dutch healthcare system and subsequently uncover how value is exchanged and flows through this particular system (Kumar, 2013). This information facilitates the construction of a visual map which specifies the involved stakeholders, their roles, and interest in a current state, without the curriculum. Based on this insight, it will be possible to uncover places inside the network where solution elements might lead to significant, enduring improvements (Senge, 1994). In this way, the descriptive value web serves (Figure 3.7) as input for the construction of a prescriptive value web, which displays at which specific places in the stakeholder network the curriculum might add value in a possible future state.

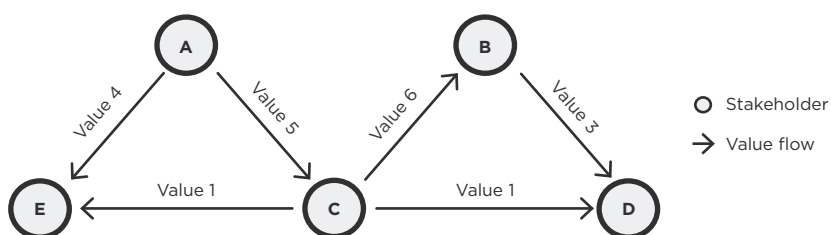


Figure 3.7 Descriptive Value Web

How

Fundamentally, the first step towards the construction of a stakeholder network is determining a point of reference. Based on this reference point, all the relevant stakeholders can be listed and presented as nodes that are connected by links with a corresponding description of what type of value is flowing from node to node (Kumar, 2013). In this research, the actor-network theory was identified as method that can substantiate the design of a descriptive value web since it makes the analysis of stakeholders independent of organisational structure and thus, more convenient. This statement is further elaborated in chapter five.

What

The result will be a visualised network diagram that displays a point of reference, the relevant stakeholders and the identified value types that are exchanged between them.

PVW

Prescriptive Value Web

Why

Where the descriptive value web analysed the different stakeholders and revealed the different value flows among them, the prescriptive value web (Figure 3.8) shows how value will flow if new nodes or links are introduced or existing nodes or links are modified (Kumar, 2013). In other words, it illustrates how relationships in the descriptive value web are introduced or altered when the curriculum is to be implemented. In doing so, the added value of the curriculum can be clarified to the different stakeholders which, in turn, could help reduce uncertainty among them. Besides, it helps in understanding which stakeholders might play an important role in the development process but also which ones might come to play a role in the implementation of the curriculum.

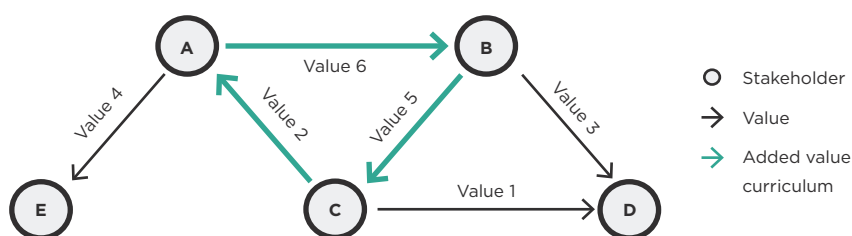


Figure 3.8 Prescriptive Value Web

How

At this point, the value proposition design and workflow analysis already discovered why and how end users should use the curriculum. The information that both concepts generated is then used to consider and determine the range of values that will be exchanged, or changes that occur as the result of the introduction of the curriculum. Eventually, these values and changes will be visualised in a prescriptive value web.

What

A visualised network diagram that displays for which stakeholders the curriculum will add value.

Solution map

Where the end user and stakeholder value map both have addressed one viewpoint, the solution map includes both perceptions, and constructs a solution based on these different insights. Chapter six describes the application of concepts in the solution map.

RS

Requirement Specification

Why

Requirements form the foundation for the development of any e-health application. In general, they explain what a product should do as well as what it is not expected to do, what content it should display, and what user experience it should provide (Van Velzen et al., 2013). Also in the design of e-health applications, the development of requirements is a crucial part. Correctly specifying requirements and verifying them with end users and stakeholders

	<p>could result in an improved overall usability and prevent the inclusion of superficial features and thus save cost and time during development (Van Velzen et al., 2013). In this research, the goal of requirement specification is to develop a minimal set of requirements that reflect the intended purpose and underlying vision of the curriculum. In other words, the requirements should at least elaborate what will be necessary for the curriculum to function in practice. At this point in the development process, it is essential to assume a minimal set of requirements. Primarily, this minimal set is adopted because the value that the curriculum is expected to add for end-users and stakeholders are, in fact, still untested hypotheses which need to be validated. Hence, the minimum set of requirements will serve as input for the design of high fidelity mock-ups, which makes it possible to measure the effects, evaluate the requirements with actual end users, and iterate the design based on the provided feedback. In this way, the approach will minimise the risk of failure during the development since it validates requirements before the actual technical realisation.</p>
How	<p>Usually, requirements are collected by different methods such as interviews, focus groups or observations. These methods help the researcher to uncover what the e-health application needs to do and how it should work in practice. However, in the case of this research, these techniques were not necessary since the end user and stakeholder value map will already have created a clear and thorough understanding of the product that needs to be developed. Based on the understanding of this mapped context, a list of requirements was derived where each requirement will be documented in such a way that it enables others to understand what needs to be made and why.</p>
What	<p>A list of requirements derived from the mapped context, where each requirement includes a user story, a brief rationale, a list of value drivers, information objects, and if applicable, a priority score.</p>



Prototype Design

Why	<p>Where the requirements specification defined and incorporated information about which requirements are needed and why they are needed, requirements alone do not demonstrate how the curriculum will look and function in practice. A prototype is the first tangible full scale, and often, functional representation of a new product or service (National Instruments, 2014). Overall, building prototypes has multiple advantages in a development process such as the possibility to fail early and inexpensively, evaluate and gather more accurate requirements, resolve conflicts between designers and developers, uncover the technical challenges of a new design, and attract financing more easily. In this research, prototyping serves two important goals. On the one hand, it is to translate the functional requirements into a (partly) functional prototype that fits with the uncovered values of the end users. This prototype should at least visualise the core functionalities of the curriculum. On the other hand prototyping is used to validate the hypothesis that was stated in the research motive, which expressed that both the platform and curriculum are expected to</p>
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have various cross-over functionalities. By translating the information collected in the previous concepts into high-fidelity mock-ups, enough insight is gained to validate this hypothesis. This visual representation can facilitate the discussion between the Quality of Life Centre and Jouw Omgeving and provide guidance for the technical realisation.

How

In general, prototypes can be made in different shapes from low-fidelity mock-ups, wireframes, storyboards and paper prototypes to high fidelity prototypes that come close to a desired product. In this research, prototyping starts with sketching low fidelity wireframes which will then be discussed and validated by both the Quality of Life Centre and Jouw Omgeving. Hereafter, high-fidelity mock-ups will be made by leveraging existing components of the platform and the design system of Jouw Omgeving. In doing so, the design process doesn't have to start from scratch and a prototype can be created more quickly. Besides, it will be directly in the existing visual style of Jouw Omgeving.

What

The result of applying prototype design will be static screens that can convey the core functionalities of the curriculum to both end users and stakeholders. The results could serve as input for the design of a functional prototype.



Future scenario

Why

Chapter two described that the Dutch healthcare system is dynamic and highly susceptible to change where demographic trends, financial setbacks, or a changing composition of the political landscape might cause the introduction of new laws and regulations. Up until now, this research only reflects a mental model of past and present developments in the Dutch healthcare landscape. However, it is an almost certainty that this landscape will continue to change in the future and that these changes will influence most of the actors inside. But without making these possible changes explicit through scenario's, it will be difficult to make strategic decisions in the present. Based on knowledge gained in the past and present, scenarios supply a hypothetical construct of possible futures. They help us articulate and explore alternative views of how long-term factors and other external and internal forces might shape the Dutch healthcare system in the future (Kosow & Gaßner, 2008). In turn, this understanding influences the way in which someone attempts to deal with the future from a present position. In the case of this research, a scenario is constructed to consider how the curriculum and platform of Jouw Omgeving will fit in a possible future healthcare system. Consecutively, advice can be provided to Jouw Omgeving and the Quality of Life Centre that might facilitate strategic discussions about development choices for both the curriculum as well as the platform of Jouw Omgeving.

How

There are numerous approaches and methods to describe a scenario. In general, there are three distinct interpretations a researcher might adopt during the construction of a scenario (Kosow & Gaßner, 2008). The first view is that the future is 'predictable' where events in the future can in theory be calculated from knowledge of the present and past. The second view is that

- the future is 'evolutive' where events in the future cannot be predicted by knowledge from the present and past and assumes that developments follow a chaotic, uncontrolled, and random path. The third view assumes a future that is 'malleable' which implicates that the course of the future events is not predictable but neither will the development be fully chaotic. This research will describe a future scenario based on the malleable perspective.
- What** A scenario that provides multi-angle viewpoints on the future of the Dutch healthcare system and subsequently, elaborates how the curriculum and platform of Jouw Omgeving might fit into this system.

3.1.3 Conclusion

This chapter constructed a conceptual framework that organised, selected, described and connected the concepts into one coherent structure. In this way, it could govern the application of those concepts in the following chapters. The underlying rationale of the framework was built upon the need for incorporating two perspectives, and proposed that e-health development should create value for end users and stakeholders through applying high impact concepts to reduce uncertainty among them, which in turn, could increase the adoption in practice. It became clear that value could be used as means of classification, since the term is understood differently by end users than by stakeholders. Concepts that can create value for end users where organised in an 'end user value map' where concepts that can create value for stakeholders where structured in a 'stakeholder value map'. In addition, a 'solution map' was constructed which could take both viewpoints and create a holistic understanding of the situation. By applying the different concepts, the following questions will be answered (Figure 3.9):

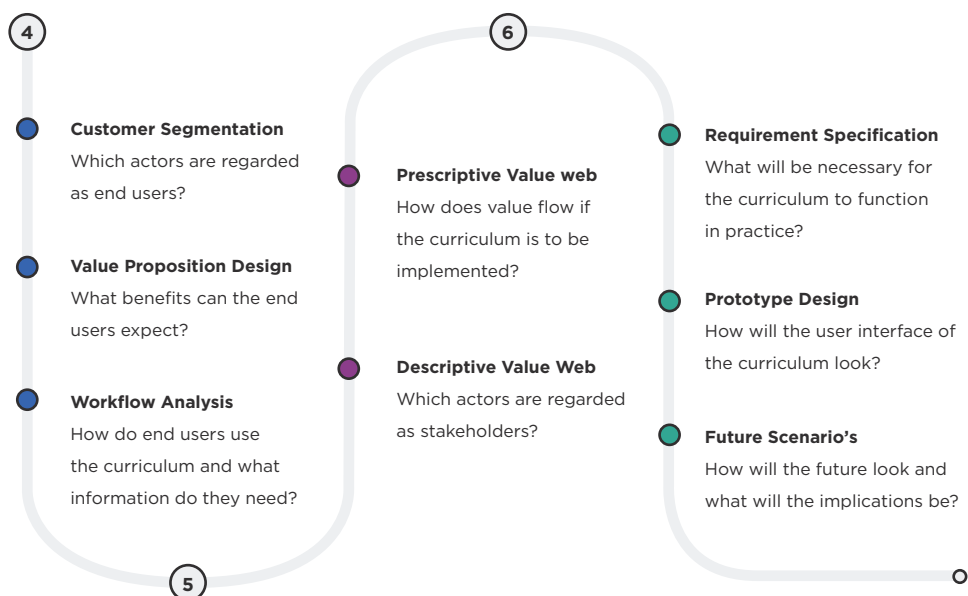


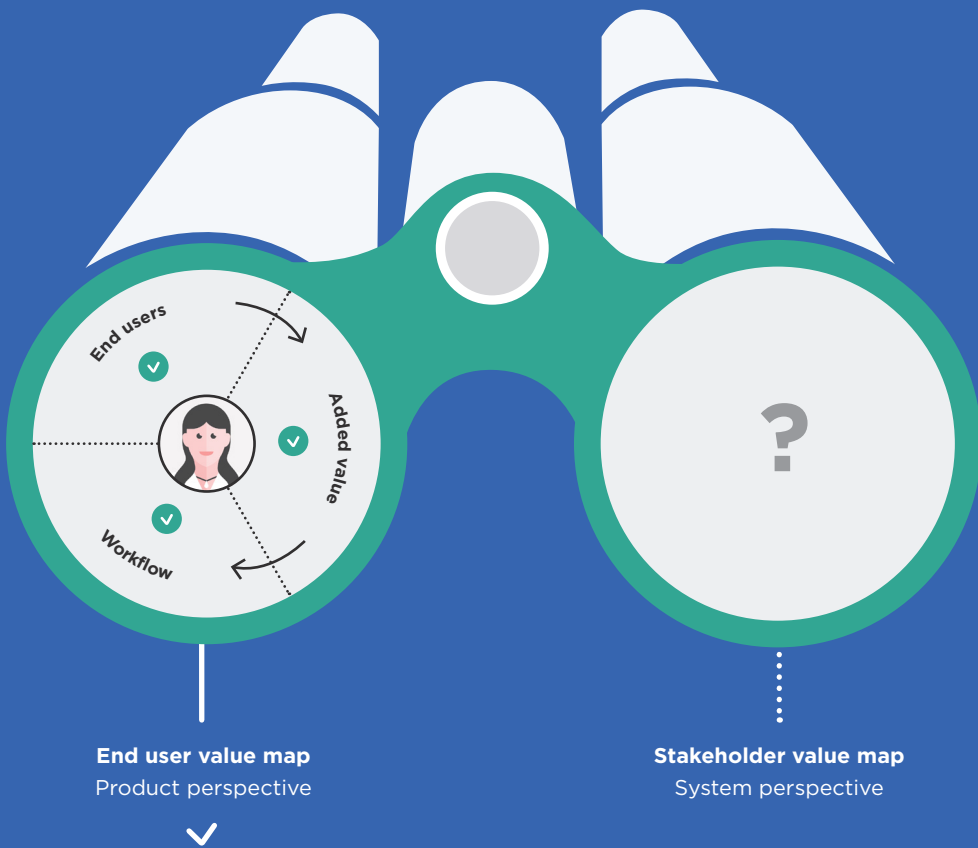
Figure 3.9 Questions that the application of the conceptual framework will answer

Chapter

04

End user value map

Describes who the end users are, what specific problems the curriculum can solve for them, and what benefits they might expect during usage



Chapter four describes the end user value map. This chapter revolves around the application of the first three concepts from the conceptual framework. Firstly, customer segmentation selected an appropriate segmentation strategy and resulted in three distinct end user groups. These three groups served as input for both the value proposition design as well as the workflow analysis. In value proposition design the needs of the end users will be research where in the workflow analysis the end use of the curriculum is uncovered.

4.1 Customer segmentation

It became clear that the development of a new product should be built on a thorough understanding of the customers and end users it attempts to serve since they are not all the same. At its core, customer segmentation is the process of dividing a market or population into distinct groups. The main aim of applying customer segmentation in this section is to define on which distinct end user groups within the disability sector the curriculum should focus.

4.1.1 Which actors are regarded as end users?

As envisioned by the Quality of Life Centre, the curriculum focuses on the care as well as the educational needs of persons with CISON. Without any further context, this sentence might imply that these individuals will directly use the curriculum. In this sense, one might consider them as an end user. However, as elaborated in section 1.4, this will not be possible since they mostly do not possess an active or passive understanding of language, often have a combination of complicated health and behavioural problems, and are 24/7 dependent on their support system. In fact, it is the dedication and attitude of this extensive support system that mainly determines their vitality, well-being, and happiness. In other words, these persons will need meaningful relations with others that can help make their world more understandable and help fulfil the needs they cannot explicitly express themselves. Therefore, persons with CISON inherently shift to a stakeholder role and the receiving end of the curriculum. In the future, it will be the individuals from inside the support system that will utilise the curriculum as intermediary to better answer the complex support questions that arise throughout the life of a person with CISON. In general, this support system consists of a plethora of actors from a wide variety of disciplines that interact with each other within a given environment such as at home, day-care, school, and multiple healthcare providers. However, this results in a wide diversity of professions ranging from behavioural therapists, occupational therapist, doctors, municipal workers and many others. This distribution implies a non-uniform population, which means that concerned professionals have specific motivations for use, different perspectives, skills, cultural backgrounds and therefore, might have contradictory opinions of the intended usage of an e-health application. In order to deal with heterogeneity, one should identify, profile and design for distinctive end user groups (Van Velzen et al., 2013).

Applying segmentation strategies to deal with heterogeneity

At its core, segmentation is the process of dividing a market or population into distinct groups. This division is often based on different strategies and ranges from a geographic, demographic, behavioural, end use to a need-based segmentation where the selection of an approach is context dependent. However, the overarching goal remains the same,

namely recognising differences between groups so that organisations can target their products or services to each cluster more effectively. In this research, the first logical step towards determining a strategy was to analyse if it was possible to derive a classification from the existing characteristics of the curriculum. The previous section already elaborated that the end user population of the curriculum was heterogeneous. From a design perspective, heterogeneity among the different end users increases the complexity of understanding which features an e-health application should offer. In general, the more similar a group, the more convenient it becomes to distinguish between features that are important. An overall established method for dealing with heterogeneity is audience segmentation, which is the process of dividing individuals into uniform groups based on defined criteria. However, it became clear that the identification of audience segments is a very resource intensive process and is, ideally, based on the analysis of a comprehensive set of quantitative data (Slater & Flora, 1991). Conversely, regarding the multiple actors involved in the care and education of a person with CISN, it is assumed that audience segmentation will not be a feasible strategy within the context of this research project. So, it is evident that segmentation requires a more feasible approach. Further analysis and consultation and discussion sessions with the Quality of Life Centre revealed that they already (un)intentionally applied a segmentation strategy, namely based on end use. They divided individuals from the support system into three end user groups considering the intended use case of the curriculum, namely into parents that use it as a personal guidance system, professionals that use it as an advisory system, and lastly, professionals that use it as work system (Figure 4.1).

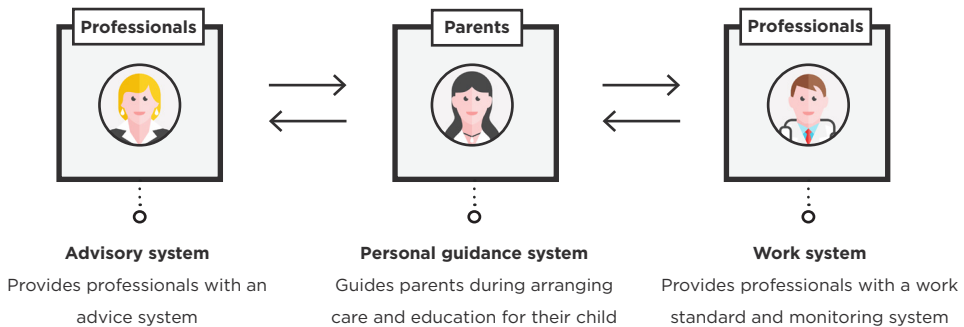


Figure 4.1 The three end users groups of the curriculum

This segmentation strategy appears to be valid since through determining how the use of the curriculum differs according to their distinct end user groups, the offering of the curriculum can be modified accordingly. In simpler words, by identifying the multiple tasks the different groups perform, it will be clear how they might use the curriculum. Nevertheless, it is argued that a segmentation based on end use alone is not sufficient for this research project. While it determines the most relevant groups and the different tasks they should perform, end use segmentation does not identify and provide information which needs those individuals have during the execution of those duties. Hence, this project adopts a second segmentation strategy, namely based on needs. A primary advantage of need based classification is that needs of the individuals within

an end user group might have a certain amount of crossover which helps in dealing with heterogeneity. For example, an occupational therapist might have the same need as a behavioural therapist despite their different characteristics and roles. Besides, from a strategic viewpoint, a need-based segmentation might offer a sustainable competitive advantage for the Quality of Life Centre because this type of segmentation is hard to copy by competitors. However, this approach is also difficult to execute. Usually, a need-based approach would not have been feasible during the timespan of this research project since they are challenging to recognise and interpret. Often, an extensive market research strategy is needed to uncover the most relevant needs. However, in this project, this market research was not necessary since the Quality of Life Centre (partly) documented most of the significant needs. In this way, the collection of needs did not have to start from scratch and made it realistic to incorporate this approach into this research project.

4.1.2 Conclusion: apply need-based and end use segmentation strategies

The application of customer segmentation resulted into three distinct end user groups, namely: professionals that use it as an advisory system, parents that use it as a personal guidance system and professionals that use it as work system. Eventually, two strategies were selected which matched the context of this research project, namely a segmentation based on needs and end use. Primary advantages of these strategies are that they can deal with the identified heterogeneity and might offer a sustainable competitive advantage since they are hard to copy by competitors. The approach based on needs is made tangible by applying value proposition design (section 4.2) which illustrates for each end user group what the benefits are and what specific problems the curriculum can solve. The strategy based on end use is made tangible by applying workflow analysis (section 4.3) which provides information on how the different end user groups will use the curriculum and what sort of information they need during use.

4.2 Value Proposition Design

By making use of the value proposition canvas (Osterwalder et al., 2014) the three end user groups could be targeted with a unique value proposition. In doing so, the value propositions can create a dialogue between the end users and the Quality of Life Centre regarding the perceived value and purpose of the curriculum, prior to the technical realisation. Besides, they focus less on what a possible solution should embody but rather emphasises the underlying problems and thus provides fundamental background information on why a solution is desirable. Hence, the main aim of this section was to uncover how the curriculum creates value for the three end user groups as defined in section 4.1.

4.2.1 Applying the value proposition design canvas

Briefly put, this section will describe the characteristics and needs of the end user groups with customer profiles, prioritise those identified needs with the support of questionnaires, and describe the value propositions with the help of value maps (Figure 4.2). In addition to providing the end users insight in the value of the curriculum, it is expected that the different value propositions could lead to better founded requirements in chapter six since value can be coupled to requirements.

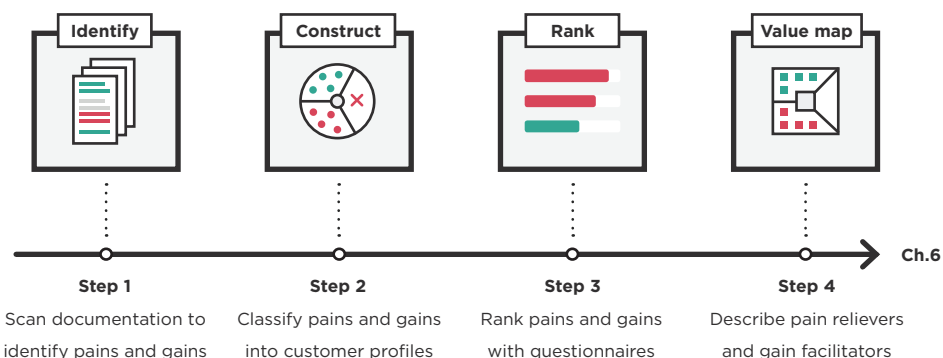


Figure 4.2 Applying the value proposition design canvas

Step 1: Identify and compose a comprehensive list of pains and gains

Before the construction of the customer profiles was conceivable a complete list of relevant pains and gains was composed (Figure 4.3). This list was founded and based on the available documentation and insights of the Quality of Life Centre, including the results of the extensive international project Enablin+ (2014 – 2017). Analysis of this documentation and multiple consultation sessions with the Quality of Life Centre resulted in a comprehensive list of pains and gains, which were then divided in different categories (Appendix G). Subsequently, this collection of pains and gains served as input for step 2 where they were filtered and classified to one of the three customer profiles.

Topic	Statement	Label	Source
Knowledge	Involved persons communicate in the same language and work in unison	●	Quality of Life Centre (2017)

Figure 4.3 ‘Collapsed’ view of the comprehensive list of pains and gains (●)

Step 2: Describing the end user groups characteristics and needs with customer profiles

Based on Osterwalder et al. (2014), the three end user groups are studied and described by a customer profile (Appendix H). As illustrated in figure 4.4, the ‘customer profile’ consists of three parts. Jobs describe the things the end user is trying to complete, pains are negative experiences that arise before, during and after trying to get a job done, and gains describe the outcomes and benefits the end users want to achieve. At this point, it is significant to note that the jobs were deliberately not described in this research. During the process of describing a customer profile, it quickly became apparent that the heterogeneity of both the professionals as well as the persons with CISN would have resulted in a massive list of jobs. The amount of effort to compose such a list would be disproportionate to what it would have yielded. Within the scope of this research, it was assumed to be sufficiently valid to only incorporate the pains and gains since these could be founded on the available documentation and insights generated in step one.

Step 3: Prioritising the pains and gains through questionnaires

While individual preferences among end users within a specific group might vary, it will be fundamental – from both a development as well as a strategic viewpoint – to get a sense of priority and to focus on the things end users really care about. The significance of the pains and gains was made insightful through questionnaires that could reveal the extent to which they were important as seen from an end user’s perspective. The ranking was done based on a five point Likert scale and the pains and gains were put as statements on the vertical axis and the rating scale on the horizontal axis. In this way, the respondents could rate the importance of each pain from ‘unimportant’ to ‘very important’ and each gain from ‘not a priority’ to ‘essential’. The results of the questionnaires can be found in appendix I and revealed that all end users groups care about their problems since the pains and gains were rated (very) high, especially among the parents. The numerical ranking served as input for the design of requirements in chapter six.

Step 4: Describing the curriculums’ value propositions with value maps

Now that the end user’s characteristics and needs were described with the help of a customer profile and ranked with surveys, a value proposition could be formulated for the curriculum. This was done by using the second format of the value proposition canvas: the value map. The value map consists of three parts. Products and services describe a list of what a company offers, the pain relievers describe how exactly the products and services alleviates specific end user’s pains, and gain creators describe how the products and services create end user gains. After filling the value map (Appendix J), a value proposition was constructed where both the gain creators as well as pain relievers were directly related to the corresponding pains and gains in the customer profiles. Figure 4.4 provides a collapsed view of the value proposition for the parents.

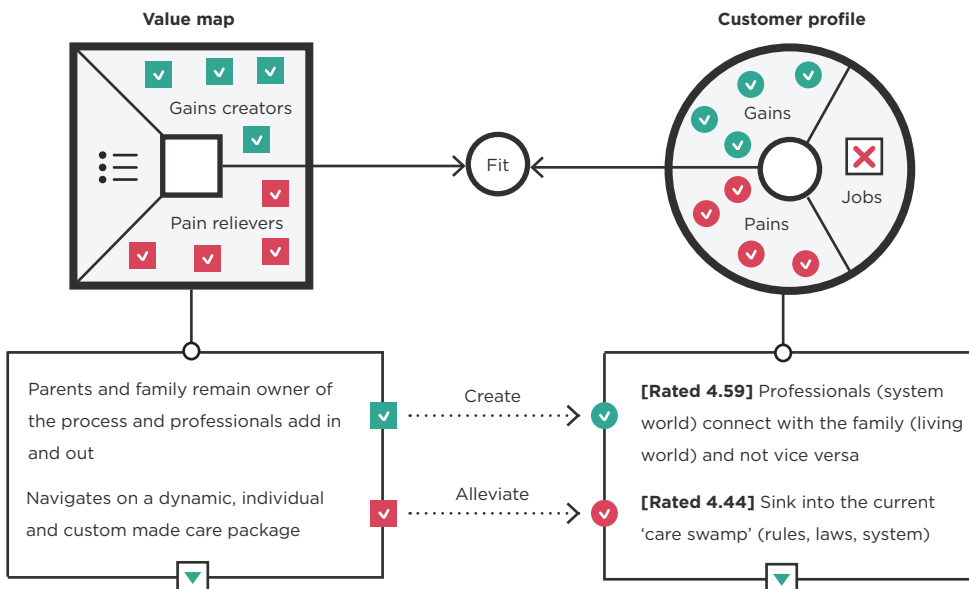


Figure 4.4 'Collapsed' view of the value proposition for the parents

4.2.2 Value proposition design is a never-ending process

It is important to note that value proposition design is never finished. It is a highly iterative search for what customers want, and a never-ending process in which one should constantly evolve the designed value propositions in order to keep it relevant and meaningful to all involved actors. However, not all the concepts of the framework of Osterwalder et al. (2014) were applied. Rather, this research made a start with the method to provide the first tangible evidence to validate if what the curriculum offers, matches with what the end users want. This process is often referred to by the start-up movement as reaching problem-solution fit. Essentially, problem-solution fit means that there is evidence that provides insights into who the end users are, why the end users need the curriculum, that the curriculum is solving the problem effectively, and that the curriculum is feasible (economically, technical, legally). In this research, only the first two claims (the problem side) were validated (Figure 4.5). Substantiating the last two claims (the solution side) falls outside the scope of this project as it requires actual testing over a longer period of time with the help of, for example, a minimal viable product (MVP).

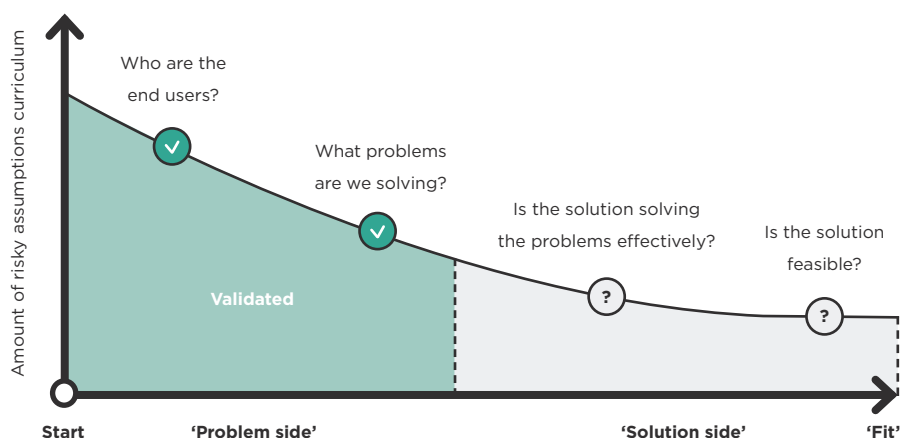


Figure 4.5 Problem-solution fit (figure based on the researchers interpretation)

4.2.3 The results are dynamic and should be managed continuously

This section made the segmentation approach based on needs tangible by applying value proposition design activities. Essentially, these activities provided insight into why the end user groups want to use the curriculum. It described the characteristics and needs of the end user groups with customer profiles, prioritised the needs with the help of questionnaires, and elaborated what value the curriculum creates for each end user group. The results of the questionnaires revealed that they care about the problems since the pains and gains were rated (very) high, especially among the parents. Furthermore, this rating provided the first validation and a sense of priority on the one hand while serving as input and substantiation for the design of requirements on the other. However, the results of value proposition design should be interpreted as dynamic since it is considered as a never-ending process. After the completion of this project, the Quality of Life Centre should manage, improve and renew the value propositions composed in this project.

4.3 Workflow analysis

Where value proposition design provides the rationale of why the different end user groups should use the curriculum, it did not provide how they will use the curriculum and what sort of information they need during use. The goal of applying workflow analysis was to get insight into which processes are executed by each end user group and subsequently, uncover which types of information objects they produce or need during use. Briefly put, this section mapped the workflow of the curriculum with the help of the terms and principles (Figure 4.6) as defined in the reference domain model care (Nictiz, 2017). By analysing and interpreting the available documentation of the curriculum and through multiple consultation sessions with the Quality of Life Centre, the workflow of the curriculum was translated and structured into five domains, twenty-six processes, and twenty-five information objects. However, to maintain a compact and accessible overview for the reader, this section only provides a general description of the domains. The elaborate overview of the processes and information objects were included in appendix K. Eventually, the results of the workflow served as input for the specification of requirements and the design of a visual prototype in chapter six.

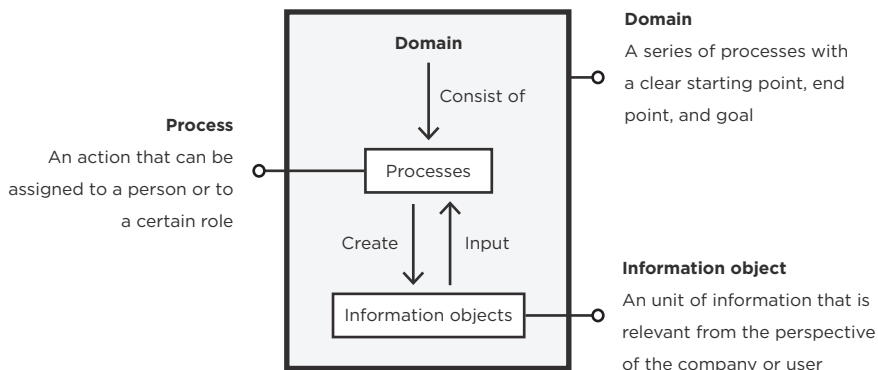


Figure 4.6 The relation between the terms domain, process, and information object

4.3.1 Mapping the workflow of the curriculum

Based on principles described in figure 4.6 and the documentation of the Quality of Life Centre, the entire workflow of the curriculum was constructed. Based on the extensive feedback of the Quality of Life Centre, the workflow went through multiple iteration cycles before it eventually coalesced into the form as depicted in figure 4.7. This figure provides an overview of the workflow – on the highest level – and depicts the relations of the five domains to the three end user groups of the curriculum. Essentially, each domain consists of a set of processes which either create an information object or need one as input. In appendix L, each process and related information object(s) are described in detail and supported with a user story, which is an informal description of a feature of a software system from the perspective of the end user. The next section provides a brief textual description of the five domains, which should provide an understandable impression of how the curriculum is used.

Workflow curriculum

A high-level overview

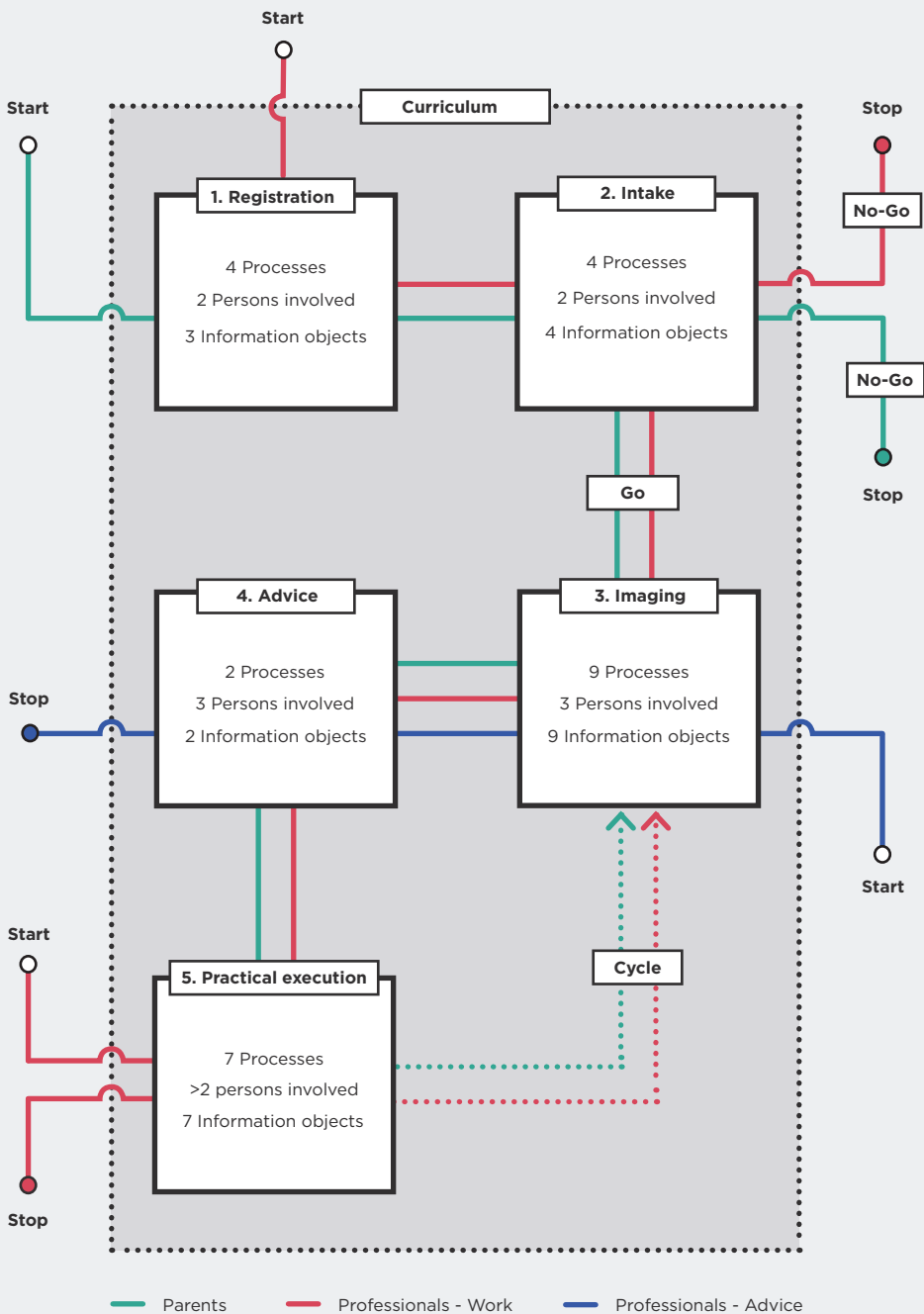


Figure 4.7 The relation between the five domains and the end user groups

Domain 1: Registration

Registering a new care recipient and planning an appointment for the intake

In this domain, the registration of a new care recipient is done. In general, the care recipients are parents or a legal representative of a person with CISON. Overall, they have specific questions about the care and education and are looking for suitable solutions for their problems. Registration for an intake can take place through filling out a form on the website or preferably, through calling with one of the lifestyle coaches of the Quality of Life Centre. Hereafter, the applicant will receive an e-mail with elaborate details about the intake and a (deep) link to a mandatory questionnaire. This questionnaire consists of a set of predefined questions which generate self-management information. This information should make the intake (domain 2) more convenient and efficient. After the registration is done, the lifestyle coach creates an account on Jouw Omgeving platform for the applicant. As of now, all information about the person with CISON will be documented in this online environment.

Domain 2: Intake

Collect information of an applicant and determine whether or not support can be offered

In this domain, the results of the questionnaire generated in the registration domain are the starting point for the intake conversation. In this informal dialogue, the lifestyle coach will, in collaboration with the applicant, fill out an intake form in the online environment, map the necessary financial details, and make the help questions of all involved insightful. Based on this data, an objective decision can be made about whether or not the Quality of Life Centre can offer the required support. In the case of a no-go, the account will be archived. However, it could always be reopened when an applicant might return in the future. In the case of a positive decision, a digital permission form is signed by the applicant, so the advisor has permission for requesting, processing, using and saving data regarding a person with CISON in domain 3.

Domain 3: Imaging ('beeldvorming')

Get insight in the (medical) history of a person and the family and add the missing pieces

In this domain, the independent advisor starts with an elaborate dossier analysis to get insight into the history of the person and the family up until now. Where necessary, this information is supplemented by interview reports, new observations in the form of photo and videos, with the available personal profiles, and if necessary, new ones. Hereafter, the most recent diagnosis, the involved informal and formal network, and the current 24/7 arrangement are mapped. The first imaging phase cycle is concluded with writing a holistic personal image, which is a brief and understandable story based on all the previously collected information. This particular description provides direction to the individual lifestyle plan for the stimulation of well-being and learning abilities, for the use of help, and ultimately to answer the present help questions and to solve problems. In general, the imaging ends with the design of long-term goals for a person.

Domain 4: Advice

Provide advice that gives direction for solving the different (complex) questions

Based on the results of the first 'imaging' cycle, the independent advisor will provide advice about the desired situation for the applicant, the person with CISN, and his or her environment. In this way, all parties will have a clear picture of what the required ratio between an ordinary family and the special support should be. Based on this advice, funded choices can be made for a suitable 24/7 arrangement, the goals, a fitting day-week program and the required support and help for the person with CISN and their environment. The advisor issues advice on all lifestyle domains that are of importance for the person with CISN. The results are made concrete in an advice report upon which all involved, both informal and formal network, can respond to. After reaching consensus among all parties, the advice report will be made final by the advisor.

Domain 5: Practical execution [PDSA cycle]

Bring advice into practice and continuously improve the day-week program of a person

Now that an unambiguous picture has been outlined about what is required, all the involved work professionals can create their own work goals that fit the central goal and perspective. Hereafter, the (lifestyle) coach will, in collaboration with the parents, fill in the lifestyle plan and design the desired day-week program. Furthermore, the coach organises and facilitates the deployment of (structural) assistance that is required for the essential custom facilities. A start is made with the day-week program, and the involved persons will check and evaluate activities in the program on a daily basis and determine whether or not the program should change (short cycle). The coach and parents study the course of the execution on a monthly basis and evaluate the different goals with the help of the various reports and evaluations (long cycle). The findings are then included in a personal lifestyle plan. At this point, the advisor can perform, if necessary, a second 'imaging' cycle and adjust the previous advice. Otherwise, the advisor will stay inactive and periodically monitor whether everyone is complying with the advice. Mostly, the processes described in this domain will repeat itself in a continuous cycle (until the parents decide to stop using the curriculum).

4.3.2 Conclusion

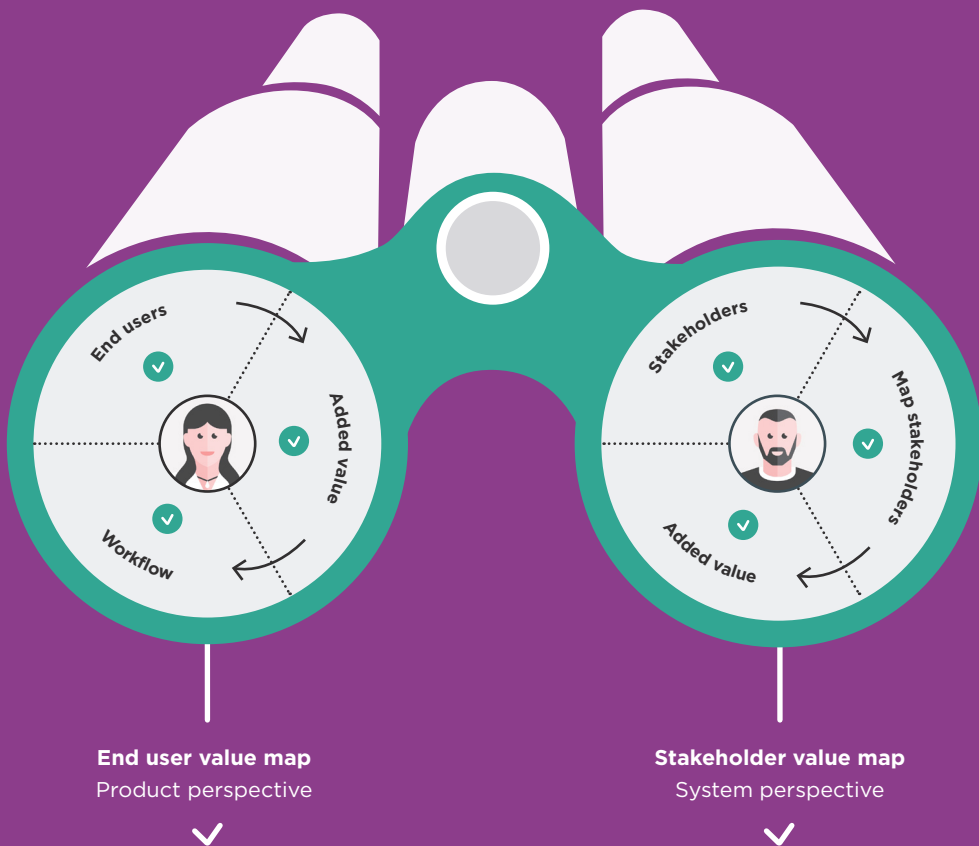
This section made the segmentation approach based on end use tangible by applying workflow analysis. Essentially, workflow analysis provided insight into how the different end user groups will use the curriculum and what sort of information they need during use. It divided the curriculum into five domains and described the corresponding processes and information objects in such a way that they could be used for both the specification of requirements as well as for the design of a visual prototype. Moreover, the processes and corresponding user stories were the foundation for the requirements, where the information objects were translated into visual representations of the curriculum. However, chapter five will firstly elaborate which stakeholders are involved and how they might be affected when the curriculum is to be introduced in the Dutch healthcare system.

Chapter

05

Stakeholder value map

Describes who the stakeholders are, defines how value is created by stakeholders, and display what value the curriculum adds to stakeholders in a future state.



So far, the end user groups of the curriculum were identified and described by means of customer profiles and targeted through a distinct value proposition. These propositions elaborated the problems the curriculum can solve for end users, the benefits they might expect during usage, and provided a sense of priority by ranking each value proposition through questionnaires. In doing so, they made the added value of the curriculum explicit in the language of end users. Furthermore, by analysing the workflow, it became clear how the curriculum will be used by the different end users and what type of information they need during that use. While chapter four provided information that helped determine the overall desirability and the specific interactions that take place between the curriculum and the end users, it doesn't elaborate which stakeholders are involved and how they might be affected by the introduction of the curriculum. Hence, this chapter will switch from a product view towards a system perspective and aims to determine what the relation of the curriculum is to the Dutch healthcare system. In this way, it should become possible to discover the impact the curriculum might have on stakeholders prior to its implementation in the Dutch healthcare system. In simpler words, the main aim of this chapter is to, if possible, thoroughly clarify to each stakeholder what the added value is when the curriculum is to be introduced. This clarification is done through the application of the concepts as determined in the stakeholder value map of the conceptual framework.

5.1 Stakeholder network (descriptive)

Before it is possible to explain what impact the curriculum will have on stakeholders, it is necessary to determine who the stakeholders are and what type of interactions they have with each other. In this section, a three-step process is followed towards the design of a descriptive stakeholder network (Figure 5.1). The first step was determining a point of reference around which the network is built up. Hereafter, the actor-network theory was identified and described as a method that can facilitate the design of the stakeholder network. Based on this reference point and theory, all the relevant stakeholders were listed and presented as nodes that are connected by links with a corresponding description of what type of value is flowing from node to node. The activities resulted in a stakeholder network which served as input for section 5.2, which will display at which specific places in the stakeholder network the curriculum might add value in a future state.

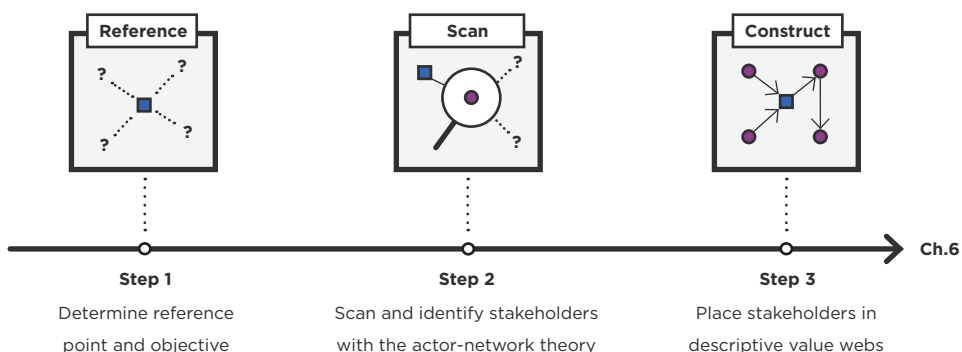


Figure 5.1 Process for constructing a descriptive stakeholder network

Step 1: Parents as reference point for the descriptive value web

Chapter two, and specifically, section 2.1.2 already clarified that the gravity and complexity of a care need eventually determine which path an individual should follow from initial request to receiving care. Section 2.1.3 concluded that there were four distinct pathways where each one is related to one of the four core healthcare acts and thus, has its own procedures and network structure of stakeholders. This is vital knowledge for the design of a stakeholder network as it implies that there will be one descriptive value web for each healthcare act. Moreover, the objective is then to determine which healthcare acts apply for persons with CISN since this will determine how many descriptive value webs need to be constructed. Section 4.1 described that persons with CISN will not be the end user of the curriculum since they often have a combination of complex health and behavioural problems. This makes parents or any other legal representatives responsible for arranging all the care and educational services. Since the support needs are often complex and severe, parents are confronted with a situation where they repeatedly deal with at least three, and in exceptional cases, even four healthcare acts at the same time. For example, parents should arrange a transport service for their child through a local municipality (Social Support Act), an indication statement through the Centre for Indication Care (Long-Term Care Act), and receive specialistic medical care through a referral of a general practitioner (Healthcare Insurance Act). The Youth Care Act primarily applies for children from zero to four since it is often not known how the disease of a child will develop. During this four-year period, all care will fall under the Youth Care Act. However, to make the situation more complex, local municipalities often interpret and apply the rules differently due to the introduced decentralisation. So, while it is explicit that parents should arrange care for their child through various stakeholders and that the procedures vary depending on the healthcare acts, it is currently still abstract which stakeholders are involved, what their relationship is with respect to the parents, and what type of value they exchange with each other. The next section will briefly describe the actor-network theory as method that can facilitate the design of descriptive value web.

Step 2: The actor-network theory

Simply put, a network structure is defined as an interconnected system of individual elements. According to the actor-network theory, elements can both be human as well as non-human objects and argues that all elements are equally important for the stability and functioning of a network. Essentially, the theory provides a means to explore how particular networks are built or assembled and maintained to achieve a specific objective (Thwink, 2017). Put in perspective of this project, the design challenge is then to uncover individual elements and their relations that jointly form a specific network structure that is needed to achieve the objective, namely arranging care of a person with CISN. An important characteristic of this theory is that it does not emphasise the importance and specific structure of those individual elements. For example, a car can be regarded as a complex structure which consists of many individual electronic and mechanical elements. From a design point of view, the theory states that it is not useful to explain, for example, how an engine works or what its technical characteristics are. Rather, it considers the relation of that engine to other elements that are present in the car. In doing so, it makes the analysis of stakeholders' independent of organisational structure, tasks, and work procedures and, thus more convenient.

Step 3: Place stakeholders in a network structure

In the first step towards the creations of a descriptive value web, it became explicit that parents should arrange care for a person with CISN through various stakeholders and varying procedures. Based on the actor-network theory and available information of the Dutch government on the healthcare acts, this section revealed the involved stakeholders, their relationships and their (mutual) value transactions. Subsequently, they were placed in four descriptive value webs with the help of the building blocks that are visualised in figure 5.2. On page 86-87 a combination of a descriptive and prescriptive value web is visualised. The other three stakeholder networks can be found in appendix L.

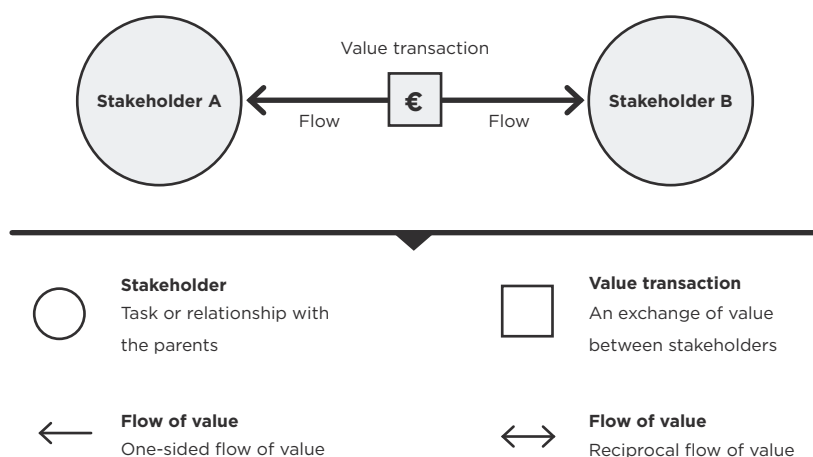


Figure 5.2 Building blocks stakeholder network

5.2 Stakeholder network (prescriptive)

Section 5.1 revealed the stakeholders and their interactions with the help of the descriptive value web. The next and final step is to plot the added value of the curriculum inside the four constructed stakeholder networks. This section will utilise the results of the workflow analysis to determine which specific value transactions the curriculum is expected to influence. Since the workflow analysis uncovered how the different end users will use the curriculum and what sort of data they create and need during use, it was possible to identify value transaction in the networks where the curriculum might be of added value. In order to clarify what is meant with this statement, the next section will illustrate for one particular value transaction from the stakeholder network of the Long-Term Care Act (page 86-87), in which way the curriculum can improve this specific transaction. This example could serve as inspiration for the Quality of Life Centre to work out the other value transactions (green arrows in the stakeholder network) in the same way.

An example of a value transaction where the curriculum might add value

Before parents can arrange and receive care that falls under the Long-Term Care Act, they have to request and receive an indication statement for their child from the Centre of Indication ('CIZ'). However, to issue an indication statement, the 'CIZ' needs different information about a person. For instance, they need to gain insight into the diagnosis, their functioning, additional problems, and determine if 24/7 care is required. However, as the independent advisor systematically collects and records most of this data in the medical file of the person, it enables, hypothetically speaking, the 'CIZ' to issue a more qualitative indication statement in less time.

- **Value proposition 'CIZ'** - The curriculum enables the 'CIZ' to issue a more reliable indication statement, with less effort, over a shorter period of time.
- **Value proposition parents** - The curriculum enables parents to enter conversations with the 'CIZ' on the basis of more complete and coherent information.

Validity of each stakeholder network

As already revealed in chapter two, the healthcare system is highly regulated, dynamic, susceptible to change, and consist of a plethora of actors that are highly interrelated and dependent on each other. Hence, the four constructed networks in this research project are not believed nor meant to be comprehensive or capable of visualising the numerous exceptions and procedures in healthcare. Instead, they were constructed with the goal of determining who the stakeholders of the curriculum are and, subsequently identifying where it is capable of adding value in the current healthcare system. In doing so, this research arrived at a better understanding of the stakeholders and at the way they interact and exchange value with each other. Furthermore, it's important to realise that the modelled stakeholder networks change alongside changes in the healthcare acts. They should be viewed as snapshots of dynamic systems and should be revisited and built upon as new information becomes available (Kumar, 2013). Therefore, the researcher recommends that the Quality of Life Centre continues to monitor changes in the political landscape to recognise potential opportunities or roadblocks for the development and implementation of the curriculum.

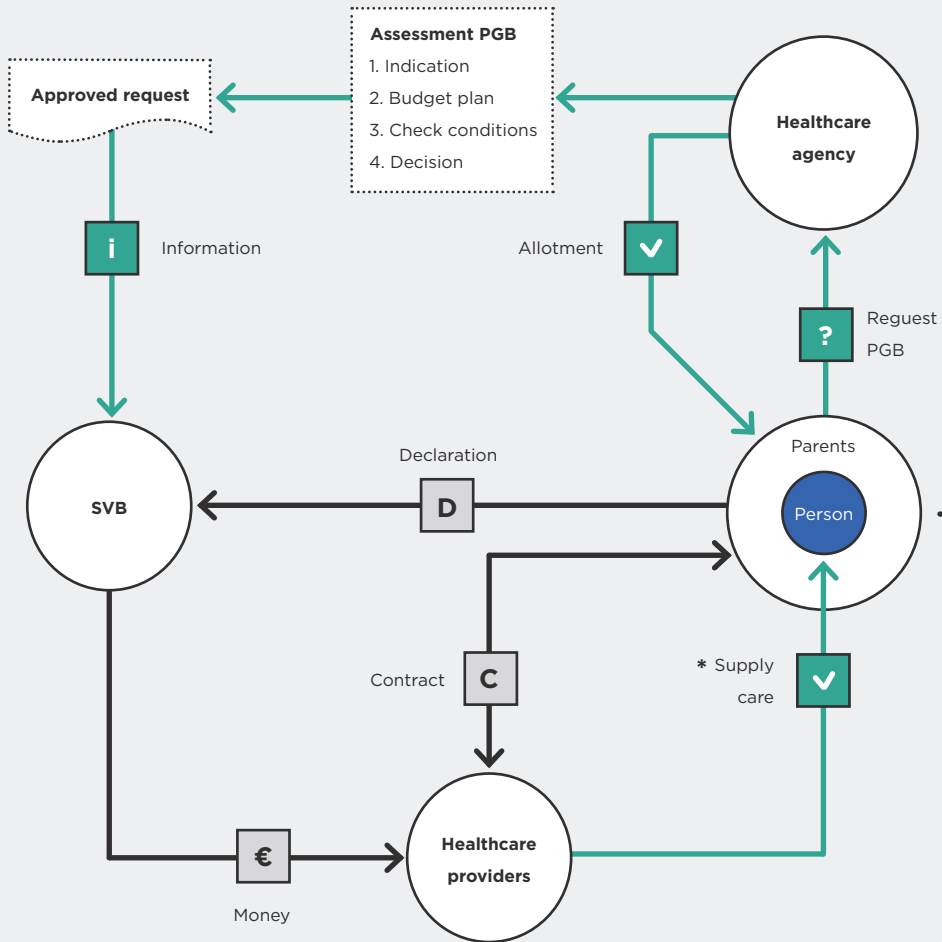
Additional benefits of the four stakeholder networks

This research constructed the stakeholder networks with the purpose to identify the stakeholders, their mutual relations, and in which way the curriculum affects them in the case of an introduction in the healthcare system. However, it is believed that the modelled structures could have additional use cases. Firstly, they could facilitate early discussions between the Quality of Life Centre and stakeholders about the perceived value of the curriculum, prior to technical realisation. Secondly, they help to gain insight into which parties will play an essential role in the development process and which stakeholders may come to play a role during the implementation process. Thirdly, they could serve as input for the design of a business case since the networks revolve around value transactions. Lastly, they aid in conveying complex connections of a system between stakeholders in a more visual way.



Long-Term Care Act ('WLZ')

Scenario 1: Care with PGB (personal budget)



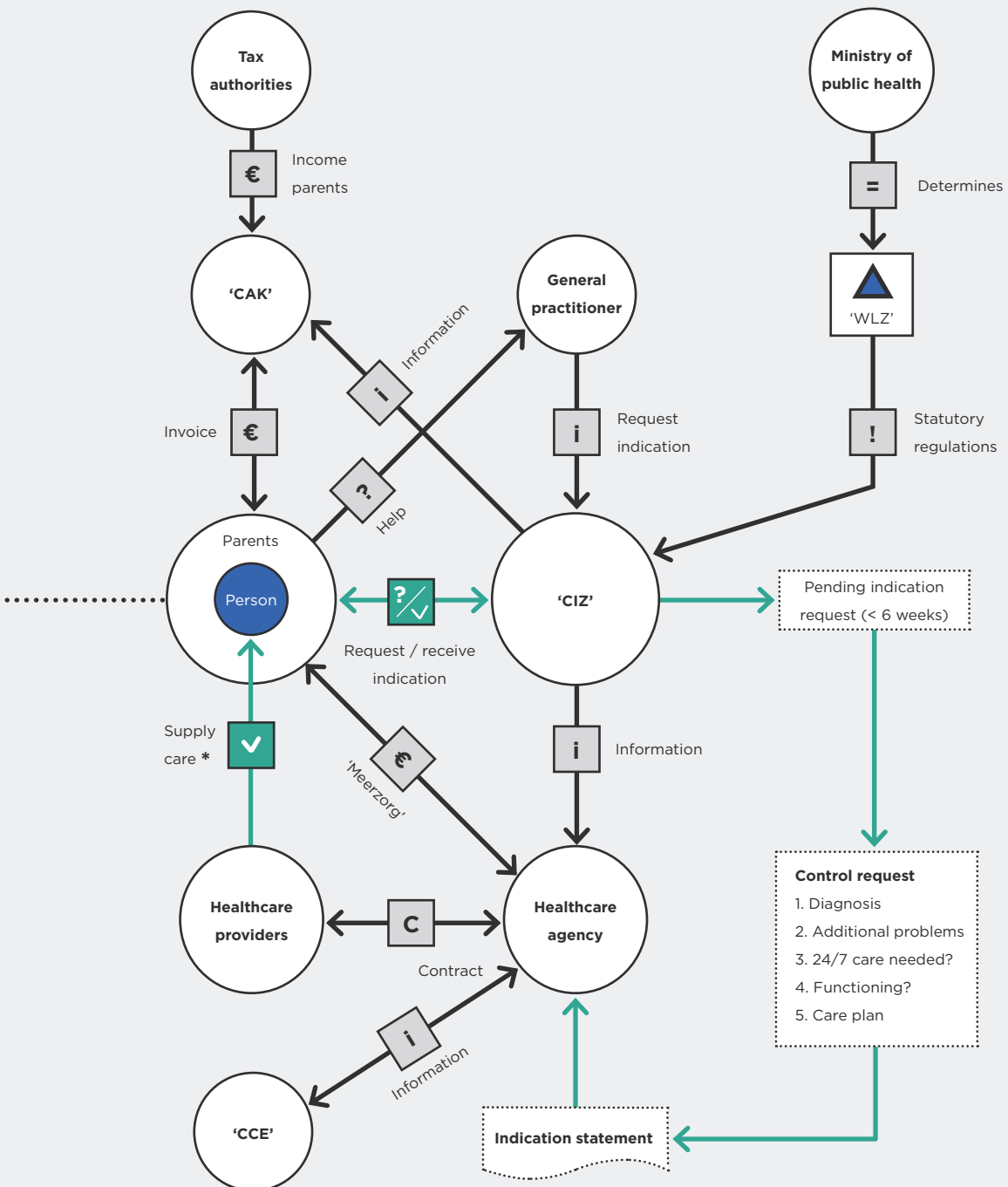
* Care and provisions that fall under the Long-Term Care Act

Individual/group guidance	Living
Short stay (protected living)	Help in household
Personal care	Nursing care



Long-Term Care Act ('WLZ')

Scenario 2: Care 'in kind'

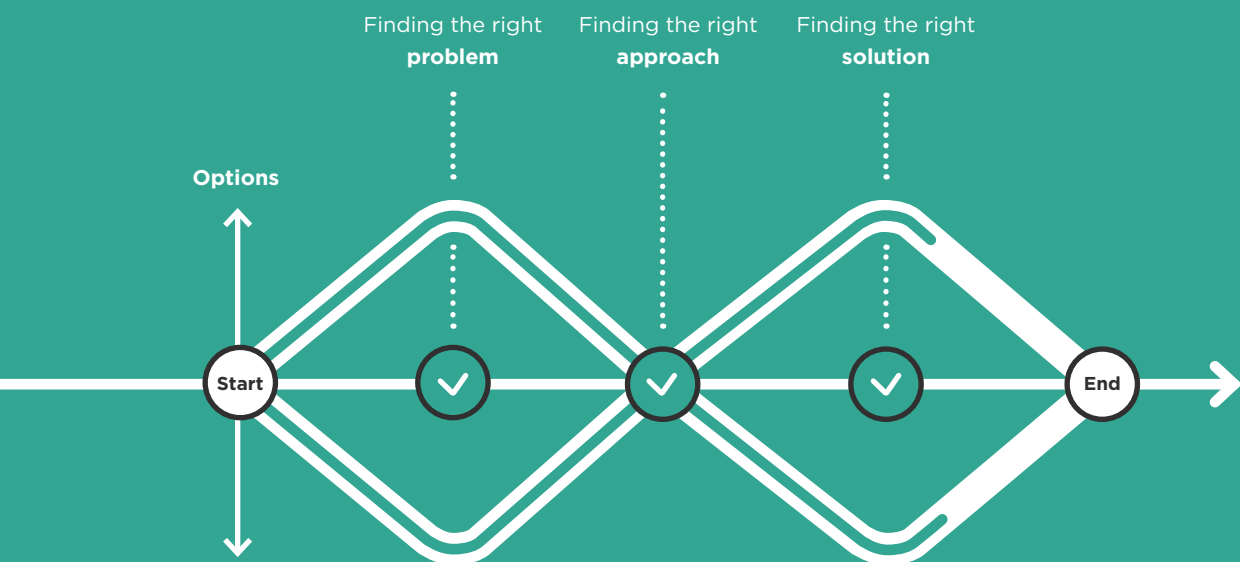


06

Solution map

Integrating the insights from chapter four and five, and translating them into a solution

Time



So far, the overall desirability and specific interactions that take place between the curriculum and end users (product perspective) as well as the relation of the curriculum to the stakeholders inside the Dutch healthcare system was made insightful (system perspective). This chapter takes both viewpoints and integrates and translates them into a solution (Figure 6.1). In doing so, the aim of this chapter is twofold: lay a funded basis for the system development of the curriculum on the one hand while determining whether the proposed solution fits inside the existing infrastructure of *Jouw Omgeving*. Therefore, section 6.1 starts with specifying a minimal set of requirements based on the viewpoints of end users and stakeholders. Subsequently, in section 6.2 these requirements are translated into high-fidelity mock ups and offer a high-level overview of how the curriculum should function in daily practice. Finally, section 6.3 describes how the proposed solution could be coupled to the current healthcare system and, subsequently, to a possible future system with the help of constructing a future scenario.

It is important to note that the results presented in this chapter are the outcome of one development cycle and are, therefore, not validated. During the evaluation phase, which falls outside the scope of this research project, the requirements should be evaluated with actual end users and stakeholders, and iterated based on the provided feedback.

6.1 Requirement specification

Requirements form the foundation for the development of e-health applications. In this research the goal of requirement specification is to develop a minimal set of requirements that reflects the intended purpose and underlying vision of the curriculum. Simply put, the requirements should at least embody what will be necessary for the curriculum to function in practice. It is more convenient to start with a small set of core functionalities and redefine and refine them during the evaluation phase. This approach prevents the inclusion of superficial features and minimises the risk of failure during the development since it validates requirements before actual technical realisation. Besides, this early in the development process, the value that the curriculum is expected to add for end-users and stakeholders are, in fact, still untested hypothesis that need to be validated. Incorporating a minimal set of requirements enables, for instance, more focused evaluation. Thus, this section will firstly define a requirement template, subsequently specify the requirements for the curriculum based on the requirement template, and finally, determine if the curriculum fits inside the existing infrastructure of *Jouw omgeving*.

Defining a requirement template

In order to ensure that the vision and intended purpose of the curriculum were not lost in translation each requirement was documented with the help of a predefined template (Figure 6.2). The template has five distinct parts: a rationale that elaborates why the requirement is incorporated in the design, a value driver that describes the goals and interests of users, a priority score that illustrates how essential the requirement is for end users, a user story that explains how the users interact with the e-health application, and finally, an information object that captures relevant information from the perspective of both end user and stakeholder. By adopting this format, it facilitated the assimilation of the results of the previous chapters into one coherent and clear structure.

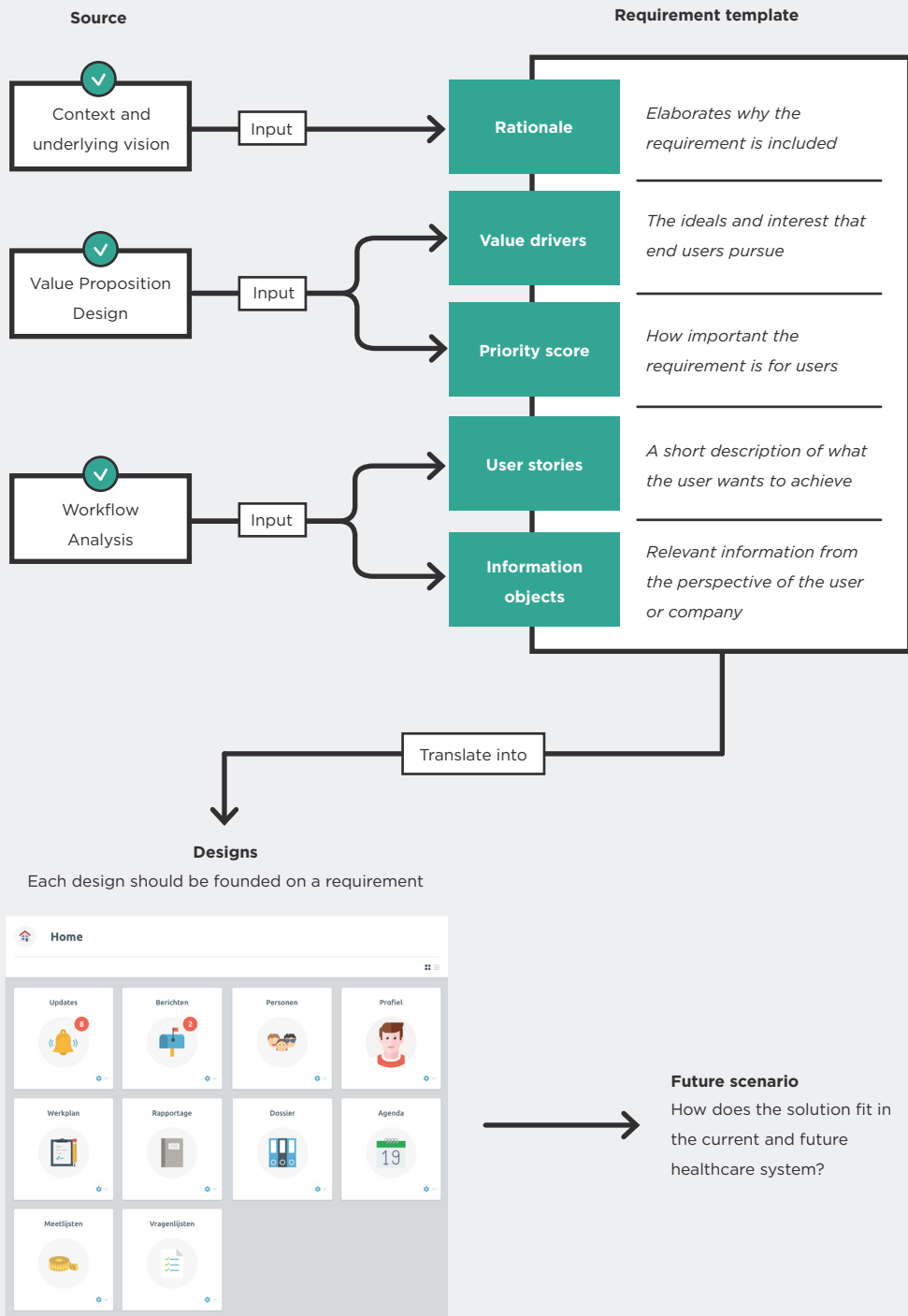


Figure 6.1 Structure of chapter six

Specifying functional requirements

With the help of the requirement template, the information and insights from the previous chapters were assimilated and translated into functional requirements. Figure 6.2 highlights one of the specified requirements, where the remaining ones can be found in the design document in appendix M. This document embodies the minimal set of requirements that are required for the curriculum to function in practice. Each requirement is based on the viewpoints of end users and stakeholders (value drivers), reflects the intended purpose (user stories) of end users, and elaborates the underlying vision (rationale) of the curriculum. Furthermore, they inform system development on what needs to be made (information objects) and, if applicable, in which specific order (priority score). By following such a systematic approach during the requirements specification, it serves multiple purposes; it makes it possible to estimate the cost of creating the technology, it prevents loss of knowledge when a team member leaves a project, it justifies the need for each requirement, and finally, facilitates a better match between the e-health application, its end users, and specific context of use.

Requirement #1	
User story	As parents, I want to invite professionals or family members so they can (temporarily) access (certain parts) of the online environment of my child.
Rationale	In its life, an individual with CISN moves back and forth between multiple places such as day care, healthcare organisations, etc. Therefore, the data generation and collection should be aggregated around the individual and stay in ownership of the parents (or the Quality of Life Centre) since they are their legal representatives, have a full overview of the situation, and are constantly involved with the care
Value drivers	<ul style="list-style-type: none">• Parents (and their family) have full ownership during the process and professionals add in/out (ranked 4.59)• Equal partnership between formal and informal network (ranked 3.61)
Information object	Not applicable
Priority score	4.10 (0 = low 5 = high)

Figure 6.2 Filled in requirement template

Does the curriculum fit into the infrastructure of Jouw Omgeving?

At this point, it became clear that the platform of Jouw Omgeving could facilitate the intended purpose of the curriculum since they have multiple similarities. However, it is important to note that this decision was not solely based on the set of requirements. Instead, the knowledge to make an informed decision grew organically throughout this research. By constantly relating new research results to the platform of Jouw Omgeving, the course of the translation process could be intentionally adjusted. Section 6.2 discusses what will be necessary for embedding the curriculum in the Jouw Omgeving platform.

6.2 Visual design

This section will translate part of the functional requirements into (static) visual designs with the help of the design principles and existing components of the Jouw Omgeving platform. The goal was not to design and specify every information object from the workflow analysis since this would not be very useful nor feasible at this stage in the development. Rather, a selection was made from the requirements that were assumed to be fundamental for the functioning of the curriculum (Figure 6.3). In doing so, this section attempts to provide the reader with an overall and high-level overview, without going in to much detail. Besides, it is more important to uncover why and how certain parts of the design relate (the system architecture) to each other rather than generating a lot of visual designs. When these relations are missed or neglected prior to, and during development, it might result in a less functional product that will be difficult to fix afterwards. Hence, this section incorporated the 'work model' of the curriculum in order to determine how the different components relate to each other.

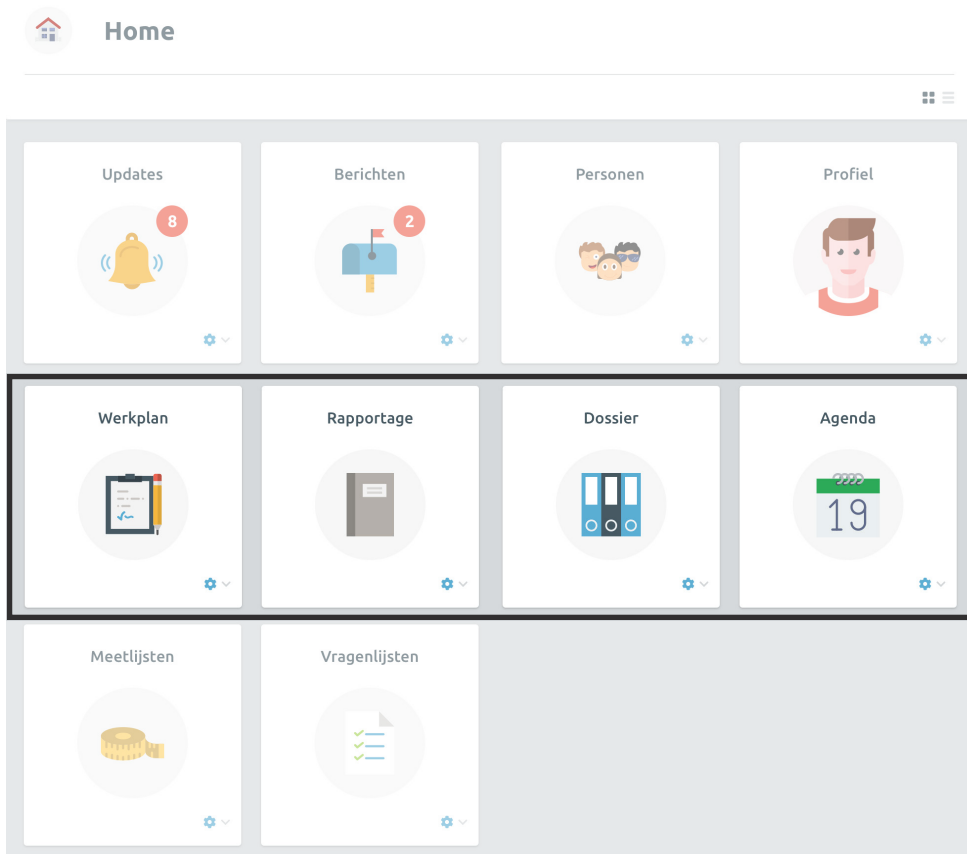


Figure 6.3 Main focus of section 6.2


















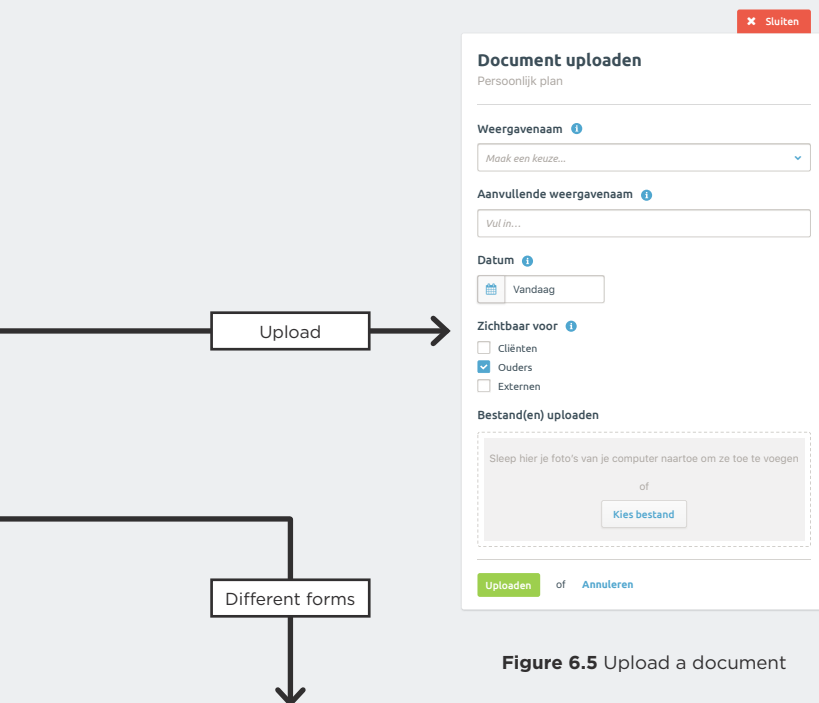
<div>  Dossier </div>				
<div> ● Definitief ● Gepubliceerd ● Concept </div>				
● 	Intake	ma 13 nov 2017	+ Toevoegen	Toon alle (1) >
● 	Toestemmingsformulier	ma 13 nov 2017	+ Toevoegen	Toon alle (1) >
● 	Taksatieschaal	ma 13 nov 2017	+ Toevoegen	Toon alle (1) v
	20180108_Taksatieschaal_Alex.pdf	ma 13 nov 2017		
	Ondersteuningsprofiel	ma 13 nov 2017	+ Toevoegen	Toon alle (0) >
	Dossieranalyse	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Gespreksverslag	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Media	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Persoonlijke profielen	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Diagnose	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Medicatie	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
● 	Holistisch persoonsbeeld	ma 14 nov 2017	+ Toevoegen	Toon alle (1) >
	Arrangement 24/7	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Adviesrapport	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Netwerk	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >
	Leefstijlplan	ma 14 nov 2017	+ Toevoegen	Toon alle (0) >

Figure 6.4 The dossier module

Dossier

The dossier (Figure 6.4) has a prominent position in the proposed solution and is also fundamental for a PHR. The medical record is centered around the individual and follows them across services, locations, treatments and other interventions. In doing so, all the data is aggregated around the individual rather than around departments of healthcare providers. In this way, all the involved persons (parents, network, and professionals) will have a comprehensive overview of the situation and this enables them to make more funded choices. Furthermore, information can be added in two ways: by uploading an external file (Figure 6.5) or through filling out a predefined form (Figure 6.6). These forms capture information that is relevant for the care process. To enhance collaboration, the forms have three states: concept, published, and definitive. Once a form is set to definitive, the content cannot be altered anymore.



Sluiten

Document uploaden

Persoonlijk plan

Weergavenaam ⓘ

Maak een keuze...

Aanvullende weergavenaam ⓘ

Vul in...

Datum ⓘ

Vandaag

Zichtbaar voor ⓘ

☐ Cliënten
☒ Ouders
☐ Externen

Bestand(en) uploaden

Sleep hier je foto's van je computer naartoe om ze toe te voegen

of

Kies bestand

Uploaden of Annuleren

Figure 6.5 Upload a document

Upload a document

Users can upload different types of documents. Besides, they have full control over the visibility for others (Figure 6.5)

Terug naar het dossier

Intake

1 Algemene gegevens

Naam Cees Ligtelijn

Datum gesprek 14-01-2015

Aanmelder

Aanwezigen gesprek

Juridische status ☐ Vrijwillig ☒ Niet vrijwillig

Gezag ☐ Beide ouders ☒ Vader ☐ Moeder ☐ Voogd ☐ Cliënt zelf

Er is sprake van ☐ (Voorlopig) ondertoezichtstelling (VOTS)

Laatste wijziging
12 oktober 2016 (14:17), door Geert de Jong

Status
☒ Concept

Invalhistorie
[1. wo 17 augustus 2016](#)
[2. do 18 augustus 2016](#)

Vergeet niet de wijzigingen op te slaan!

Opslaan

Klaar met bekijken?
[Breng je collega's op de hoogte](#)
 De betrokken collega's worden geïnformeerd dat jij dit verslag hebt bekeken

Figure 6.6 A form inside the dossier

Schematic overview of the 'work model'

The relation between the different elements of an individual program

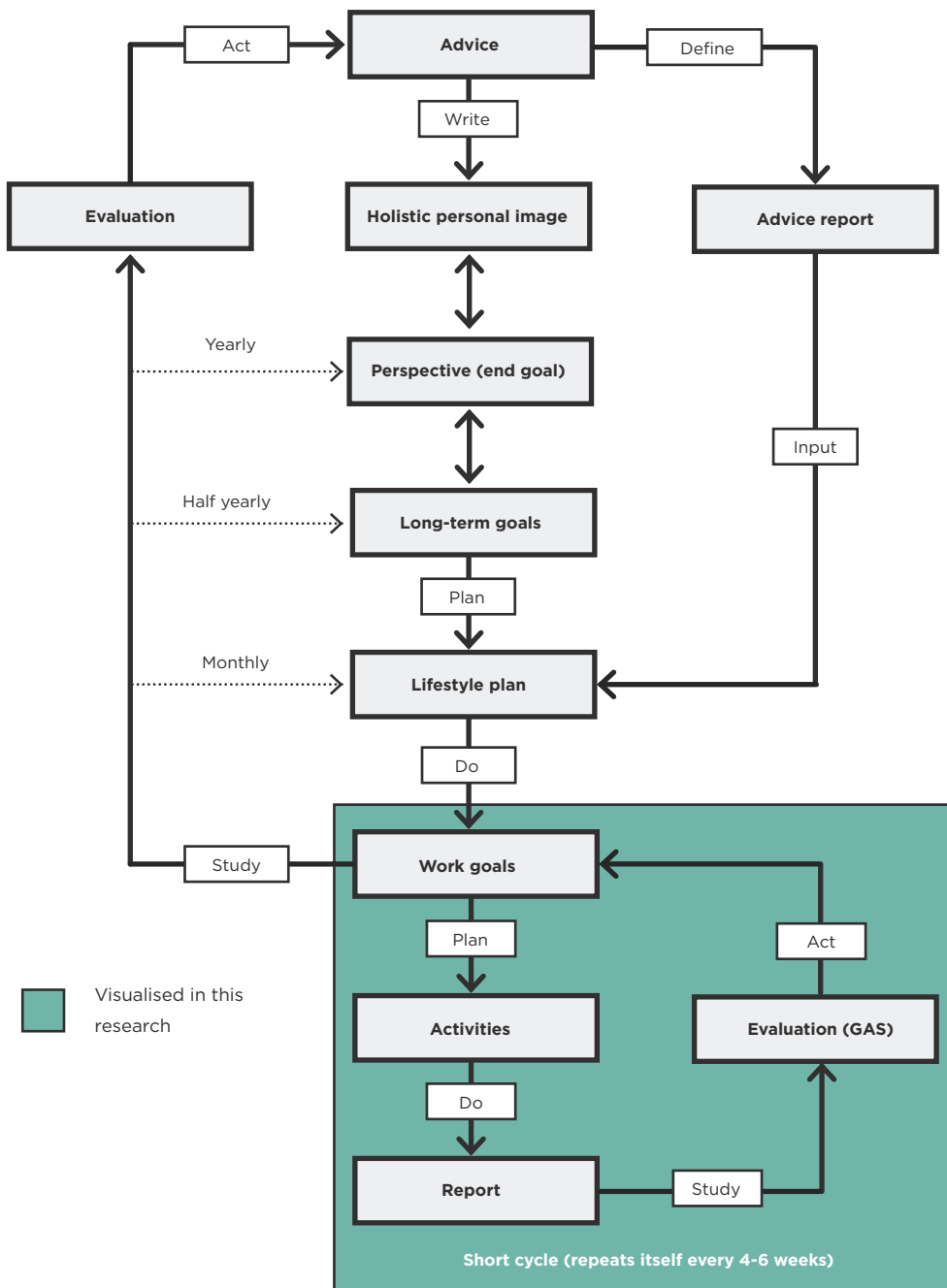


Figure 6.7 The relation between the different elements of an individual program

6.2.1 The 'work model' of the curriculum

In order to better understand what needs to be built, it is crucial to incorporate the work model of the curriculum (Figure 6.7). Part 1 is mainly focused on information gathering which is included in the medical record of the individual. This research will visualise part 2 of the work model since that's where the actual execution takes place (page 98-99).

Part 1: Long term goals (Lifestyle plan)

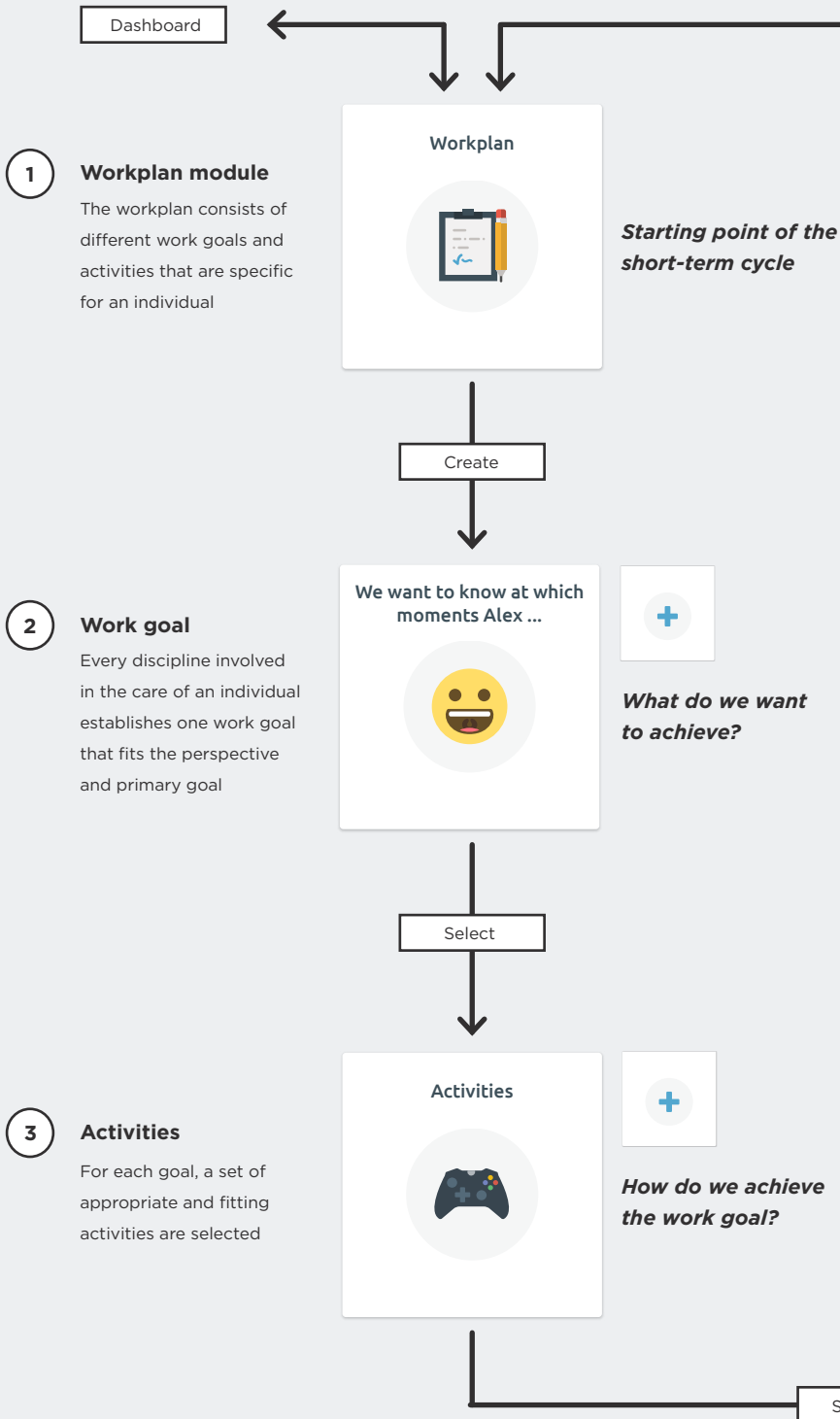
Raising a person with CISN takes place from a viewpoint that these individuals can actively influence their living environment. A prerequisite for exerting influence is that the involved persons understand the behaviour of the person in question. In order to achieve this, they should have a clear picture of their characteristics. Essentially, this image is created from different pieces of experience and knowledge concerning the individual. The results are recorded in a (holistic) personal image, which is a short story based on all information that is previously collected. Based on the personal image, a perspective is determined which states how involved persons should deal with the individual. It also indicates the desired situation (end goal). Since a perspective is too broad to actively work with, multiple long-term goals are derived from the perspective. According to Vlaskamp (1993), the long-term goals should comply with the following characteristics:

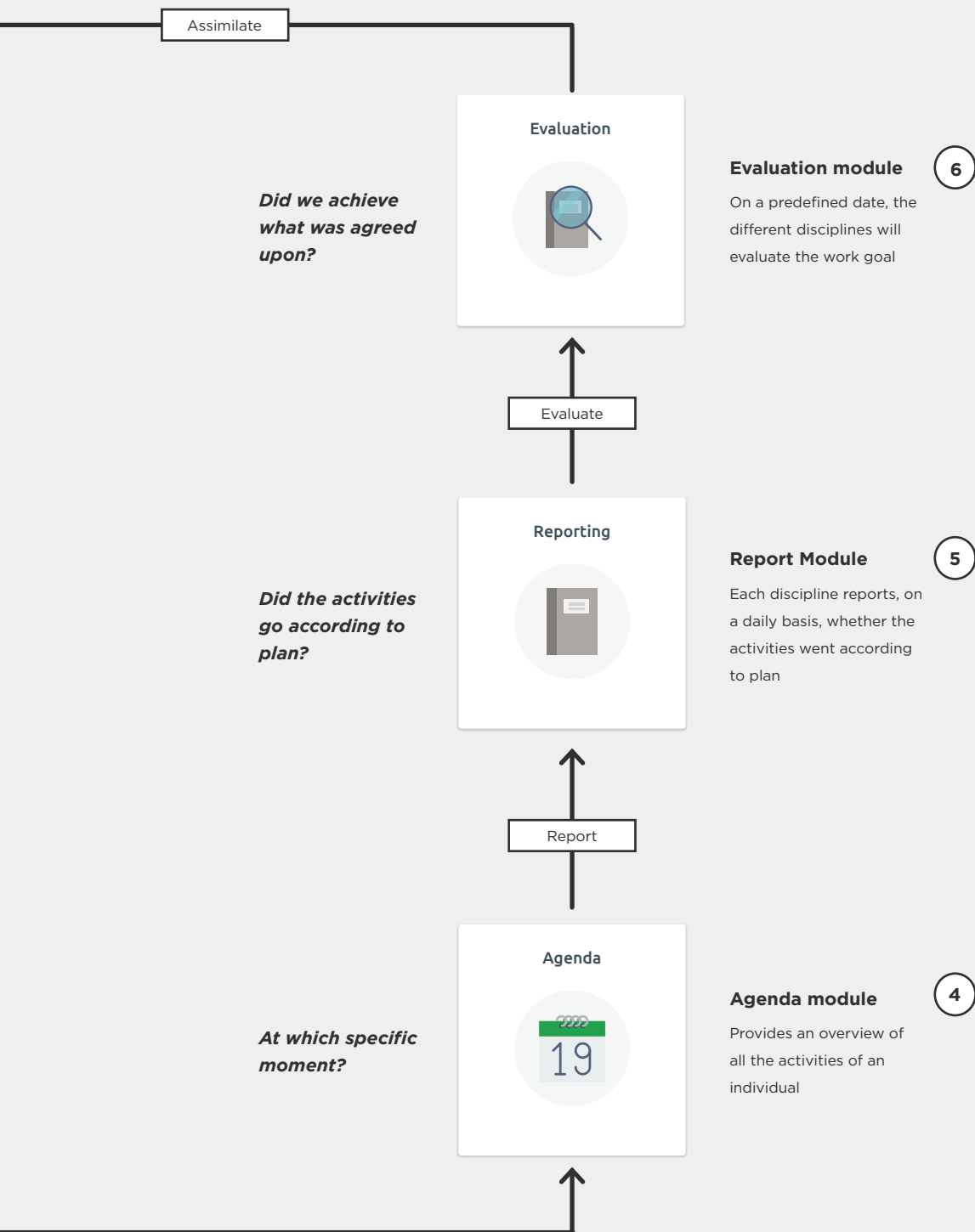
- They are based on the information from, and in consultation with all involved individuals
- There is consensus on the content: everyone is willing and able to work on these goals in collaboration with others
- There are multiple goals needed to achieve the perspective
- There is always a (new) perspective

Part 2: Concretize the long term goals with short term goals (PDSA Cycle)

The short-term cycle makes an individual's program concrete through the creation of work goals. Every discipline that is involved with the person establishes a work goal that fits within the long-term goal and the perspective. Work goals are essential because they enable fast and focused information gathering from the person in question. Hereafter, appropriate activities are linked to the work goals. For each activity, it is determined at what time, in which situation, and at which specific topics professionals should report on. Every day, the relevant discipline reports on the activities. At agreed times, mostly four to six weeks, the professionals will check whether a work goal has been achieved by evaluating it on the basis of the Gain Attainment Scale (GAS). Based on the obtained results, the professionals can decide to adjust the work goal or, in the case of success, to close and archive the goal. According to Vlaskamp (1993), the work goals should comply with the following characteristics:

- Each discipline sets its own work goal for the person in question
- They are supported with well-defined activities, clear implementation conditions, explicit report points, and a GAS on the basis of which the goal can be evaluated. In this way, the individual in question has control over what is happening.
- There are multiple work goals needed to achieve a main goal
- All those involved are aware of the content and result of short term work goals





1

Work plan module

An overview of all work goals and corresponding activities (Figure 6.8)

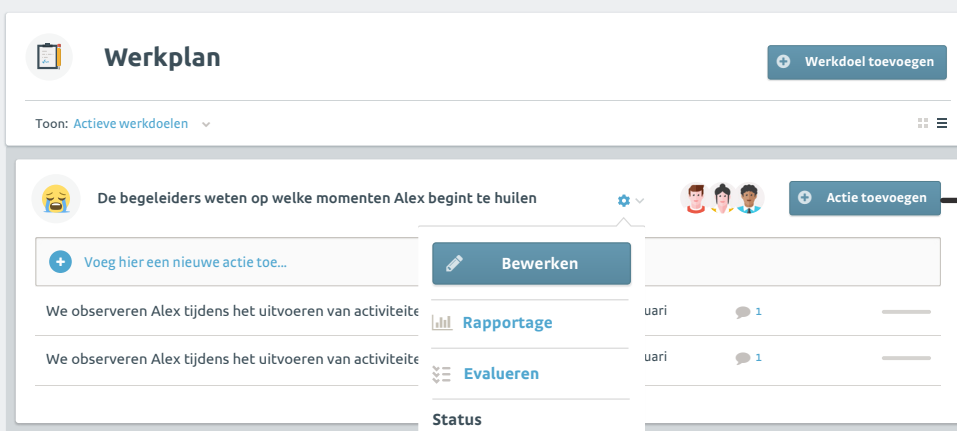


Figure 6.8

2

Work goal



Edit a work goal (Figure 6.9)

Figure 6.9

3

Add activity

Add an activity to a work goal (Figure 6.10)

Activiteit toevoegen   Annuleer

Titel van de activiteit (verplicht)

Voer hier een titel in voor dit actiepunt...

Beschrijving (verplicht)

Geef een korte toelichting voor deze activiteit

Hoe ga je de activiteit uitvoeren? (optioneel)

☒ Alleen

☐ Op de groep





☐ Anders, namelijk

Figure 6.10

4

Agenda

Plan activities in the agenda (Figure 6.11)

Agenda     Nieuw agendapunt

< november 2015 december 2017 januari 2016 >

maandag	dinsdag	woensdag	donderdag	vrijdag	zaterdag	zondag
Eetdagboek invullen 09:15		Emotiedagboek invullen 07:50		3G schema invullen 09:45		
	Afspraak met Hans 12:10		Afspraak met Hendrik 12:10		Eetdagboek invullen 12:30	Eetdagboek invullen 11:10
Eetdagboek invullen 20:30			Eetdagboek invullen 18:30			

Figure 6.11

5 **Report module**
Report daily on the executed activities (Figure 6.12)

Dit is een activiteit open activiteit

Vandaag

Schrijf hier een nieuwe rapportage voor deze activiteit...

24 december 2015 rapporteer voor deze dag

Cees Ligtelijn

Nulla vitae elit libero, a pharetra augue. Morbi leo risus, porta ac consectetur ac, vestibulum at eros. Donec id elit non mi porta gravida at eget metus. Cras justo odio, dapibus ac facilisis in, egestas eget quam.

Geplaatst: gisteren om 16:08 uur
Bewerk of verwijder binnen 22 uur

Stephan Netten

Nulla vitae elit libero, a pharetra augue. Morbi leo risus, porta ac consectetur ac, vestibulum at eros. Donec id elit non mi porta gravida at eget metus.

Geplaatst: vandaag om 16:08 uur (laatst gewijzigd 20 minuten later)

Activiteiten snelmenu
Dit is een activiteit

Figure 6.12

6 **Evaluation module**
Evaluate the work goal with the predefined GAS Score (Figure 6.13)

Alex neemt initiatief tijdens het verschonen door te veranderen van houding toon werkdoel

Schrijf hier een nieuwe evaluatie voor dit werkpunt...

Score

Datum

Vandaag Gisteren Eergisteren Kies datum

Score

2 Alex draait zich uit eigen initiatief van rug naar zijlig

1 Alex begint uit eigen initiatief de draaiing, maar zet niet door

0 Alex toont geen initiatief om te draai van rug naar zijliging

-1 Alex neemt ook in andere situaties geen initiatief tot draaien

Score opslaan of Annuleren

Status

Dit werkpunt is: ☐ behaald ☐ niet behaald ☐ afgesloten

Werkdoel snelmenu
Alex neemt initiatief tijdens het verschonen door te veranderen van houding

Figure 6.13

Dashboard

All important functions of the Jouw Omgeving platform (Figure 6.14)

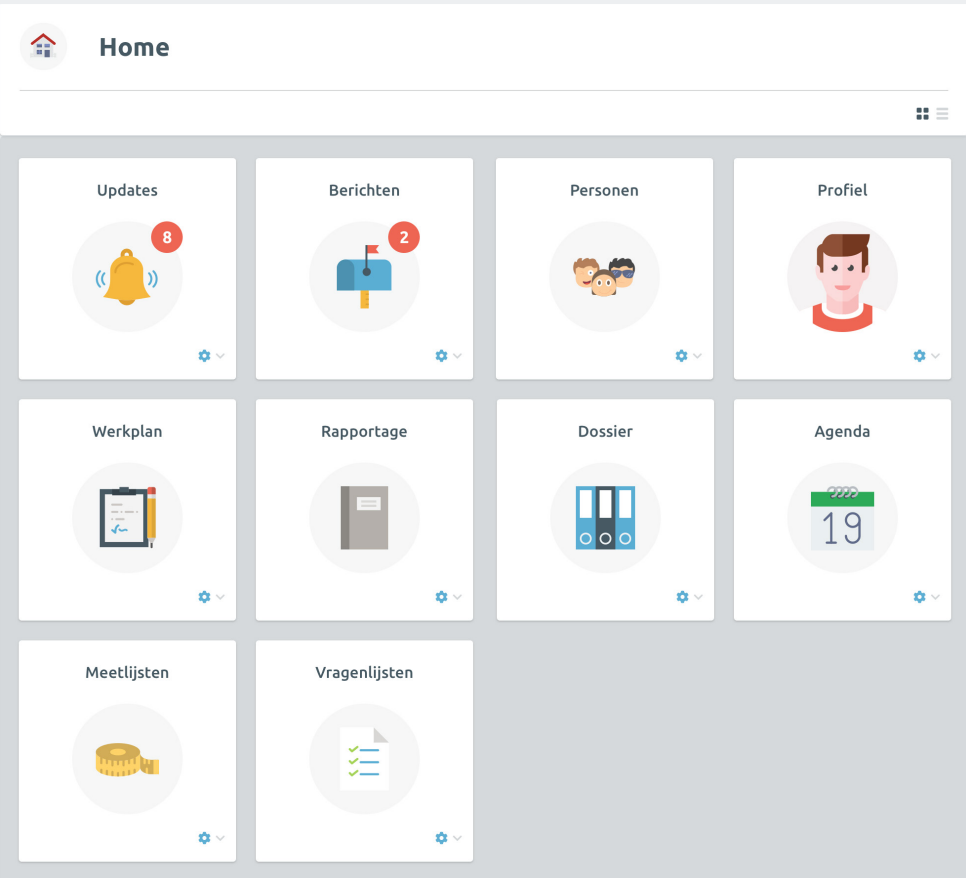


Figure 6.14

Back to

6.3 Future scenario

Up until now this research only reflected a mental model of past and present developments in the Dutch healthcare system. However, it is a certainty that this landscape will continue to change in the future. As a result, these changes are likely to influence the solution that is proposed in this research. This section attempted to get a grasp on these possible changes and implications. This objective was achieved through constructing a scenario that adopted a malleable view which implicates that the course of future events is not predictable nor will it be entirely chaotic. The knowledge and insights gained throughout this research project were extrapolated to predict a possible future of the Dutch healthcare system. After that, an attempt was made to determine how the proposed solution might fit into this future. As this is one of the many likely future prospects, the described scenario and conclusions should ideally only be used to encourage discussion, to find a shared vision, or to facilitate long-term strategic planning.

6.3.1 Positioning the solution in the current healthcare system

In order to determine the relation of the curriculum to the current and future healthcare system, it is first necessary to define the characteristics of the proposed solution. Fundamental properties of the curriculum are that it is founded on an underlying vision, an extensive knowledge framework, and an evidence-based methodology. This combination of factors made the curriculum capable of transcending domains and entirely independent of legislation, type of care or living environment. In this sense, it is important to note that the curriculum is not a stand-alone solution but rather a product- and process innovation at the same time. The curriculum intends to simultaneously offer significant improvements to the provided services for parents and professionals involved in the care of persons with CISN (product), as well as the way in which these services will be delivered to them (process). Moreover, it is crucial to acknowledge that this fact results in initial problems and resistance towards the implementation of the curriculum.

While the curriculum is already in line with current legislation, there are still many barriers that make it difficult to implement it into the existing healthcare system sustainably. Financial incentives for this type of solution are frugal, the knowledge and care delivery for persons with CISN is still fragmented, stakeholders have contradictory opinions, and health information sharing is inadequate due to siloed information systems. For example, delivering advice before the start of a new care trajectory is a fundamental part of the methodology behind the curriculum, but advisory services are currently not reimbursed by healthcare purchasers or very selective. These kinds of barriers have to be overcome for the curriculum to reach its real potential and to be fully adopted. However, most of the mentioned barriers are systemic and therefore, hard to overcome. The most crucial step after completion of this project will be to prove to stakeholders and end users that the curriculum can deliver more excellent care on outcome indicators such as health, quality of care, and patient satisfaction at constant or lower cost. When these outcomes are collected and reported publicly, healthcare purchasers will face incredible pressure to acknowledge and adopt the curriculum as the benchmark for care delivery to persons with CISN. However, proving the effectiveness of a process innovation is only possible after its implemented over a more extended period, and to apply it, it has to be realised.

At this moment, the Quality of Life Centre already started with the verification process of the curriculum through a trial run, which is a small-scale research project. Based on twenty-five case studies they want, among other things, to validate the use of the curriculum over a timespan of two years. This controlled setting will be ideal to gradually introduce high fidelity prototypes of the proposed solution and collect valuable feedback for the technical realisation and evaluation.

6.3.2 The healthcare landscape in 2025

In 2025, the complexity of society has further increased due to demographic trends such as an ageing population and continuous technological innovations. The number of individuals with (complex) care questions has increased while persons with a limitation or profound disability will have more and more problems to keep up with this fast-changing world. As a result, those individuals might get a less preferred position in society due to a decreasing tolerance for deviant behaviour. These demographic and technological developments have impacted the way the government regulates, healthcare purchasers buy, healthcare providers deliver, and private individuals receive healthcare services.

Since the broad reform of the Dutch healthcare system was put in motion in 2015, the government continued to focus its efforts on the promotion of prevention, self-reliance, and the empowerment of individuals. Through the introduction of additional legislation, the autonomy and freedom of choice among individuals were further stimulated, even for the (most) vulnerable groups. Following these legislative changes and the increasing pressure to keep healthcare affordable and accessible, healthcare purchasers responded with new incentives. They will have gradually shifted from a supply-driven healthcare system organised around what providers do towards a more patient-centred system that is built around what patients need. This transition was slow but caused a paradigm shift that changed the way healthcare is regulated, measured, and reimbursed. New value-based care and financial models were designed that focus on maximising the value of care for the patient while reducing healthcare cost rather than paying predetermined standardised fees for a delivered care service. As a result, healthcare providers that effectively improved patient outcomes entered contract discussions with healthcare purchasers from a position of strength whereas organisations that failed to increase value lost contracts, and thus clients, in the process. Healthcare providers are rewarded for delivering value, concerning patient outcomes, rather than only increasing the volume of provided services. The widespread adoption of performance-based reimbursements has paved the way for individuals to act more like consumers as they do in other marketplaces. Supported by legislation, financial incentives, and an increase in disease knowledge and technical literacy, patients can actively seek higher value by selecting the care they want, at any place and time they want, from a healthcare provider of their choice. This increased freedom of choice has addressed part of the information asymmetry between actors in the healthcare system and provide individuals with resources to manage the risks of their disease more effectively.

New technological advancements in the fields of e-health, big data, artificial intelligence, wearables, and robotics have enabled healthcare providers to transfer almost all of the supporting care functions from their physical locations into the home of individuals.

Traditional healthcare institutions gradually became superfluous and were replaced with organisations in which services for particular medical conditions are integrated to deliver (complex) high-value care. Through smart applications, persons are enabled to continuously measure health parameters such as heart rate and blood sugar, monitor their medication intake, ask online advice from healthcare professionals, and inform and involve their informal network more efficiently. These opportunities changed the relation between the individual and healthcare provider. Delivery of care is increasingly independent of time and place. Persons gained access to opportunities for performing self-diagnosis and self-treatment where professional clinicians shifted their focus to complex diagnostics and joint decision making, in which personal needs are decisive. The emphasis of professionals is less fixed on the disease, but instead focused on informing, reassuring, and preventively adjusting the course of treatment of an individual. Professionals in autonomous care teams moved from multidisciplinary collaboration towards interdisciplinary teamwork, where the professionals formulate common goals in a shared language that is accessible and comprehensible to all parties involved.

In order to enable a value-based healthcare system and interdisciplinary work practices, personal health records (PHR) were broadly adopted. A PHR is mainly an information platform through which individuals can access, manage and share their health information, and that of others from whom they are authorised, in a private, secure, and confidential environment. However, the road to widespread adoption of these platforms has not been very convenient. Early demonstration projects with PHR's yielded limited benefits due to siloed information systems, absent financial reimbursements, a lack of early adopters, and organisational and behavioural barriers. This complex combination of factors made it immensely difficult to measure cost and outcome indicators, impeding the intended value improvements PHR platforms could reach. Thus, healthcare purchasers, healthcare providers, and developers gradually realised that for a PHR to be genuinely beneficial, commitment and long-term investments into the development of a value-enhancing information platform were required. Since individuals are not capable of providing all types of health data reliably, a 'two-way communication street' between the PHR and the different internal data systems of healthcare providers had to be realised. By connecting multiple data sources with each other, it was possible to create a complete medical file of an individual that transcended the internal systems of healthcare providers. In 2020, the results of the 'MedMij' project paved the way for seamlessly exchanging health information among different system by defining information standards. The implementation of these standards in PHR systems proved to be the 'tipping point' for widespread adoption. After the technology matured in the following years, the PHR proved to be superior to the expensive, customised and interdependent systems healthcare providers once had.

Positioning the solution in the future healthcare system

Assuming that the Quality of Life Centre is indeed capable of proving that the curriculum can solve the most pressing problems in an economically feasible manner, it is bound to gain traction in the future. The curriculum is already consistent with developments that are described in the scenario. It facilitates autonomy and freedom of choice, it is patient-centred rather than supply driven, focuses on improving patient outcomes, facilitates interdisciplinary work practices, and enables individual personalised care. Initially, the

Quality of Life Centre focused on a tiny and relatively economically unattractive market segment. However, from this starting point, Jouw Omgeving and the Quality of Life Centre gradually improved the solution in ways that even appealed the more mainstream segments. Because the curriculum focused on persons with the most complex care questions, the solution proved to be scalable to other less complicated groups.

6.3.3 Worst-case scenario

Today and in the unforeseeable future, persons with CISN will always require complex 24/7 care and will, therefore, be completely depended on others for their well-being. Persons with CISN as well as parents and their family are, throughout their lives, unwillingly dependent on demanding intrusion of others. So, no matter how the system changes in the future, this statement is the only predictable constant in the sea change of variables that could influence and shape the future healthcare system. Put simply, any solution that can solve the most pressing problems for this group has, from a societal perspective, a viable reason to exist, even when it does not (yet) fit into existing structures, procedures, and financial structures. Besides, two essential characteristics of the curriculum are assumed to make it less prone to future changes in the healthcare system. Firstly, the development followed a bottom-up approach which put the needs of persons with CISN and their support system first, rather than those of healthcare providers and other stakeholders. Since in the end, there is only one stakeholder with an absolute commitment to the health of a person with CISN: the parents. If the Quality of Life Centre can convince parents of the intrinsic value of the curriculum, other stakeholders should and are almost obliged to follow. Secondly, the curriculum is based on an underlying vision, an extensive knowledge framework, and an evidence-based methodology. This research has systematically translated and codified this knowledge into an e-health application. In this sense, the proposed solution should be regarded as a vehicle that makes the underlying vision and expertise usable and applicable for parents and healthcare professionals. Future developments (e.g. technological changes or new laws) might change the vehicle and its content, but the underlying rationale and principles remain unchanged.

6.3.4 The future role of the Quality of Life Centre and Jouw Omgeving

Looking beyond the curriculum and at the overall role of the Quality of Life Centre concerning the healthcare system, it should ideally be positioned at the start of the healthcare chain because from this position it will be able to maximise its value to the involved stakeholders. By providing advice and individual custom-made care to parents directly at the start of a new 'care trajectory', it will be possible to anticipate on and even prevent problems that might arise further down the chain where the cost, both financially as well as emotionally, will be exponentially higher. In doing so, the Quality of Life Centre envisions to achieve a triple aim with their services: increasing both the health and quality of care for persons with CISN while decreasing cost through preventing unnecessary diagnostics and treatments. Furthermore, the goal of Jouw Omgeving is to use its platform as PHR. The realisation of the curriculum inside their existing infrastructure can significantly contribute to reaching this objective, as it is primarily a rudimentary version of a PHR. They can learn along the way what is required for a PHR to function in practice. In doing so, they can slowly ready their platform and significantly expand their total addressable market as the patient federation envisions a PHR for every citizen by 2020.

Chapter

07

Conclusions

How can the curriculum of the Quality of Life Centre be translated into an e-health application to aid a sustainable implementation in the Dutch healthcare landscape?



This research has started off with a proposal for collaboration which suggested that the curriculum, a framework from the Quality of Life Centre aimed at persons with CISON, should be translated into an e-health application and embedded into the existing online platform of Jouw Omgeving. After endorsement of this proposal, this research was centred around the question how to translate the curriculum into an e-health application to aid a sustainable implementation into the Dutch healthcare system. This primary research question has been addressed by three secondary research questions that will each be answered in this concluding chapter.

How does the Dutch healthcare system function and what is its relation to e-health?

Products naturally belong to a broader context. In this research, it became clear that the curriculum is part of the Dutch healthcare system. Inside this it needs to function to be successful. So, to recognise the value of the curriculum and uncover implications for its design, it needs to be observed with respect to the Dutch healthcare system. However, since this system was perceived as dynamic and multifaceted, this research only focused on the core actors and concepts of healthcare to get a general sense of how it functions the way it does.

In 2015, the government answered the need for safeguarding the sustainability, accessibility, and quality of healthcare through the introduction of three new laws and decentralisation. As a result, it introduced fundamental systemic changes for delivering healthcare services to citizens. Currently, the functioning of the Dutch healthcare system is embodied by a triangle of three actors that interact and exchange value with each other. In this way, its functioning could be captured in one sentence: *“Private individuals buy a policy or request a personal budget from a healthcare purchaser who, in turn, grant them access to care or provisions from healthcare providers who, individually, sign a delivery contract with the concerned healthcare purchaser.”* Without rules, the triangle would collapse, so the government outlined and implemented four core acts which govern the underlying structure of its functioning. Correspondingly, the four core acts serve two different purposes: regulating the type of care and establishing a pathway for an individual for receiving care services. Finally, each pathway has its specific procedures and stakeholders. Since demographic trends, economic prosperity, and politics strongly influence the way healthcare is organised, it is very likely that the functioning of the Dutch healthcare system will change in the future. In this view, its functioning was regarded as dynamic and highly susceptible to change.

E-health is a field that is intertwined with the healthcare system and essentially revolves around the application of information and communication technologies to improve healthcare. However, in itself, the notion e-health is regarded as an umbrella term and has no explicitly defined meaning. There are multiple definitions in circulation, and the numerous perspectives of involved actors on e-health consequently raise different questions. Moreover, the fragmented use of classification results in (purchase) decisions that are often not based on scientific evidence. Without a clear understanding of an e-health application in question, uncertainty among the involved actor's increases, which in turn, decreases the probability of a successful implementation. Both literature and large research organisations mention that there is still a broadly varying success in the

implementation of e-health applications. There is a multitude of obstacles, and as a result, few e-health applications achieve a sustainable and structural implementation. From a design perspective, it is essential to differentiate between barriers that have a high impact on the adoption in contrast to those with low impact. Therefore, this research strategically addressed factors that have a high effect on implementation to better meet the conditions for a successful implementation. This was achieved through the selection of concepts (frameworks, approaches, methods, tools) that were mentioned in literature and regarded capable of overcoming one or more of the identified problems. Finally, a list was composed and provided the basis for the application of the selected concepts.

How should the principles of e-health development be applied to the translation process of the curriculum?

While the composed list originating from the literature study narrowed the scope of this research, the concepts inside were not directly applicable in this research. In order to apply the concepts efficiently and rationally, they were selected and organised into a conceptual framework that guided this research towards the translation of the curriculum into an e-health application. The underlying rationale of the conceptual framework was built upon the need for incorporating two perspectives, and proposed that e-health development should create value for end users and stakeholders through applying high impact concepts to reduce uncertainty among them, which in turn, could increase the adoption in practice.

The term value could be used as means of classification, since the term is understood differently by end users than by stakeholders. Based on this conclusion, the conceptual framework was then divided into three interconnected maps where each map represented a connected set of concepts. For each concept, an explanation was provided as to why it was selected, how it might be applied, and what the result(s) of that application will be. The 'end user value map' consist of concepts that create value for end users and its application helps to uncover who the end users are, what specific problems the curriculum can solve for them, and what benefits they might expect during usage. The 'stakeholder value map' contains concepts that create value for stakeholders and its application helps to determine who the stakeholders of the curriculum are, how they exchange value, and what value the curriculum might add in the case of implementation. Finally, the 'solution map' consists of concepts that could take the insights generated in the previous two maps and create a holistic understanding of what is required to translate the curriculum into a (sustainable) e-health application. In this way, the conceptual framework provided the basis for further study and starting point for the actual application of the concepts.

Regarding the validity of the developed conceptual framework, its application is not believed to be limited to this particular research project since it was built upon an extensive literature study and revolves around value creation which is a core activity for each organisation. Developers and researchers could utilise the framework as inspiration, reference, or starting point for the development of (new) e-health applications. Due to its structure, concepts might be easily added or supplemented with other ones. In this way, the users can tailor the conceptual framework to their specific needs and, if necessary, modify it to fit the unique context of their development project.

How should the results of the translation process be embedded in the existing infrastructure of Jouw Omgeving?

So, after it was clear why and how the concepts for e-health development were to be used in this research, the conceptual framework was applied to the curriculum in chapter four, five and six.

Chapter four started with customer segmentation and identified that the curriculum had three end user groups. Since the individuals inside these group were not uniform, two segmentation strategies were applied. These approaches could deal with the identified heterogeneity on the one hand while offering a competitive advantage to the Quality of Life Centre on the other. The first segmentation strategy, based on needs, was made tangible through the application of value proposition design. Value proposition design activities provided insight into the value that the curriculum could generate and deliver to the end user by designing unique value propositions for each end user group. Questionnaires among the three groups ranked the value propositions, and its results verified that the curriculum could address the most critical needs of the distinct end users. Since the needs of end users are dynamic and dependent on external factors, the Quality of Life Centre should monitor, improve and renew the value propositions as new information becomes available. The second segmentation strategy, based on end use, was made tangible through applying workflow analysis which provided detailed insight into the processes that are executed by each end user group on the one hand while uncovering the information objects they need or use on the other. It divided the curriculum into five distinct domains and described the corresponding processes and information objects in such a way that they could be used for both the specification of requirements as well as for the design of visualisations.

As chapter four provided information on the overall desirability and the specific interactions between the end users and the curriculum, it didn't elaborate which stakeholders are involved and how they might be affected by the introduction of the curriculum. Thus, chapter five described the added value of the curriculum from the perspective of stakeholders. During the arrangement of care for a person with CISON, parents likely come into contact with each of the four healthcare acts. Since every healthcare act has different procedures and stakeholders, a stakeholder network was designed for each healthcare act. These visual structures revealed the involved stakeholders on the one hand while illustrating the various value flows among them on the other. Based on the results of chapter four, multiple leverage points were identified where the curriculum was expected to be of added value. In doing so, this research arrived at a better understanding of the stakeholders involved. In addition to illustrating the added value, the stakeholder networks have additional use cases: they could facilitate early discussions between the Quality of Life Centre and stakeholders about the perceived value of the curriculum, they could help gain insight into which parties will play an essential role in the development and implementation process, and finally, they could serve as input for the design of a business model. However, it is important to note that the stakeholder networks change alongside modifications in the healthcare acts. Thus, they should be viewed as snapshots of dynamic systems, and the Quality of Life Centre should revisit and built upon these networks as new information becomes available.

Where chapter four and five both addressed one perspective, chapter six took both viewpoints and integrated and translated these insights into functional requirements for the design of an e-health application. Each requirement was documented with the help of a predefined template to ensure that the vision and intended purpose of the curriculum were not lost in translation. The template has five distinct parts: a rationale that elaborates why the requirement is incorporated, a value driver that describes the goals and interest of users, a priority score that illustrates how essential the requirement is for end users, a user story that explains how the users interact with the e-health application, and finally, an information object that captures relevant information from the perspective of both end user and stakeholder. In doing so, a minimal set of requirements is specified, based on the viewpoints of end users and stakeholders (value drivers), which reflect the intended purpose (user stories) and underlying vision (rationale) of the curriculum. Furthermore, they inform system development on what needs to be made (information objects) and, if applicable, in which specific order (priority score). Based on the set of requirements, it was concluded that the platform of Jouw Omgeving offers sufficient opportunities for embedding the curriculum in its infrastructure. After this conclusion, the information objects were translated into (static) visual representations with the help of design principles and existing components of the platform. The designs offered a high-level, visual overview of the use of the curriculum in daily practice. In doing so, the translation process created a holistic understanding of what Jouw Omgeving needs to develop to embed the curriculum in their platform and work toward a PHR for the target group.

This research concluded with determining how the proposed solution fits into the current healthcare system and in a possible future system with the help of a future scenario. Despite the fact that the curriculum is in line with current legislation, there are still various barriers that prevent sustainable implementation in the current healthcare system. Financial incentives are frugal, the knowledge and care delivery are still fragmented, and health information sharing is inadequate due to siloed information systems. These barriers can be overcome by proving to stakeholders that the curriculum can deliver more excellent care on outcome indicators at constant or lower cost. When these outcomes are collected and reported publicly, healthcare purchasers will face incredible pressure to acknowledge the curriculum as the benchmark for care delivery to persons with CISN.

When the Quality of Life Centre is indeed capable of proving that the curriculum can solve the most pressing problems in an economically feasible manner, it is bound to gain traction in the described future. It facilitates autonomy and freedom of choice, it is patient-centred rather than supply driven, focuses on improving patient outcomes, facilitates interdisciplinary work practices, and enables individual personalised care. Even in a worst-case scenario, it has from a societal perspective still a viable reason to exist. Today and in the unforeseeable future, persons with CISN will always require complex 24/7 care and will, therefore, be entirely depended on others for their well-being. In this sense, the proposed solution should be regarded as a vehicle that makes the underlying vision and expertise of the curriculum usable and applicable for parents and healthcare professionals. Future developments (e.g. technological changes or new laws) might change the vehicle and its content, but the underlying rationale and principles remain unchanged.

Chapter

08

Recommendations

Recommendations for further
development, evaluation and
implementation



This thesis has been conducted with the specific goal to translate the curriculum into the existing e-health application of Jouw Omgeving. The results have been concluded to meet the needs of both Jouw Omgeving and the Quality of Life Centre. Extensive documentation, including requirements as well as visual designs, have been delivered that provide insight into how the curriculum could be embedded in the platform of Jouw Omgeving. However, the scope of this research was primarily focused on informing system development. This chapter discusses recommendations for further development, evaluation, implementation, and ends with the construction of a vision for the future development of the platform of Jouw Omgeving.

Evaluation of prototypes

This research concluded with a set of static designs that fit with the values of end users and functional requirements. Nevertheless, within the scope of this research, there was insufficient time to refine and validate these designs through user testing. By translating the static designs into functional prototypes, they can be tested sequentially and iteratively with the intended users. It is highly advised that the prototypes will be based on real-life case studies to examine whether they match the expectations and mental models of its intended end users. The results of the user tests and feedback of the end users should be used to assess metrics such as functionality, reliability, usability, accessibility, perceived utility and acceptability. Based on the outcomes of the user tests, the designs should be refined until the quality of the designs is regarded as sufficient.

Develop an operationalisation plan for realisation, implementation and evaluation

The researcher recommends that Jouw Omgeving and the Quality of Life Centre develop an operationalisation plan for the technical realisation, introduction, adoption, and employment of the curriculum in practice. This plan should consist of a set of structured activities that are assumed to be essential for guiding the solution through the different phases of maturity. In the development phase, the prototypes should be evaluated and refined during pilots with the intention to inform system development. In the validation phase, the emphasis should shift towards actually proving the added value of the curriculum which can be achieved by selecting and applying an appropriate scientific validation method. Of absolute importance is to carry out baseline measurements directly at the start of this phase because the results can then be used to gauge the effectiveness of the curriculum on predefined metrics after the pilots are completed. In the acceptance phase, a business case could be constructed to help decide why and how the project is to be (dis)continued. Finally, the last and most challenging phase consists of activities that focus on widespread implementation and finding structural financial reimbursements to make the solution sustainable in the long-term.

The importance of education and training

Maybe even more important than the technical functioning and financial aspects is attention for training and education. Simply put, the proposed solution is nothing more than knowledge and expertise captured in a 'tool'. Without proper training and education, end users might never understand and comprehend how the curriculum could add value for them in daily practice inevitably leading to resistance. Since the solution is both a process as well as a product innovation they have to be educated in two key principles.

End users need to understand and learn why the processes run the way they do (e.g. transfer of vision) and subsequently how they could execute each process accordingly (e.g. how to define a proper goal attainment scale). This requires the willingness to step outside traditional working boundaries for it to work. Therefore, the Quality of Life Centre and Jouw Omgeving should find and start the training with a group of 'earlyvangelists' which are individuals that are willing and able to take a risk on a new product or service. Overall, these persons are more aware of their problems and are actively looking for solutions, thus making them more susceptible for change. In doing so, a foothold market can be built, and in the process, early adopters ideally become advocates of the curriculum persuading others of its added value.

Vision: an independent and enabling e-health technology platform

Today, most e-health applications and systems are still being designed by and favouring the incumbents. Often, e-health applications are built as replacements for or as copies of existing care services, implemented top-down, and fine-tuned to fit the current processes of healthcare providers. From the perspective of the healthcare providers, this makes absolute sense because they are primarily motivated by the financial payment structures and incentives which encourage small process improvements rather than innovative initiatives. For example, annual contracts discourage healthcare providers to invest in innovative processes since they have little to no long-term security in earning back their investments. Consequently, these conditions reflect the way Jouw Omgeving is developing its platform, but in which way?

Healthcare providers are the primary customer of Jouw Omgeving. So, when healthcare providers decide to use the platform, they expect to a certain extent from Jouw Omgeving that they customise their platform to their internal care processes, protocols, and tools. While at this point providing customisation might be an essential service for the continuity of Jouw Omgeving, it also brings upon difficulties and limitations in the development. For instance, healthcare provider X wants Jouw Omgeving to develop new functionality to support process A, while healthcare provider Y intends to disable features to make process B less complicated. This amount of customisation might be feasible with a limited number of customers, but as more healthcare providers partner with Jouw Omgeving, which is already happening, it will get more complicated to offer each provider a customised solution while on the other hand remaining to safeguard the continuity and consistency of the platform. Therefore, it is yet to be questioned whether the current approach of Jouw Omgeving will be sustainable in the future and if choices made in the development process are really backed up with research. By developing functionalities and features based on these specific procedures and wishes, it might satisfy individual healthcare providers in the short-term, but it is not perceived as an effective development strategy for the long-term. This path often leads to fragmented solutions that are only applicable to the specific setting and context of the particular providers. Besides, attempting to facilitate fragmented and broken healthcare services just results in more efficient broken processes. Ideally, Jouw Omgeving should consider ways to gradually build towards a more generic platform upon which any healthcare provider or individual could join without the need to deliver much customisation. But what does Jouw Omgeving need to do to work towards such a platform?

Fundamentally, healthcare organisations delivering care services have two core objectives, to make people better or minimise the risk of health problems among individuals with a progressive or chronic disease. Every organisation has its solitary (administrative) processes and methods to achieve those goals. However, brought back to its core; every care delivery service follows the same fundamental principles. It will always start with the care need of an individual. The healthcare professional that has the first contact with the individual will gather information to determine the further path of treatment, often with the help of a diagnosis. When the diagnosis is definitive, both parties draft a treatment plan (PLAN) that consists of clear, measurable goals and a combination of interventions and or treatments. After the agreement of both sides, they execute the selected interventions according to the plan (DO). During execution, progress is monitored and measured. Then, the results are analysed (STUDY) to check if the goals were met, and the course of treatment is adjusted accordingly (ACT). This cycle repeats itself, thus facilitating continuous quality improvement, indefinitely for individuals with a chronic disease or until the individual is cured. In conclusion, each healthcare delivery follows more or less these principles during healthcare delivery. To a certain degree, Jouw Omgeving already incorporated and facilitates this cycle with their platform. However, to make the development more independent of healthcare providers and their platform more generic, the researcher proposes that Jouw Omgeving should consider the following topics towards the development of such a generic platform:

Medical record is centred on individuals and accessible to all parties involved in care

The right kind of medical record is centered around individuals and should follow them across services, locations, treatments, and other interventions. In doing so, all the data is aggregated around the individual rather than around departments of healthcare providers. In this view, the medical record is the first cornerstone of a personal health record (PHR), that Jouw Omgeving wants to offer. However, a requirement is that it has to be designed in such a way that it is not limited to specific diseases or disorders since it can follow an individual an entire lifetime. Furthermore, information architecture, metadata and visualisations are essential requirements that a medical record should meet. The information architecture should make it convenient for users to add, save and edit relevant health information. During this process, metadata should be generated which shows for example when data was first entered, when it changed for the last time, and who did those changes. Finally, the data should be displayed as comprehensible as possible, for instance through visualisation in graphs. However, to be useful in practice, the PHR should be capable of sharing information with other people that are involved in the care. This fact makes information sharing functionality the second cornerstone of a PHR. Sharing information should be possible at three levels: sharing information inside the PHR with others, between different PHR's, and between PHR's and the various EHR systems of healthcare providers. This sharing functionality should be supported by a refined process where different user roles have access to different parts of the PHR. Finally, the third and last cornerstone of a PHR is security. User-friendly security measures should be in place to ensure that it is impossible to access the medical record without authorisation and that data is not used for other purposes without the consent of the individual. It is recommended that Jouw Omgeving takes into account the previously mentioned implications during the further development of their medical record functionality.

Measurement of outcomes that matter to patients

Improvements in any field are intrinsically linked to measuring results. By tracking improvements consistently and comparing the performance to that of peers, both inside and outside their field, results will improve. In healthcare, improving quality essentially revolves around measuring health outcomes on quality metrics that matter to patients such as the ability to return to work, the time to return to physical activities, and the ability to live independently. When healthcare providers measure these kinds of outcomes, it aids them with two important business objectives. Firstly, they can gauge how they perform as institution and determine how they can improve their health services for individuals and secondly, they can answer to healthcare purchasers, with which they entered a contract, on the basis of more grounded data. Thus, Jouw Omgeving should enable healthcare providers and individuals to report on outcomes before, during and after care is completed to enable better (clinical) decision making. Their platform should make it convenient to survey patients about relevant information and subsequently, make it easy to extract this data in order to determine health outcomes. In doing so, Jouw Omgeving enhances the value of its platform for healthcare providers invariably.

Monitoring progress and measuring health parameters

Monitoring progress and measuring health parameters enables both individuals as well as healthcare professionals to get insight into the development and effectiveness of treatments or interventions. When this information is clearly visualised, individuals and healthcare professionals can recognise risky situation more quickly, make better clinical decisions, adjust the course of treatment, or preventively act on the collected information. However, it is essential to differentiate between monitoring progress and measuring health-related parameters such as heart rate or blood sugar. Where monitoring progress is convenient, low risk and relatively easy to implement (e.g. activity performed yes or no), measuring health parameters is more complicated and even risky to implement. Focusing on the wrong data, using poorly designed consumer measuring tools, or visualising data incorrectly, might cause people to make biased decisions resulting in a dangerous situation. So, for now, it is recommended that Jouw Omgeving primarily focus its attention on monitoring functionality as its easier to implement and brings less risk. While measurement functionality is undoubtedly necessary for a PHR, there are currently still too many risky downsides to be beneficial.

Motivate users

Simply put, motivation is the reason why individuals act and behave in a certain way. Incorporating motivational cues in an e-health application is assumed to be essential for inspiring individuals to become truly engaged in self-management. By embedding persuasive techniques in an e-health application (e.g. providing rewards, send reminders, facilitate social support, provide feedback), it subtly encourages individuals to form a bonding relationship with a technique. This bond becomes increasingly important if Jouw Omgeving intends to use its platform as PHR since it might be used during a whole lifetime. When individuals are not triggered or motivated in any way, they will be less inclined to use the platform. Hence, it is recommended that Jouw Omgeving deepens its understanding, through additional research, of how their platform can motivate or inspire healthy behaviors among its end users.

Agenda functionality as ‘connective tissue’

At this moment, the platform of Jouw Omgeving is still lacking an agenda functionality. However, in the opinion of the researcher an agenda could ultimately function as the ‘connective tissue’ that is currently missing in the platform. It has the potential to support, strengthen, and connect all the different modules of the Jouw Omgeving platform into one comprehensive overview. In doing so, it is expected that such a functionality could increase the usability, the user experience, and the quality of the treatment simultaneously. Below, a number of benefits of an agenda functionality are highlighted and further elaborated:

- **Flexibility and adaptability**

Offering personalised care that is tailored to the specific needs of an individual will get more critical in the future. Fundamentally, an agenda functionality creates conditions for personalisation. An individual can, in close cooperation with the healthcare professional, tailor the selected treatment or intervention in such a way that it will fit into the personal life of the individual.

- **Facilitates self-management**

After the agenda is filled with personalised events, it provides a meaningful structure for the actual execution. It shows the individual at a glance which activities (e.g. to fill in a questionnaire, to work on a treatment program, or to write a story in a personal diary) should be done at which specific moment. Automatic notifications, briefly for the start of an activity, can engage persons to stay on track. Besides, the healthcare professional can monitor and track the treatment compliance of individuals more efficiently.

- **Facilitates continuous improvement**

The flexibility and adaptability of an agenda enable continuous evaluation of activities within the daily (treatment) program of an individual. Based on the results of the evaluation, potential bottlenecks in the execution can be detected more easily. Why are specific activities not done? Are there maybe too many activities? It helps individuals as well as healthcare professionals to answer these kinds of questions more easily. As a result, they can add, adjust or remove actions accordingly. In doing so, the feasibility and quality of the treatment program are ensured continuously.

- **Facilitates collaboration between healthcare professionals and individuals**

In the future, healthcare professionals will refer individuals more often and subsequently, more healthcare professionals will be involved with the care of an individual (‘ketenzorg’). An agenda could greatly enhance cooperation between the different professionals because they can take the agenda of an individual as starting point and take into account the personal considerations of each discipline.

Adopt a ‘jobs to be done’ approach

The ‘jobs to be done’ framework breaks down the job that a customer want to accomplish into small discrete steps. The resulting map (Figure 8.1) provides a structure that enables companies to capture all the customer’s needs and to methodically identify opportunities for innovation. If Jouw Omgeving could integrate such a approach in their development process, they could systemically look for opportunities to create value and make more decisions based on what customers want instead of what healthcare providers do.

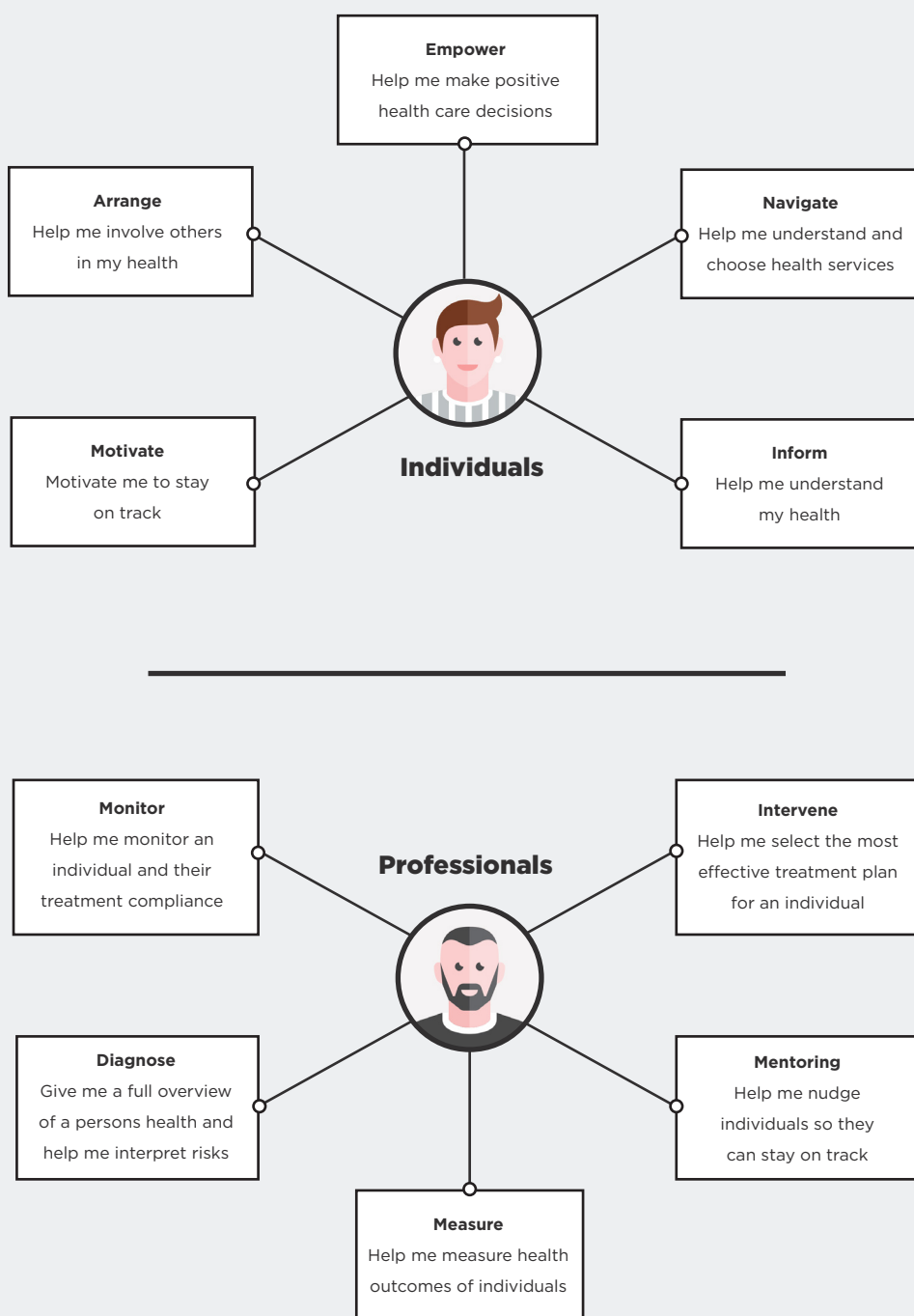


Figure 8.1 Jobs to be done approach

References

- Akkersdijk, S. M., Kelders, S. M., & van Gemert-Pijnen, J. (2016). *The Grid, Classification of eHealth Applications Towards a Better (re)Design and Evaluation*. Retrieved June 25, 2017, from: <https://ris.utwente.nl/ws/portalfiles/portal/6157530>
- Ammenwerth, E. (2015). *Evidence-based Health Informatics: How Do We Know What We Know?* Retrieved June 14, 2017, from: <http://www.ncbi.nlm.nih.gov/pubmed/26196349>
- Beernink-Wissink, J. (2015). *Floreren: Zoektocht naar goed leven voor mensen met een ernstige verstandelijke beperking en ernstige gedragsproblemen*. Eburon Uitgeverij B.V.
- Centraal Bureau voor de Statistiek. (2017). *Zorg: uitgaven en financiering vanaf 1972 [Dataset]*. Retrieved September 15, 2017, from: [http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=83075NED&D1=a&D2=0,3,8,13,18,23,29,34,39,\(1-2\)-I&HD=160517-1206&HDR=G1&STB=T](http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=83075NED&D1=a&D2=0,3,8,13,18,23,29,34,39,(1-2)-I&HD=160517-1206&HDR=G1&STB=T)
- Chugh, R. (2015). *Do Australian Universities Encourage Tacit Knowledge Transfer?* Retrieved May 12, 2017, from: Researchgate: https://www.researchgate.net/publication/286920454_Do_Australian_Universities_Encourage_Tacit_Knowledge_Transfer
- Dautzenberg, T., Dautzenberg, M., Moonen, X., & Wagemans, A. (2015). *Verkennd onderzoek naar de participatie en het netwerk van mensen met zeer ernstige verstandelijke en meervoudige beperkingen*. Maastricht: Canon Business Services.
- De Jong. (2016). *Het schijnhuwelijk tussen decentralisaties en de sociaaldemocratie*. Retrieved July 15, 2017, from: http://www.wbs.nl/system/files/arie_de_jong_-_het_schijnhuwelijk_tussen_decentralisaties_en_de_sociaal-democratie1.pdf
- De Vries, M., & Kossen, J. (2015). *This is how Dutch healthcare works*. Amsterdam, Netherlands: De Argumentenfabriek.
- Eilam, E. (2005). *Reversing: secrets of reverse engineering*. Indianapolis, America: Wiley.
- Esenbach, G. (2008). *Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness*. Retrieved May 25, 2017, from: <http://doi.org/10.2196/jmir.1030>
- Hague, P., & Harrison, M. (2017). *Market Segmentation in B2B Markets*. Retrieved October 23, 2017, from: <https://www.b2binternational.com/publications/b2b-segmentation-research/>

- Hoeymans, N., van Loon, A., van den Berg, M., Harbers, M., Hilderink, H., van Oers, H., & Schoenmaker, C. (2014). *A healthier Netherlands: Key findings from the Dutch 2014 Public Health Status and Foresight Report*. National Institute of Public Health and the Environment (RIVM).
- Houthuijs, P. (2017). *Een kind van 13 dat niet buitenkomt dat accepteren wij*. Retrieved July 12, 2017, from Nederlandse Omroep Stichting (NOS): <http://nos.nl/artikel/2182760-een-kind-van-13-dat-niet-buitenkomt-dat-accepteren-wij.html>
- Kaplan, R. M., & Babad, Y. M. (2011). *Balancing influence between actors in healthcare decision making*. Retrieved May 23, 2017, from: <http://doi.org/10.1186/1472-6963-11-85>
- Kosow, H., & Gaßner, R. (2008). *Methods of future scenario analysis: overview, assessment, and selection criteria*. Retrieved October 12, 2017, from: www.die-gdi.de/uploads/media/Studies_39.2008.pdf
- Kumar, V. (2013). *101 design methods: a structured approach for driving innovation in your organisation*. New Jersey, America: John Wiley & Sons.
- Maes, B., Penne, A., & Vlaskamp, C. (2011). *Ondersteuning van mensen met ernstige meervoudige beperkingen*. Leuven: Uitgeverij Acco.
- Miles, M., & Huberman, M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook (2nd edition)*. Beverly Hills: Sage.
- National Instruments. (2014). *Six Good Reasons to Prototype*. Retrieved October 12, 2017, from: <http://www.ni.com/white-paper/8752/en/>
- Nederlandse Omroep Stichting (NOS). (2017). *Mensen lopen complexe zorg mis door verstikkende bureaucratie*. Retrieved July 14, 2017, from Nederlandse Omroep Stichting (NOS): <http://nos.nl/artikel/2183066-mensen-lopen-complexe-zorg-mis-door-verstikkende-bureaucratie.html>
- Nussbaum, M. (2011). *Creating Capabilities: The Human Development Approach*. Cambridge, MA: Harvard University Press, p.19.
- Ossenbaard, H., van Duivenboden, J., & Krijgsman, J. (2017). *Evaluatie van eHealth technologie in de context van beleid*. Retrieved June 15, 2017, from: https://www.raadvr.nl/uploads/docs/Briefadvies_over_de_implementatie_van_e-health.pdf
- Osterwalder, A., Pigneur, Y., Smith, A., Bernarda, G., & Papadakos, T. (2014). *Value Proposition Design: How to create products and services customers want*. New Jersey, America: John Wiley & Sons.

- Oxford Dictionaries. (2017). *Value*. Retrieved October 23, 2017, from: <https://en.oxforddictionaries.com/definition/value>
- Pagliari, C., Sloan, D., Gregor, P., Sullivan, F., Detmer, D., Kahan, J. P., & MacGillivray, S. (2005). *What is eHealth(4): A Scoping Exercise to Map the Field*. Retrieved May 2, 2017, from: <http://doi.org/10.2196/jmir.7.1.e9>
- Raad van Volksgezondheid en Zorg (RVS). (2017). *Implementatie van e-health vraagt om durf en ruimte*. Retrieved June 8, 2017, from: https://www.raadrvs.nl/uploads/docs/Briefadvies_over_de_implementatie_van_e-health.pdf
- Rijksoverheid. (2013). *Zeer grote decentralisatie naar gemeenten*. Retrieved May 12, 2017, from: <https://www.rijksoverheid.nl/actueel/nieuws/2013/02/19/zeer-grote-decentralisatie-naar-gemeenten>
- Ross, J., Stevenson, F., Lau, R., & Murray, E. (2016). *Factors that influence the implementation of e-health: a systematic review of systematic reviews (an update)*. Retrieved May 17, 2017, from: <http://doi.org/10.1186/s13012-016-0510-7>
- Scott, R. E., & Mars, M. (2013). *Principles and Framework for eHealth Strategy Development*. Retrieved March 5, 2017, from <http://doi.org/10.2196/jmir.2250>
- Senge, P. (1994). *The Fifth Discipline: The Art and Practice of the Learning Organization*. New York, America: Doubleday.
- Slater, M., & Flora, J. (1991). *Health lifestyles: audience segmentation analysis for public health interventions*. *Health Educ Q.*, p. 221-233.
- Thwink. (2017). *Root cause*. Retrieved September 12, 2017, from <http://www.thwink.org/sustain/glossary/RootCause.htm>
- Thwink. (2017). *Systemic*. Retrieved October 12, 2017, from <http://www.thwink.org/sustain/glossary/Systemic.htm>
- Van Gemert-Pijnen, J., Nijland, N., Ossebaar, H., Kelders, S., Eysenbach, G., & Seydel, E. (2011). *A Holistic Framework to Improve the Uptake and Impact of eHealth Technologies*. Retrieved May 2, 2017, from <http://doi.org/10.2196/jmir.1672>
- Van Limburg, M., van Gemert-Pijnen, J., Nijland, N., Ossebaard, H., Hendrix, R., & Seydel, E. (2011). *Why Business Modeling is Crucial in the Development of eHealth Technologies*. Retrieved May 15, 2017, from: <http://doi.org/10.2196/jmir.1674>
- Van Velsen, L., Wentzel, J., & van Gemert-Pijnen, J. (2013). *Designing eHealth that Matters via a Multidisciplinary Requirements Development Approach*. Retrieved May 9, 2017, from: <http://doi.org/10.2196/resprot.2547>

- VGN. (2017). *Feiten en cijfers*. Retrieved January 05, 2017, from <http://www.vgn.nl/feitenencijfers>
- VGN. (2017). *Onhoudbare situatie in zorg voor meervoudig ernstig gehandicapten*. Retrieved July 12, 2017, from: <http://nos.nl/artikel/2182728-onhoudbare-situatie-in-zorg-voor-meervoudig-ernstig-gehandicapten.html>
- Vlaskamp, C. (1993). *Een kwestie van perspectief. Methodieontwikkeling in de zorg voor ernstig meervoudig gehandicapten* (Academisch proefschrift). Assen: Van Gorcum.
- World Health Organization. (2012). *International Classification of Functioning, Disability and Health (ICF)*. Fifty-Fourth World Health Assembly. Geneva.
- World Health Organization. (2016). *Global diffusion of eHealth: Making universal health coverage achievable (Report of the third global survey on eHealth)*. Retrieved July 3, 2017, from <http://apps.who.int/iris/bitstream/10665/252529/1/9789241511780-eng.pdf>

**Developing and applying a conceptual framework
to translate and embed '*the curriculum*' into an
existing e-health application**



Tom Oostewechel

Master Thesis Industrial Design Engineering

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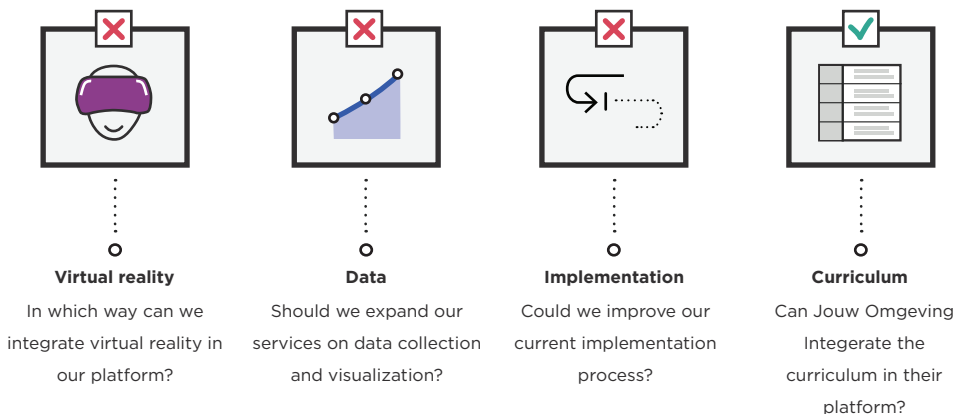
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Appendix A

Selecting a final research direction

The objective of the initiation phase was twofold: elaborate which topic could deliver the most value to Jouw Omgeving on the one hand while investigating if the topic was comprehensive enough for a graduation project on the other. The topics were researched in an iterative manner by briefly examining the rationale behind these topics and their corresponding opportunities, limitations and probable boundaries.



Topic 1: Virtual reality

Currently, healthcare organisations acknowledge virtual reality as a valid application for delivering treatments. Many researchers, companies, and healthcare organisations are exploring and evaluating areas where virtual reality can add value over traditional assessment and intervention approaches. Jouw Omgeving wants to anticipate on this development through investigating the possibilities for integrating virtual reality in their platform so they could enhance and diversify their services.

The rise of virtual reality in healthcare

The first applications of virtual reality for health care slowly began to emerge in the '90s. Since its introduction, the promise of the technology has always been high (Shapiro & McDonald, 1992). Initially, hospitals used virtual reality primarily for visualising complex data and educating key personnel, such as surgeons (Satava, 1994). Hereafter, the application of virtual reality gradually extended to other areas in the medical field such as mental health therapy, motor skills enhancement, rehabilitation, the treatment of post-traumatic stress syndrome and eating disorders (Riva, Dakanalis & Mantanovi, 2015). Despite the fact researchers and companies were given the opportunity to immerse themselves in complex virtual environments, the adoption was still slow. This slow adoption rate was partly due to the lack of usability of the technology and the high initial costs of the equipment. Firstly, it was difficult or almost impossible to use the technology without having to request the assistance of a trained technician. Also, the equipment and

the development of three-dimensional environments was still costly and time-consuming. The gap between the possibilities offered by and the actual application of virtual reality in daily practice was often too big (Riva & Wiederhold, 2015). However, this situation is changing rapidly by the recent introduction of various low-cost devices (e.g. Oculus Rift, Samsung Gear VR, Google Cardboard). These devices show promise for significant market uptake at an affordable cost. Furthermore, the continued shift from desktop to mobile devices contributes to a faster adoption of virtual reality. Using mobile devices for virtual reality has a lot of potential for both developer and user. Mobile devices are more user-friendly, better accessible, affordable and equipped with a lot of sensors that can measure relevant user data. Overall, the technique for virtual reality is quickly maturing and on the verge of a broad adoption by healthcare organisations.

The use case of virtual reality in healthcare

In general, the healthcare sector concentrates on two specific areas of virtual reality, as a simulation tool for physicians and surgeons and secondly, as an interaction tool for the (behavioural) therapists (Srivastava, Das & Chaudhury, 2014). Due to the flexibility of virtual reality, the applications are extensive, ranging from diagnosis, treatment, and rehabilitation to the design of operations rooms.

- **Simulation tool**

One of the main aims of researchers and companies is to strive towards virtual reality environments that are indistinguishable from situations in the real world. In other words, the design and interpretation of virtual objects that can affect human senses should be identical to their natural counterpart (Riva & Wiederhold, 2015). For instance, an engaging virtual reality system for the education and training of surgeons should provide realistic body parts that interact with external devices as close as possible to real life situations.

- **Interaction-tool**

The other area focusses on creating new human-computer interaction types. In this case, healthcare professionals make the shift from utilising paper-based protocols and interventions to generated 3D computer environments for treating their patient. Within this environment, the patient has the opportunity of learning, in a highly-enriched fashion, to manage a problematical situation related to their illness. On the other hand, the virtual reality environment provides the healthcare professionals with a high level of control over the course of the treatment (Girini, Gagnoli, Vigna & Riva, 2008).

The challenges of virtual reality in healthcare

Despite the recent technological advancements and development of low-cost devices, virtual reality technology is still in its infancy. In general, the more complex and costly a technology is, the less likely the user is to accept it (Riva & Wiederhold, 2015). This statement also applies to the healthcare sector. However, a significant additional condition is that the technology and related treatment forms should be widely accepted as evidence-based practices. An evidence-based practice involves integrating individual clinical expertise with the best available external evidence from systematic research, combined with the preferences, wishes, and expectations of the client. Simply put, if

certain (virtual reality) treatments or interventions are not evidence-based, healthcare organisations are much less likely to adopt it into daily practice. While there already exist many (paper-based) evidence-based protocols for the treatment of various conditions, it remains difficult to convert these protocols directly into a virtual reality based treatment. This conversion causes new obstacles ranging from technical complexity (e.g. the development of affordable, high-quality hardware), practical challenges (e.g. establishing practice and safety parameters) to user specific problems (e.g. lending virtual reality equipment to users).

Motivation

Jouw Omgeving collaborates with several organisations that are increasingly interested in deploying virtual reality as an interaction-tool for the treatment of specific conditions. Most of those organisations already have, to some extent, access to the equipment (mostly to an Oculus Rift) and have been moderately experimenting with virtual reality treatments. Nevertheless, there are still some underlying, more fundamental challenges than specified above, present in practice. Currently, these limit the adoption and use of virtual reality in healthcare organisations. At this moment, there is no framework present that defines the application and use of virtual reality in various treatment scenarios. Most of the healthcare organisations already have access to virtual reality-based treatments, but these are often very generic and mostly not evidence-based. For example, a development partner of Jouw Omgeving offers 360-degree movies to support the treatment of anxiety disorders. However, the therapist cannot tailor the video's (in real-time) to the specific needs of the client due to their static nature and lack of interactivity. The more fundamental problem is the absence of an 'inventory phase' in which researchers and healthcare professionals concur on the most relevant parameters for each condition or disease. Simply put, a patient with a fear of spiders could be afraid of the colour (parameter x) of the spider while the other might be frightened by the number of legs (parameter y) of a spider. The collection and arrangement of those parameters are decisive for designing virtual reality treatments that have the potential to be effective, interactive and, in real-time adaptable to the individual needs of the clients. Subsequently, there must be determined which technology (both hardware and software) are best suited to represent those parameters. After the design of the underlying framework, the more practical and user specific challenges should be addressed ranging from drafting practice and safety guidelines to the establishment of logistic criteria.

Conclusion

Virtual reality is quickly maturing, and the equipment is cheaper to acquire and better accessible due to the continued shift from desktop to mobile devices. Moreover, Jouw Omgeving collaborates with several healthcare providers that are increasingly interested in deploying virtual reality through the platform of Jouw Omgeving as an interaction-tool for the treatment of specific conditions. Most of those organisations already have, to some extent, access to the equipment and have been moderately experimenting with virtual reality based treatments. Nevertheless, there are still some fundamental challenges with the use of virtual reality in healthcare practice. A major obstacle is that it remains difficult to convert evidence-based protocols directly into virtual reality based treatments since this conversion creates a whole range of new barriers. At this point, the fundamental

problem is the lack of an underlying framework that indicates what parameters are most relevant for each condition or disease and subsequently, in which way these parameters should be used in the design of virtual reality treatments. Besides, researchers and healthcare professionals should concur on which hardware and software are best suited to represent those parameters. Finally, there are various practical (e.g. quality of hardware) and safety barriers (e.g. unattended treatment) that need to be tackled. While the mentioned challenges are extensive enough to be addressed in a possible graduation project, it was concluded that pursuing virtual reality does not fit well within the context of Jouw Omgeving. The bottom line is that virtual reality has currently too many downsides that make it not financially or strategically attractive for Jouw Omgeving to pursue this direction at this point.



Topic 2: Data collection and visualisation

Currently, technology continues to evolve, and the data creation is growing exponentially, where 90% of the data in the world has been created only during the last two years. Healthcare organisations face new challenges regarding data collection and visualisation where having access to data is not enough since healthcare data is complex and voluminous. To fully leverage data to improve a patient health, healthcare organisations must be able to integrate and align data from different sources so they can create insights that can directly impact and improve the quality of human lives. At this moment, Jouw Omgeving is already analysing the online behaviour through their platform by applying various analytical tools. Mainly, Jouw Omgeving wants to identify if they need to expand their services on data collection and visualisation.

Data in healthcare

Historically, the healthcare sector has always generated vast amounts of data. Essentially, thorough record keeping, compliance and regulatory requirements, and the complexity of patient care all attributed to this high data generation (Raghupathi, 2010). Now, healthcare organisations still record many types of data in paper archives but are digitising patient records in an ever-increasing rate. Furthermore, they are increasingly monitoring patient related data through connected medical equipment, smartphone applications, and home automation.

The challenges of data in healthcare

The rapid digitalisation and collection of patient related data also bring new challenges. Research indicates that big data is growing faster than healthcare organisations can consume (Hansen et al., 2014). Besides, 80% of this data is still unstructured, which means it is not contained in a database or some other data structure (specific format for organising and storing data). However, most of this data is regarded as clinically relevant. One of the fundamental challenges of data collection is to leverage this 'big data' to gain a better understanding of, for example, the patient's needs, the course of the treatment and the effectiveness of treatment or medicine. However, this complex process requires very specialistic knowledge. Furthermore, after the data is collected and structured, the data must be visualised and presented in such a way that the users are motivated to make the right decisions to improve their health independently.

Motivation

Jouw Omgeving can contemplate on two possible objectives with data collection and visualisation. On the one hand, they could utilise data to improve the user experience of their platform while on the other, they could provide healthcare organisations with valuable insights into the progress of treatment, which eventually could empower them to improve their care services. However, due to the fact Jouw Omgeving operates in the healthcare landscape, there are strict privacy and confidentiality restrictions which ensure that tracking of individual users, for example with Google Analytics, is prohibited. These limitations make it troublesome to collect data that could be used to optimise the functionality and user experience of the platform. Furthermore, Jouw Omgeving analyses, through their platform, the specific online behaviour of clients and professionals of associated healthcare organisations by applying various analytical tools. In contrast to, e.g. Google Analytics, these tools do not store data beyond the secure certified servers of Jouw Omgeving, and therefore, this form of data collection is permitted. Simply put, these tools retrieve data from the platform and subsequently, visualise this data in a web portal that is accessible for affiliated healthcare organisations. The analytical tools monitor, among other things, the following daily components: the number of active users, the amount of chat and messages sent, awards created and handed out, and completed action points. Currently, healthcare organisations utilise this data, for example, to create actionable management information.

Conclusion

Historically, the healthcare sector has always generated vast amounts of data but are currently digitising patient records in an ever-increasing rate. Potentially, if this data is structured, interpreted and presented in the right way, it holds the promise of supporting a broad range of medical and healthcare functions. However, 80% of this data is still unstructured while healthcare professionals regard most of this data as clinically relevant. One of the fundamental challenges of data collection is to leverage this data to gain a better understanding of the patient's needs, the course of the treatment and the effectiveness of treatment or medicine. However, this complex process requires very specialistic knowledge. Besides, the visualisation of the data should motivate users to make the right decisions which improve their health independently of a healthcare professional. Currently, it is debatable whether the platform, in its current structure, can gather enough relevant data and subsequently, present it to healthcare organisations and clients in such a way that could incite activities which could improve, for example, the current treatment. Primarily, the main concern is the limitation in tracking users, which eventually is causing fewer opportunities for both improving the user experience of the platform as providing valuable insights into the progress of treatment. Therefore, the conclusion is that it is currently not worthwhile for Jouw Omgeving to offer additional services for data collection and visualisation.



Topic 3: Implementation

Nowadays, it is apparent that e-health technology has, despite the present issues and challenges, a lot of potential for substantially reducing cost and improving the efficacy of healthcare. Nevertheless, e-health technologies often face adoption problems. Overall,

there are many reasons for the difficulties encountered with the implementation of e-health ranging from fragmented literature, poor communication between stakeholders to sceptical healthcare professionals (Ross, Stevenson, Lau, & Murray, 2016). Now, Jouw Omgeving is struggling, to some extent, with these widespread difficulties and wants to explore in which way they could improve and optimise their implementation method.

Motivation

Implementing an e-health technology has a large impact on the primary care processes and business operations in general. Hence, Jouw Omgeving has implementation experts who are actively involved in the implementation of the platform in healthcare organisations. To support the complex process, they developed a method which offers guidance to organisations in the implementation process. The method is based on the normalisation process model (NPM) which is a sociological model explaining why some new technologies become fully embedded in practice, and others do not (Murray, May & Mair, 2010). Furthermore, Jouw Omgeving supplemented the method with extensive knowledge and experience, which was built up over the years during the deployment of the platform to several healthcare organisations. The method enables healthcare organisations to make an initial scan of their business and on which scale they are ready to start an implementation process. The scan is repeated multiple times throughout the implementation phase to monitor the process and to determine if goals were reached or need adjustment.

Conclusion

Overall, implementation is a complex process with a lot of interdependencies and widespread difficulties. However, it became evident that Jouw Omgeving is already putting a lot of effort in the implementation process. They developed their implementation tool and have experienced implementation managers that guide the implementation process in healthcare organisations. In conclusion, there were no concrete opportunities present within this direction that provide sufficient cause to start a new project.



Topic 4: Curriculum

The Quality of Life Centre is a company that supplies coherent products and services to all key stakeholders in the healthcare sector in the Netherlands. They position themselves as expertise and resource centre in the knowledge landscape of persons with complex intensive support needs (CISN). CISN is a generic term for all in the Netherlands existing subgroups within the disabled care and specifically emphasizes on questions of people instead of their limitations or disabilities. The Quality of Life Centre identified an existing fragmentation in the field of care and education for people with CISN. They regard the current curricula as incomplete since they are not capable of transcending domains and are not integrally applicable. Most of these curricula are not sufficient for the parents and children with CISN (from now on referred to as end users). These end users and close relatives get astray in the healthcare landscape and do not receive care and education tailored to their needs. Besides, professionals have no prescriptive advisory and work system that could be applied integrally and is capable of transcending domains (not related to legislation, type of care or living environment).

Currently, the Quality of Life Centre has partly solved the described problem. They combined the current care and educational curricula into one coherent curriculum that is both integrally applicable and capable of transcending domains. Furthermore, the Quality of Life Centre based their curriculum on a knowledge framework, which serves as a basis for all their products and services. This framework revolves around the Capability Approach (Nussbaum, 2011) and the derived intervention 'Floreren' (Beernink, 2015), the Quality of Life Concepts (Schalock et al., 2002), the International ICF framework (WHO, 2001), and principles of the UN Treaty (WHO, 2001). A central pillar of the curriculum development was the evidence-based methodological framework of Vlaskamp (Vlaskamp, 1993). This method describes a roadmap that enables parents and professionals to offer support tailored to the needs and wishes of persons with profound and multiple disabilities. The Quality of Life Centre applied this roadmap as the foundation for their curriculum and supplemented it with additional (sub)steps and filled it with (existing) knowledge products and services. Presently, these products and services are mainly deployed solitary and used in the care and educational practice whether appropriate or not. Therefore, the Quality of Life Centre organized and classified those products and services through utilizing the systematic steps embedded in the Vlaskamp method. This process further detailed the curriculum and intends to make the Vlaskamp program more user-friendly and better accessible to the end user and professionals from the care and educational field. It should provide them a founded prescriptive advisory and work system. However, in its present form, the Quality of Life Centre cannot provide the curriculum in an efficient and widespread manner to the end users and professionals. Presently, there is a lack of a digital infrastructure and accompanying software. According to the Quality of Life Centre, the curriculum needs to be converted into a convenient 'online version.' This transformation process requires additional product as well as process development to ensure that the vision and intended purpose of the curriculum are secured.

Proposition for collaboration between Jouw Omgeving and Quality of Life Centre

During the initiation phase, it became evident that Jouw Omgeving has the right resources and knowledge, such as an existing online platform and the technical know-how to facilitate the problem of the Quality of Life Centre. Ordinarily, in a typical client – contractor relationship, the Quality of Life Centre will compile a set of requirements and collaborative conditions and will pay Jouw Omgeving for the services that are needed to develop an online version of the curriculum. However, considering the recent developments in the healthcare landscape and the observed problem of Jouw Omgeving, this project plan proposes to make Jouw Omgeving co-owner of the problem of the Quality of Life Centre and vice-versa. Both parties operate in the same healthcare landscape and are both equally subjective to the developments that are taking place. They should move along and adequately adjust their services to those recent developments. These adjustments enable organisations to respond actively to new developments rather than reactive, and may eventually yield key advantages over competitors. More specifically, both parties operate in the disability sector, where the Quality of Life Centre has the universal and specialistic knowledge and services, while Jouw Omgeving has the appropriate online platform and the intention to become the market leader e-health in the entire disability sector. Hence, it is evident that both parties can strengthen each other through collaboration. On the one hand, the curriculum can potentially contribute

to the observed problem of Jouw Omgeving. The curriculum is equally relevant to a person, regardless of the complexity of the support questions. Theoretically speaking, the current assumption is that the curriculum could provide the necessary knowledge foundation for Jouw Omgeving of working towards a universal platform. Furthermore, the curriculum primarily focuses on people with CISON, which means it can contribute to a market expansion for Jouw Omgeving. Meanwhile, Jouw Omgeving can contribute to the need of the Quality of Life Centre since they have an existing digital infrastructure and the technical knowledge needed to translate the curriculum into a suitable online variant. Through cooperating on an equal basis, both parties can create circumstances in which they could reach significant synergy advantages. Consequently, both companies will feel equally responsible for execution and results of this project. Through providing preliminary insight into these synergy benefits, it should be easier to reach consensus on the allocation of the roles and responsibilities throughout the project and more importantly, ensure continuity after the completion of this project. Table A.1 depicts an overview of the comparison of both companies on multiple areas.

Area	Quality of Life Centre	Jouw Omgeving
Supply channel	All key stakeholders in the healthcare sector in the Netherlands	All key stakeholders in the healthcare sector in the Netherlands
Market position	An expertise and resource centre in the knowledge landscape of persons with CISON	Market leader in e-health for youth care and persons with a mild mental disability
Short term goal	Disclose the curriculum in an efficient manner that fits the current technology driven society	Achieve a leading position for supplying e-health to the entire disability sector
Long term goal	Become market leader regarding a standardised curriculum for health and education for the entire disability sector	Systematically work towards a platform that is suitable to use as a personal health environment (PHR)
Method	Applies a process-orientated method, where it attempts to work as closely as possible with different stakeholders	Applies a process-orientated method, where it attempts to work as closely as possible with different stakeholders
Expertise	Extensive knowledge on the care and education of persons with CISON, training, supporting children, advice	Visual design, user interface, design, technical realisation, and training and implementation of e-health in practice

Table A.1 Comparison of both companies on multiple business areas

Appendix B

The implications of CISN for a person

In their daily lives, persons with CISN are very 'care intensive' for persons in their direct environment. Compared to 'normal' peers, they have additional support questions and are permanently and often non-stop (24/7) dependent on the help of others. In all situations, there is a disorder and/or mental disorder present which varies from mild to very severe. Thus, the support questions of these persons also span and range over different areas such as nursing, physical care, medical treatment, regular treatment, therapy, permanent supervision, communication support, daily life activities, learning, behavioural interventions, continual stimulation, and individual as well as group support (Expertisecentrum EMB, 2017). The nature and gradation of support questions eventually determine the intensity and complexity of care. Hence, the target group CISN is comprised of persons who form a heterogeneous population. Heterogeneity implies that individuals with CISN all have different characteristics and are therefore difficult to define unambiguously. The Quality of Life Centre uses the term CISN as a generic term for existing subgroups within the disabled care and specifically emphasises on questions of people instead of their limitations or disabilities.

What immediately strikes persons with CISN is that their limitations are profound and unquestionable. Consequently, their limitations are thus much more exposed than their possibilities. Besides severe cognitive and physical limitations, there are often additional motorial limitations that impede persons with CISN to walk independently or without the help of tools (Hiemstra, Vlaskamp, & Wiersma, 2007). Usually, there are also critical limitations in their sense of perception which indicate that the processing of sensory information in the brain is severely disturbed. Hence, they often cannot hear or see correctly, where the extent to which they can process information is problematic to map. In addition to limited eyesight and hearing, some persons with CISN have problems with their sense of touch and are therefore hypersensitive or even less sensitive for physical contact. Along with a lack of sight and hearing, the taste, sense of balance, posture and movement, smell, and taste could be absent or might not function correctly.

Communication on a different level

People with CISN often do not possess an active or passive understanding of a language (speech, gestures or use of symbols). Mostly, they communicate through body language and use different movements that alter in frequency, intensity, and direction. They make sounds with a changing intonation, pace, pitch and they show physiological responses such as variations in the tempo of respiration, muscle tension or pupil dilation. Even the most basal facial expressions such as raising eyebrows or making eye contact are a means of communication. It is evident that persons with CISN have communication possibilities, but the signals are often so subtle that they require a lot of observational ability to even recognize those signals in the first place and subsequently, act accordingly. Hence, for many persons it is hard to participate in group activities since they might not perceive what others are doing or they do not grasp the right social skills needed for group interaction such as 'waiting till it's your turn'. This highly influences the way in which these persons function in social situations.

Health and behaviour

Overall, persons with CISN are very vulnerable and have a substantially increased risk of health problems. Diagnosis and treatment are difficult since a person cannot verbally express and indicate what is wrong with him or her. There is often a question of epilepsy, constipation, and reflux. Sleep problems are also very common. Often, they have trouble with falling asleep, problems in staying asleep, and even following another sleep rhythm and thus sleep at times when there are day time activities. Many persons with CISN have problems with eating due to swallowing problems. Consequently, respiratory tract infections often occur. With the advancement in age, even more, health problems might come to the surface or develop. For example, there is a change that due to growth, abnormalities occur in the skeleton or that existing problems grow in intensity. Besides the physical limitations, there are often various behavioural problems such as self-inflicted injuries, stereotyping (e.g. making the same movements, screaming), and finally, retracted behaviour.

Small differences, major implications

Within the heterogeneous group, all the previous mentioned disabilities and disorders might vary in severity and occur in different combinations from person to person. Most of the time, the severe disabilities were caused by brain damage due to a chromosomal aberration, infection, metabolic disorder or complication before, during or after birth. It frequently occurs that the cause is not known. Thus, persons with CISN differ from each other in physical condition, motorial skills, and visual and communicative possibilities. Some of them are indeed able to point out things, grab objects or even say a few basic words. Thus, they can make clear what they want, while others are not able to communicate at all. Some people can move independently, while other persons depend on caregivers to move. Other people have a short attention span regarding things in their immediate environment which makes it difficult to establish contact or learn new things. Some can see over a distance of a few meters so they can see who enters or leaves a room while others are dependent on their other senses and stimuli such as smell or the sound of a voice.

Furthermore, one person might indicate that he has pain and thus ask for comforting while the other is not able to do this and might retract himself. Another important attribute is time since the behaviour from certain persons might change as they age, and even lose opportunities that they previously had. These differences might seem small and irrelevant at first but often have significant consequences for direct interaction. Another characteristic is the lack of compensating possibilities. People with CISN experience limitations that extend over all areas of human functioning and their support needs, therefore, differ greatly per individual. Generally, they don't have a strong area that they can use for compensating a deficit on other fields.

Almost completely dependent

Simply put, persons with CISN are all very different. However, a common feature is that their limitations almost always result in an excessive 24-hour dependence on the support system of a person with CISN (Maes et al., 2011). Obviously, persons with CISN have the right to the best possible development, but they are not able to independently discover

the world and obtain experiences. To this end, they need relationships with others such as their family and associated professionals. These relations can make their world understandable and secure on the one hand while keeping it also exciting and challenging enough on the other. This process asks for much commitment from all those involved, and the vitality, well-being, and happiness of persons with CISN are therefore mainly determined by the attitude and dedication of those involved.

Social network

In general, persons with CISN that are living at home or in an institution often have a (very) small social network. This social system primarily consists of members of the family, grandparents, and the professional network that is formed by the family. Generally, they don't have their connections and are not able to enter individually into one. Besides, a family member with CISN heavily influences the whole dynamic within a family. The intensity of care has a tremendous impact on the life of the members of a family since their daily tasks and activities mainly revolve around addressing the care needs of the person with CISN. Other, also important family duties and activities, are often organised around the care needs, postponed, or even neglected. As a result, parents experience little freedom and flexibility due to the intensive care tasks they perform every day and are often physical, practical and emotionally burdened. Contact and social activities are taking place less frequently and spontaneous. Consequently, the social network around the family decreases over the years. Besides, when a person with CISN gets older, the intensity and gravity of the support need gradually increase. Certain care tasks become so precise, complicated or liable that these cannot be carried out by caregivers in the direct network. These difficulties force the parents to rely on professionals to continue the care at home.

Conclusion

In their daily lives, persons with CISN are very 'care intensive' for persons in their direct environment. Compared to 'normal' peers, they have additional support questions and are permanently and often non-stop (24/7) dependent on the help of others. They often do not possess an active or passive understanding of a language (speech, gestures or use of symbols). Overall, persons with CISN are very vulnerable and have a substantially increased risk of health problems and with the advancement in age, even more, health problems might come to the surface or develop. Within the heterogeneous group, disabilities and disorders might vary in severity and occur in different combinations from person to person.

Hence, they differ from each other in physical condition, motorial skills, and visual and communicative possibilities but their limitations almost always result in an excessive 24-hour dependence on the support of others. Due to their limitations, their social system primarily consists out of members of the family and their professional network. Often, they don't have their connections and are not able to enter individually into one. Finally, a family member with CISN heavily influences the whole dynamic within a family. The intensity of care has a tremendous impact on the life of the members of a family since their daily tasks and activities mainly revolve around addressing the care needs of the person with CISN. Consequently, the social network around the family decreases over the years.

Appendix C

Business Environment Analysis

This appendix presents the results of an elaborate analysis of the Dutch healthcare landscape, which is the environment both the Quality of Life Centre and Jouw Omgeving operate in. The objective of the analysis was to uncover the changes that are happening in the field that might influence and affect the topic described in this research project. The business environment is described alongside three topics: key trends, market forces, and industry forces.

Key trends

(Technology, regulatory, societal, cultural, and socioeconomic trends)

- **Rising life expectancy due to prevention and improved healthcare**
Since 1950, the average life expectancy increased by nearly eleven years, to eighty-one years in 2014. According to recent scenarios, the life expectancy will continue to rise, but less steeply than over the last decades (Hoeymans et al., 2014).
- **People are developing chronic diseases at an earlier age**
This growth is partly attributable to the ageing population but also to the improvements made to medicine and diagnostics. Diseases that were once untreatable became treatable, and besides, an early detection of a chronic illness implies that people will live longer with their disease. As with the life expectancy, the prevalence rate of chronic illnesses is expected to increase.
- **Rising healthcare expenditures**
Between 1973 and 2014 healthcare expenditures grew from 8,7% to 14,2% of GDP (CBS, 2017), where the highest cost was for the categories cardiovascular disease, other mental disorders and intellectual disabilities. The expenditures are expected to rise, but at which rate remains difficult to predict.
- **Legislation and initiatives shift towards autonomy and freedom of choice**
Individuals with health problems are more engaged in managing their own care and reinforced with technological and e-health resources resulting in more personally tailored care, more self-management and self-reliance. It is expected that future generations will prefer and demand more shared decision-making (Hoeymans et al., 2014).
- **A stronger voice for the individual, more empowerment**
The patients right act gives patients, clients and their representatives a stronger voice in their treatment (De Vries & Kossen, 2015)
- **Decentralisation: 'bringing care closer to the people'**
The transfer of functions and responsibilities from the central government to the local authorities. In doing so, the government assumes that local authorities can offer more targeted care and better meet the individual needs against lower cost and with less bureaucracy (Rijksoverheid, 2013).
- **Laws encourage reliance on social network**
Before relying on publicly provided care, citizens should arrange care within their own personal networks (parents, friends or relatives).

- **Changing relation individual – healthcare provider**

Delivery of care will be increasingly independent of the time and place. Private individuals will gain access to opportunities for performing self-diagnosis and self-treatment where healthcare providers will probably shift their focus to complex diagnostics and joint decision-making, in which personal considerations are decisive (RVZ, 2015).

- **New technological developments**

Fast rise of new e-health resources, that enable self-management, such as applications for smartphones and wearables, health platforms, and personalized health records. Future technological developments such as artificial intelligence, sensors and robotics will allow decision-support, self-diagnosis and self-treatment (RVZ, 2015).

- **The demand for care will increase in which there will be regional differences**

People are growing older which will result in an increase in the demand of care. Besides, due to demographic differences, young people living in the cities will need other types of care than elderly that live in the province.

Market forces

(Market issues, market segments, needs & demands, revenue attractiveness)

- **Imbalance between actors**

There is a market imbalance between the three actors in the healthcare landscape: individuals experience huge information asymmetry compared to health providers and purchasers and therefore, lack resources to manage the risk of illness properly.

- **Few early adopter's resulting in slow adoption**

In the healthcare market, there are barely any paying consumers and thus, few early adopters. The largest part of the market is determined and controlled by financing health insurers (Dohmen, 2013)

- **Payment structure penalizes new ways of working**

Generally, healthcare purchaser's work with annual contracts which discourage healthcare providers to invest in innovative processes since they have no long-term security in earning back their investments (RVZ, 2017).

- **Fragmented market**

The healthcare market has multiple sub-markets (sectors) which differentiates itself by sector-bound characteristics. Effectively, there is no single healthcare market but all sub-areas that interfere with each other. However, they all have their distinct dynamics and financial frameworks. (Dohmen, 2013).

- **Highly regulated market**

The collective payment of healthcare results in strong regulation which is defined by norms, standards, and guidelines which obstruct and delay new ways of working (RVZ, 2017).

- **Primary focus on process improvement**

Annual contracts between healthcare purchasers and healthcare providers discourages them to invest in innovative processes since the return on investment is highly uncertain.

Industry forces

(Competitors, substitute products, services, stakeholders, suppliers, value chain actors)

- **An plethora of stakeholders**

The healthcare sector has a plethora of stakeholders that each have an own agenda with often conflicting and competing interests. The incumbent stakeholders have many resources and power to influence public policy and opinions (Herzlinger, 2006). Ideally, innovators should be capable of recognizing the complex interests of the different stakeholders.

- **Lack of funding and investors**

Funding innovations in healthcare brings multiple financial challenges for investors. Beforehand, it is often not clear who will pay for the eventual product or service. Besides, the healthcare sector has complex, regulations, payment structures and reimbursements, which deter investors.

- **Accountability for the innovator**

Healthcare purchasers often make (technology) innovators accountable for their innovation. They require that the innovator meets the demand of the payer, for instance, by proving cost-effectiveness, long-term safety, and safety requirements. However, without funding these demands are not easy to meet.

- **Provider shortages**

Patients have to wait longer and longer for (specialistic) care or treatments due to a shortage of personnel.

Appendix D

The four core acts

The Healthcare Insurance Act (2006)

Focus - Providing curative care with an emphasis on serving to cure or heal.

Context - All private individuals that work or live in the Netherlands are required by this law to insure themselves for medical expenses (Healthcare Insurance Act, 2006). They can buy insurance policies from health insurance companies. This policy gives them access to basic entitlements such as general practitioner care and much of specialized medical care, medicines, and mental care. Furthermore, they might choose to purchase supplementary insurance, for example, physiotherapy or maternity care.

Dutch abbreviation: *'ZVW – Zorgverzekeringswet'*

The Long-Term Care Act (2015)

Focus - Government of high level care and intensive forms of support

Context - Covers private individuals who require 24/7 care and supervision, for example, due to a (severe) mental or physical disability. The act ensures that they are entitled to either home-based or institutional care (The Long-Term Care Act, 2015). This act is primarily designed for individuals who are not able or no longer capable to look after themselves, mostly because they have a disability or are old.

Dutch abbreviation: *'WLZ – Wet Langdurige Zorg'*

The Social Support Act (2015)

Focus - Support private individuals to live at home for as long as possible

Context - The act states that local authorities (often municipalities) are responsible for supporting people who are not self-reliant (Social Support Act, 2015). The act ensures that private individuals can be self-reliant and productive members of society for as long as possible. Local authorities must ensure that individuals receive the appropriate care that they need, for instance help with housekeeping.

Dutch abbreviation: *'WMO – Wet Maatschappelijke Ondersteuning'*

The Healthcare Insurance Act (2006)

Focus - Government of all health services for young people in the Netherlands

Context - The act states that local municipalities are responsible for decreasing the number of children in specialized care, increasing preventive and early intervention support, and the promotion of utilizing the social network of the private individual (Dutch Youth Care System, 2015).

Dutch abbreviation: *'Jeugdwet'*

Appendix E

Literature study

This appendix presents the results of an elaborate literature study of e-health applications. The objective was to identify failure factors of e-health and successful concepts for e-health development. Subsequently, failure factors were classified into one of the four groups and coupled to the identified successful concepts (Appendix F).

Class	Failure factor	Source	Concept (Appendix F)
System	Standardisation of products and processes limits exploration of new ways of working and small-scale customisation	RVS (2017)	[-]
System	Annual contracts discourage healthcare providers to invest in innovation processes since they have no long-term security in earning back their investments	RVS (2017)	Bypass by transferring ownership of the e-health application from healthcare provider to the individual
System	Innovations inherently provide a potential saving elsewhere in the care chain resulting in that the investor is not necessarily the one that collects the reimbursements	RVS (2017; Ossenbaard et al. (2017)	Social Return On Investment (SROI); Cost Effectiveness Study; Business modeling
System	Savings and budget cuts are realized through (small) yearly decreases in budgets of healthcare providers which stimulates them to focus on incremental improvement rather than innovation	RVS (2017)	Bypass by transferring ownership of the e-health application from healthcare provider to the individual
System	Payment structure penalizes healthcare providers for successful e-health applications where it leads to high investments and lower revenue, which eventually results in a decrease of budget	RVS (2017; Schippers & van Rijn (2014)	Bypass by transferring ownership of the e-health application from healthcare provider to the individual

Class	Failure factor	Source	Concept (Appendix F)
System	The collective payment of healthcare results in strong regulation defined by norms, standards, and guidelines which obstruct and delay new ways of working	RVS (2017; Van Limburg et al. (2011); Van Gemert-Pijnen et al. (2011)	[-]
System	A lack of early adopters within the healthcare sector	RVS (2017	[-]
Development	An unawareness of complex stakeholder relationships with interdependencies between technology, people and sociocultural environment	Van Gemert-Pijnen et al. (2011); Van Limburg et al. (2015)	System thinking, Stakeholder identification, Stakeholder network
Development	A lack of adaptability to adjust the e-health application to better fit the local context.	Ross et al. (2016)	End user participation
Development	A lack of interoperability and open API's results in high cost due to extensive system adjustments. There is an inability of new systems to exchange information with systems already in place	RVS (2017); Ross et al. (2016); Schippers & Van Rijn (2014)	[-]
Development	A lack of end-user and stakeholder engagement in the development	Ross et al. (2016); Van Gemert-Pijnen et al. (2011)	Value Proposition Design, Customer Segmentation
Development	A lack of cooperation between healthcare providers, health insurance companies and ICT providers results in the development of solitary solutions that often serve the same goal	Schippers & Van Rijn (2014)	Establish partnerships, involve patient associations

Class	Failure factor	Source	Concept (Appendix F)
Development	The high cost of e-health systems associated with development, implementation, ongoing cost and cost related to a loss of revenue.	Ross et al. (2016); Van Limburg et al. (2011)	Cost-effectiveness study, Business modelling
Development	A lack of evidence about the distinct effects of e-health technologies on health and healthcare	Ross et al. (2016); Van Gemert-Pijnen et al. (2011)	[-]
Development	The fragmented use of classification leads to a biased comparison, non-standardised evaluation and an overall lack of scientific evidence on efficiency and quality	Ossenbaard et al. (2017); Akkersdijk et al. (2016)	Formal evaluation, Summative evaluation
Organisational	E-health applications do not fit well within work practices of end users or the daily clinical work	Ross et al. (2016)	Workflow analysis
Organisational	E-health applications disrupt existing workflow and established professional roles	Ross et al. (2016)	[-]
Organisational	A lack of leadership engagement and involvement of implementation champions	Ross et al. (2016)	[-]
Organisational	Organisation readiness for the implementation of e-health applications	Ross et al. (2016)	[-]
Individual	Uncertainty among the involved actors about the expected benefits and impact of e-health applications hinders choosing	Ossenbaard et al. (2017); Van Limburg et al. (2011)	[-]
Individual	Low e-health literacy	Ross et al. (2016)	[-]

Appendix F

Successful concepts

This appendix presents an overview of different concepts (frameworks, approaches, methods, tools) mentioned in literature and are assumed to be capable of overcoming one or more failure factors.

Concept	Goals	Source
Business modeling	To explore early opportunities for an e-health application, to make the development process stakeholder focused and value driven, to provide evidence of cost-saving	Van Limburg et al. (2011), Osterwalder et al. (2010)
Customer Segmentation	To divide the target market into segments, to identify the most valuable groups, to determine the end user groups of an e-health application	Van Velzen et al. (2013), Hague & Harrison (2017)
Descriptive Value Web (DVW)	To reveal the stakeholders that are involved in the development or use of an e-health application	Kumar (2013)
End user participation	To improve usability, to increase adaptability, to reduce complexity, to uncover needs and wishes	Ross et al. (2016), Dohmen (2012), Van Limburg et al. (2011)
Formal evaluation	To inform system development, to evaluate impact, to monitor and measure the Consumer Quality Index (CQI)	Pagliari (2007)
Human centered approach	Approach that starts with the people you're designing for and ends with new solutions that are tailor made to suit their needs	Van Gemert-Pijnen et al. (2011)
Prescriptive Value Web (PVW)	To show how value will flow in a network structure if new nodes or links are introduced or existing nodes or links are modified	Kumar (2013)
Prototype Design	To fail early and inexpensively, evaluate and gather more accurate requirements, resolve conflicts between designers and developers, uncover the technical challenges of a new design, attract financing more easily	National Instruments (2014)

Concept	Goals	Source
Requirement specification	To improve usability, to prevent inclusion of superfluous features, to prevent spending of money	Van Velsen et al. (2013)
Scenario's	To facilitate the discussion about the e-health application, to present conceptual models, to provide multi-angle viewpoints (political, social, clinical, and behavioural)	Van Gemert-Pijnen et al. (2011)
Schooling	To increase staff acceptance of e-health applications, to challenge negative attitudes	Ross et al. (2016)
Stakeholder identification	Aims at creating a list of stakeholders that need to be involved in the design of the e-health application	Van Velsen et al. (2013)
Stakeholder network	To map the involved stakeholders, to understand the relations between them, to grasp how value is exchanged and flows between stakeholders	Van Gemert-Pijnen et al. (2011)
Stakeholder participation	To retrieve value needs of involved stakeholders which guide the design of the technology as well as the success of implementation	Van Gemert-Pijnen et al. (2011), Van Limburg et al. (2011), Dohmen (2012), Ross et al. (2016)
System thinking	Approach that offers a set of analytical tools to improve the capability of identifying and understanding systems, predicting their behaviours, and devising modifications to them to produce the desired effects	Arnold & Wade (2015)
Value Proposition Design (VPD)	To reveal value drivers of an e-health application, to determine the benefits end users can expect from an e-health application	Osterwalder et al. (2014)
Workflow analysis	To provide insight into the specific collection of tasks, to reveal resources and information objects that are present in an organisation and determine how they relate to an e-health application	Ross et al. (2016)

Appendix G

A comprehensive list of ‘pains’ and ‘gains’

This appendix presents the results of an elaborate analysis of the available documentation and insights of the Quality of Life Centre, including the results of an extensive international project Enablin+ (2014 – 2017). By analysing this documentation and through multiple consultation sessions with the Quality of Life Centre, a comprehensive list with ‘pains’ (●) and ‘gains’ (●) was compiled.

Topic	Statement	Label	Source
Knowledge	Professionals are often unable to properly apply knowledge products	●	Project Enablin+ (2017)
Knowledge	Knowledge is available in a fragmented manner (internet, books, organisations)	●	Project Enablin+ (2017)
Knowledge	The quality and reliability of knowledge products can hardly be controlled	●	Quality of Life Centre (2017)
Knowledge	Insufficient information about existing tools and knowledge products	●	Project Enablin+ (2017), Quality of Life Centre (2017)
Knowledge	There is no insight and overview of the necessary facilities for education, rehabilitation and treatment in the region	●	Quality of Life Centre (2017)
Knowledge	Local networks insufficiently share knowledge with each other	●	Project Enablin+ (2017)
Knowledge	Existing knowledge regarding my child's support questions is poorly accessible and difficult to apply	●	Quality of Life Centre (2017)
Knowledge	There is no common terminology framework available for the target group CISN	●	Quality of Life Centre (2017)
Knowledge	Available knowledge products are applied solitary and ‘ad hoc’	●	Quality of Life Centre (2017)
Knowledge	The transfer of knowledge over CISN through vocational training is minimal	●	Quality of Life Centre (2017)
Knowledge	My experience is insufficiently included in the choices that are made for my child	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Knowledge	Involved persons communicate in the same language and work in unison	●	Quality of Life Centre (2017)
Knowledge	Provide better information and advice on knowledge for the target group CISN	●	Quality of Life Centre (2017)
Knowledge	Communicate in the same language with the different stakeholders that are involved	●	'POZ' (2017)
Knowledge	An (regional) overview of facilities that are suitable for my child	●	'POZ' (2017), Quality of Life Centre (2017)
Knowledge	Get insight in which knowledge products are already investigated for the target group	●	Quality of Life Centre (2017)
Knowledge	Targeted and efficient application of knowledge products	●	Quality of Life Centre (2017)
Knowledge	Understanding the context and application of knowledge products (situational awareness)	●	Quality of Life Centre (2017)
Knowledge	Knowledge products are rated with a quality mark	●	Quality of Life Centre (2017)
Care and education	Daily programs within organisations are not tailored to the needs of my child	●	Quality of Life Centre (2017)
Care and education	The offered help for my child and our family is often incidental and not preventive	●	Quality of Life Centre (2017)
Care and education	We as parents are surrendered to the current services for my child	●	Quality of Life Centre (2017)
Care and education	These children learn fragmentarily and that requires expert guidance	●	Quality of Life Centre (2017)
Care and education	Students achieve inadequate outcomes during learning activities	●	Quality of Life Centre (2017)
Care and education	Fragmented collaboration between care and education	●	Quality of Life Centre (2017)
Care and education	There is insufficient and fragmented imaging and diagnostic available for my child	●	Quality of Life Centre (2017)
Care and education	Fragmented 'imaging' and care services for the target group CISN	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Care and education	The indication statement for the support of my child is often not complete	●	Quality of Life Centre (2017)
Care and education	The facilities of these children do not increase as the child grows older and the care needs increase	●	'POZ' (2017)
Care and education	Sink into the current 'care swamp' (rules, laws, system)	●	Quality of Life Centre (2017)
Care and education	Practical help is often too far away, incidental, or not available	●	Quality of Life Centre (2017)
Care and education	The offered help is often incidental and problem driven	●	Quality of Life Centre (2017)
Care and education	The daily program for my child is not significant for him or her	●	Quality of Life Centre (2017)
Care and education	The staff in 'living groups' have not been adequately trained to be able to deal with the support questions of my child	●	'POZ' (2017), Quality of Life Centre (2017)
Care and education	Too little empathy among professionals for my child and his or her situation	●	Quality of Life Centre (2017)
Care and education	The values that are of importance to my child are insufficiently incorporated in his or her life	●	Quality of Life Centre (2017)
Care and education	Insufficient coherence in the care and educational offer for persons with CISON	●	Quality of Life Centre (2017)
Care and education	No comprehensive education offering for the target group	●	Quality of Life Centre (2017)
Care and education	The topics that are studied are isolated and not applied in other situations	●	Quality of Life Centre (2017)
Care and education	Development oriented offering in education is not self-evident	●	'POZ' (2017), Quality of Life Centre (2017)
Care and education	The learned topics do not adequately integrate into the child's daily life	●	Quality of Life Centre (2017)
Care and education	Offer care that matches the specific questions of my child	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Care and education	Offer care that matches the specific questions of my child and family	●	Quality of Life Centre (2017)
Care and education	Offer tailored care and structural solution within the 'WLZ'	●	Pamflet 2CU (2017)
Care and education	Contribute to assistance focused on prevention	●	Quality of Life Centre (2017)
Care and education	Integral support plan for the child which is managed by the parents instead of organisations	●	Quality of Life Centre (2017)
Care and education	A balanced individual (24/7) day- and week program for my child	●	Quality of Life Centre (2017)
Care and education	A meaningful daily schedule for my child	●	Quality of Life Centre (2017)
Care and education	Better cooperation between healthcare organisations	●	Quality of Life Centre (2017)
Care and education	An integral care and educational arrangement for my child	●	Quality of Life Centre (2017)
Care and education	Learning can take place in every environment and doesn't stop after school time	●	Quality of Life Centre (2017)
Care and education	There are possibilities for individual, dynamic customisation	●	Quality of Life Centre (2017)
Care and education	Education is tailored to the care and educational questions of my child	●	Quality of Life Centre (2017)
Care and education	The lifestyle of my child should be put central, just like in a normal life	●	Quality of Life Centre (2017)
Care and education	In an institution my child is regarded as an individual beside group member	●	Quality of Life Centre (2017)
Care and education	In an institution my child is regarded as an individual beside group member	●	Quality of Life Centre (2017)
Logistics	We as parents do not have support during the multiple logistical issues (what should we do, and when?)	●	Quality of Life Centre (2017)
Logistics	No unambiguous reference framework care and education for the target group (each organisation has it own care program)	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Logistics	The groups in 'living forms' are too large and the number of supervisors too little to provide individual attention and support	●	Quality of Life Centre (2017)
Logistics	There is a lack of appropriate and qualitative 'guest spots' for my child (nothing for 18+)	●	'POZ' (2017)
Logistics	The waiting lists for receiving help, support, and care are often too long	●	'POZ' (2017)
Logistics	There is no night supervision / night service available at the residence	●	'POZ' (2017)
Logistics	The care question for my child must be repeatedly proven	●	'POZ' (2017)
Logistics	Parents have ownership over the dossier and should coordinate all care	●	'POZ' (2017)
Logistics	Transfer care is not arranged after hospitalisation, referred to 'meerzorg' procedure	●	'POZ' (2017)
Logistics	A lack of qualitative and appropriate living facilities for my child	●	'POZ' (2017)
Logistics	Organisational structure hinders an efficient individual support of my child	●	'POZ' (2017)
Logistics	Not enough support from politics for addressing problems and providing solutions regarding the target group CISN	●	Pamflet 2CU (2017)
Logistics	Residents that are living in 'living forms' only come outside when parents or family are visiting	●	Pamflet 2CU (2017)
Logistics	No insight and overview of what my child wants, can and does at school, or in a living group	●	Quality of Life Centre (2017)
Logistics	We as parents are on their own and don't feel supported by others	●	Quality of Life Centre (2017)
Logistics	Found poli's in which medical, paramedical, and behavioral knowledge is bundled, developed, and people with CISN are treated	●	Pamflet (2017)
Logistics	Anticipate on new milestones in the life of my child through providing advice or reassessment	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Logistics	Decrease the bureaucratic process and put more trust in parents	●	Pamflet (2017)
Logistics	Parents want to have insight in waiting times and want to decrease these, if possible	●	Pamflet (2017)
Logistics	Structural and concrete collaboration between informal and formal network	●	Quality of Life Centre (2017)
Logistics	Relieve parents as much as possible in incidental procedural matters	●	Quality of Life Centre (2017)
Logistics	Professionals should be educated more emphatically	●	'POZ' (2017)
Logistics	Personalised small scale care opportunities for my child	●	'POZ' (2017)
Logistics	Involve 'experience experts' such as parents in the design of day-week programs	●	'POZ' (2017)
Logistics	Practice manager who carries out the following roles as a generalist: family coach, confidant, support, and lifestyle coach	●	Quality of Life Centre (2017)
Logistics	Advisor who carries out the following roles as a generalist: diagnostics and imaging, allocation of care and education, design of individual care and learning path of the child	●	Quality of Life Centre (2017)
Politics and laws	Due to the different laws, my child's questions are approached in a fragmented manner	●	Quality of Life Centre (2017)
Politics and laws	Budgets are allocated to each domain (care, education) and for an individual child	●	Quality of Life Centre (2017)
Politics and laws	The system is too rigid with many rules which hinders the structural solving of problems	●	Pamflet 2CU (2017)
Politics and laws	Problems with the allocation of 'PGB' money for school and hospitalisation	●	'POZ' (2017)
Politics and laws	Employees of institutions do not understand the target group CISN well enough	●	'POZ' (2017)
Politics and laws	More investments targeted at well balanced day-week programs	●	Pamflet (2017)
Politics and laws	An indication that is substantiated and financed from one central 'place'	●	Pamflet (2017)

Topic	Statement	Label	Source
Politics and laws	Indication statement is based on a 24/7 arrangement and covers all lifestyle domains	●	Quality of Life Centre (2017)
Politics and laws	Provide structural solutions within the long-term healthcare act ('WLZ')	●	Quality of Life Centre (2017)
Politics and laws	Financing for care and education should be combined into one source	●	Quality of Life Centre (2017)
Politics and laws	Solutions that are carried, controlled and facilitated by politics	●	Quality of Life Centre (2017) Pamflet 2CU (2017)
Politics and laws	Identify and acknowledge the group CISON in all its complexity and their lifelong very complex disability	●	Pamflet 2CU (2017)
Politics and laws	Tailor the system towards the individual instead of the other way around	●	Quality of Life Centre (2017)
Politics and laws	Special status for target groups which facilitates the design of a customised profile	●	Quality of Life Centre (2017)
Politics and laws	Government should support innovative open processes instead of closed systems	●	Quality of Life Centre (2017)
Politics and laws	There should be room for experiments where the different laws are combined into one	●	Quality of Life Centre (2017)
Family life	The values that are of importance to my child are insufficiently incorporated into his or her life	●	Quality of Life Centre (2017)
Family life	Too little support for the family, despite the heavy care burden	●	Pamflet 2CU (2017)
Family life	A big separation between my child's formal and informal network	●	Quality of Life Centre (2017)
Family life	More attention for the question of how we as family can deal with life together	●	Quality of Life Centre (2017)
Family life	Coordinated support (social, emotional, business) for my child and our family	●	Quality of Life Centre (2017)
Family life	Professionals (system world) connect with the family (living world) and not vice versa	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Family life	Less care tasks, more relaxation to feel like a 'normal' parent	●	Quality of Life Centre (2017)
Family life	Protect and expand the social network of the child	●	Quality of Life Centre (2017)
Family life	Keep my child at home for as long as possible	●	Quality of Life Centre (2017)
Good life	That my child is seen as a human being and is thus more than his or her diagnosis or behaviour	●	Quality of Life Centre (2017)
Good life	Focus on both the ordinary life and special support for my child	●	Quality of Life Centre (2017)
Good life	More control and participation opportunities for my child	●	Quality of Life Centre (2017)
Good life	The lifestyle of my child should be put central, just like in a normal life	●	Quality of Life Centre (2017)
Good life	My child is seen as child instead of as a client	●	Quality of Life Centre (2017)

Appendix H





Value proposition canvas: three customer profiles


This appendix presents the customer profiles of the three end user groups as based on the framework of Osterwalder et al. (2014). Jobs were not described in this research, pains are negative experiences that arise before, during and after trying to get a job done, and gains describe the outcomes and benefits the end users want to achieve.



Customer profile

Parents





 Jobs	 Pains	 Gains
	<ul style="list-style-type: none"> • Surrendered to the current offering for my child • Sink into the current 'care swamp' (rules, laws, system) • We parents are on their own • There is insufficient and fragmented imaging and diagnostics available of my child • We as parents do not have support during the multiple logistical issues (what should we do, and when?) • Daily programs within organisations are not tailored to the needs of my child • The offered help for my child and our family is often incidental and not preventive • A big separation between my child's informal and formal network • The care question or my child must be repeatedly proven 	<ul style="list-style-type: none"> • A balanced individual day- and week program • Focus on both the ordinary life and special support for my child • Involved persons communicate in the same language and work in unison • There are possibilities for individual, dynamic customisation • More control and participation opportunities for my child • An integral lifestyle plan for my child • Learning can take place in every environment and doesn't stop after school time • Professionals (system world) connect with the family (living world) and not vice versa • Coordinated support (social, emotional, business) for my child and our family


	<ul style="list-style-type: none"> • The values that are of importance to my child are insufficiently incorporated in his or her life • My experience is insufficiently included in the choices that are made for my child • The daily program for my child is not significant for him or her • The indication statement for the support of my child is or was incomplete and inconsistent • No insight and overview of what my child wants, can and does at school, or in a living group 	<ul style="list-style-type: none"> • That my child is seen as human being and is thus more than his or her diagnosis or behaviour • My child receives an integral 24/7 care and education package including care, counselling, and treatment • More attention for the question of how we as family can deal with life together
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Customer profile

Advice professionals





 Jobs	 Pains	 Gains
	<ul style="list-style-type: none"> • The system is too rigid with too many rules which hinders the structural solving of problems • The support, care and learning questions of persons with CISON are approached in a fragmented manner due to different laws • Employees of organisations (municipalities, indication agency) often do not know and understand the target group CISON well enough 	<ul style="list-style-type: none"> • Indication statement that is based on a 24-hour arrangement which covers all living areas • Well balanced day-week programs (balance between nursing and care on the one hand and treatment, development, activation and individual attention on the other) • Decrease the bureaucratic process and put more trust in parents


	<ul style="list-style-type: none"> • No unambiguous reference framework care and education for the target group CISON • Too little support for the family, despite the heavy are burden • No comprehensive education offering for the target group • Insufficient coherence in the care and education offer for the target group CISON • These children learn fragmentarily and this requires expert guidance • Students achieve inadequate outcomes during learning activities • Development oriented offering in education is not self-evident • The facilities for these children do not increase as the child grows older and the care needs increase • Fragmented collaboration between care and education 	<ul style="list-style-type: none"> • A balanced individual day- and week program • Focus on both the ordinary life and special support for my child • Involved persons communicate in the same language and work in unison • There are possibilities for individual, dynamic customisation • More control and participation opportunities for my child • An integral lifestyle plan for my child • Learning can take place in every environment and doesn't stop after school time • Professionals (system world) connect with the family (living world) and not vice versa • Coordinated support (social, emotional, business) for my child and our family
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Customer profile

Work professionals









 Jobs	 Pains	 Gains
	<ul style="list-style-type: none"> • No time for individual attention for a person during work time • The passion for work is increasingly disappearing to the background 	<ul style="list-style-type: none"> • More possibilities to work from a collaborative perspective • More insight in the support questions of the perspective of all those involved

	<ul style="list-style-type: none"> • Parents and others are hard to deal with • The care questions of persons are becoming increasingly complex • We have to work on too much goals at the same time • There is no qualitative day-week program for a person • There is too little attention for development oriented offering of a child • In our work, we have to deal with a lot of persons and disciplines • The digital dossier often does not fit to the applied approach in practice (method) • There is often no (traceable) history of the child available • There is a lot of individual documentation and lacks consistency 	<ul style="list-style-type: none"> • Parents are equal partner of professionals • I want to execute my work as carefully and efficiently as possible • More clarity about the expectation of a child • More support during work • Facilitates communication • Facilitates possibilities to 'follow the customer' • Insight in what is custom made care means for a person • Brings all the different interests together on an equal level
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Appendix I

Prioritise 'pains' and 'gains' with questionnaires

This appendix presents the results of the questionnaire that was held under the three end user groups: parents, professionals advice, and professionals work.

Parents	Professionals - Advice	Professionals - Work
Statement ('pains')	Weighted average*	Total
Surrendered to the current offering for my child	 4.56	n = 18
Sink into the current 'care swamp' (rules, laws, system, etc.)	 4.44	n = 18
We parents are on our own and feel 'abandoned'	 4.06	n = 18
There is insufficient and fragmented imaging and diagnostic available of my child	 3.78	n = 18
We parents do not have support during logistical issues (what, how and when?)	 3.78	n = 18
Daily programs within organisations are not tailored to the needs of my child	 3.76	n = 17
The offered help for my child and our family is often incidental and not preventive	 3.61	n = 18
A big separation between my child's informal and formal network	 3.61	n = 18
The values that are of importance to my child are insufficiently incorporated in his or her life	 3.61	n = 18
The care question for my child must be repeatedly proven	 3.56	n = 18
My experience is insufficiently included in the choices that are made for my child	 3.17	n = 18
The daily program for my child is not significant for him or her	 3.00	n = 18
The indication statement for the support of my child is or was incomplete and inconsistent	 2.94	n = 18
No overview of what my child wants, can and does at school, or in a living group	 2.94	n = 18

* (1 = unimportant to 5 = very important)

Parents	Professionals - Advice	Professionals - Work
Statement ('gains')	Weighted average*	Total
That my child is seen as human being and is more than his or her diagnosis or behaviour	 4.88	n = 16
Involved persons communicate in the same language and work in unison	 4.59	n = 17
Professionals (system world) connect with the family (living world) and not vice versa	 4.59	n = 17
Focus on both the ordinary life and special support for my child	 4.53	n = 17
A balanced individual day- and week program for my child	 4.47	n = 17
There are possibilities for individual, dynamic customisation	 4.47	n = 17
Learning can take place in every environment and doesn't stop after school time	 4.35	n = 17
My child receives an integral 24/7 package including care, counselling, and treatment	 4.35	n = 17
More attention for the question of how we as family can deal with life together.	 4.31	n = 16
More control and participation opportunities for my child	 4.25	n = 16
An integral lifestyle plan for my child (and family)	 4.13	n = 16
Coordinated support (social, emotional, business) for my child and our family	 3.94	n = 17









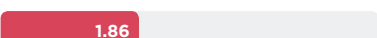
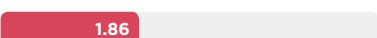
* (1 = not a priority to 5 = essential)

Parents	Professionals - Advice	Professionals - Work
Statement ('pains')	Weighted average*	Total
Too little support for the family, despite the heavy care burden	 4.17	n = 12
The system is too rigid with too many rules which hinders the structural solving of problems	 4.08	n = 12
Employees of organisations (municipalities, indication agency) often do not know and understand the 'target group CISON' well enough	 4.00	n = 12
The support, care and learning questions of persons with CISON are approached in a fragmented manner due to the different laws.	 3.83	n = 12
These children learn fragmentarily and this requires expert guidance	 3.83	n = 12
The facilities for these children do not increase as the child grows older and the care needs increase	 3.75	n = 12
Development oriented offering in education is not self-evident	 3.67	n = 12
Insufficient coherence in the care and education offer for the target group	 3.50	n = 12
No unambiguous reference framework care and education for the target group (each organisation has its own care programs risking tunnel vision)	 3.42	n = 12
Fragmented collaboration between care and education	 3.42	n = 12
Students achieve inadequate outcomes during learning activities	 3.25	n = 12
No comprehensive education offering for the target group	 3.25	n = 12











* (1 = unimportant to 5 = very important)

Parents	Professionals - Advice	Professionals - Work
Statement ('gains')	Weighted average*	Total
Well balanced day-week programs (balance between nursing and care on the one hand and treatment, development, activation and individual attention on the other)	 4.27	n = 11
Tailor the system towards the individual instead of the other way around	 4.27	n = 11
Protect and expand the social network of the child	 4.10	n = 10
Indication statement is based on a 24-hour arrangement which covers all living areas	 4.09	n = 11
Identify and acknowledge the group CISON in all its complexity and their lifelong very complex disability	 4.09	n = 11
Decreases the bureaucratic process and put more trust in parents	 3.91	n = 11
Offer care that matches the specific question of the child and family	 3.91	n = 11
Offer tailor made care and structural solution at this level	 3.82	n = 11
Advisor who carries out the following roles as a generalist: diagnostics and imaging, allocation of care and education, design of individual care and learning path of the child	 3.55	n = 11

* (1 = not a priority to 5 = essential)

Parents	Professionals - Advice	Professionals - Work
Statement ('pains')	Weighted average*	Total
No time for individual attention for a person during work time	 3.43	n = 8
The care questions of persons are becoming increasingly complex	 3.29	n = 8
In our work, we have to deal with a lot of persons and disciplines	 3.14	n = 8
There is often no (traceable) history of the child available	 3.00	n = 8
We have to work on too much goals at the same time	 3.00	n = 8
The digital dossier often does not fit to the applied approach in practice (method)	 2.86	n = 8
There is too little attention for development oriented offering of a child	 2.86	n = 8
There is a lot of individual documentation and it lacks consistency	 2.71	n = 8
There is no qualitative day-week program for a person	 2.57	n = 8
Parents and others are hard to deal with during our work activities	 1.86	n = 8
The passion for work is increasingly disappearing to the background	 1.86	n = 8

* (1 = unimportant to 5 = very important)

Parents	Professionals - Advice	Professionals - Work
Statement ('gains')	Weighted average*	Total
I want to execute my work as carefully and efficiently as possible	 4.71	n = 8
More possibilities to work from a collaborative perspective	 4.57	n = 8
Insight in what custom made care means for a person	 4.43	n = 8
Bring all the different interests together on an equal level	 4.17	n = 8
Parents are regarded as equal partners of professionals	 4.14	n = 8
More insight in the support questions of the perspective of all those involved	 4.14	n = 8
Facilitate better communication between involved persons	 4.14	n = 8
Facilitates possibilities to 'follow the customer'	 4.00	n = 8
Provides more clarity about the expectations of all those involved	 3.71	n = 8
More support during the execution of our work	 3.14	n = 8

* (1 = not a priority to 5 = essential)

Appendix J




Value proposition canvas: the three value maps

This appendix presents the value maps of the three end user groups. The value map consists of three parts. Products and services describe a list of what a company offers, the pain relievers describe how exactly the products and services alleviates specific end user's pains, and gain creators describe how the products and services create end user gains.

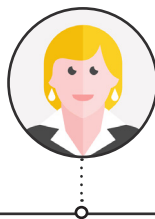


Value map

Parents




 Product	 Pain relievers	 Gain creators
Curriculum	<ul style="list-style-type: none"> • Experience expert will get an equivalent position • Equal partnership between formal and informal network • Provides space for the childs' story including the values that are of interest to him or her • Guides the users towards a more meaningful offering for care and education • Advises for individual day-week programs • Provides an overview of what a child wants, can and does • Makes insightful who needs what and at which moment • Provides logistical support in one place • Makes the (structural) care and educational question comprehensible • Navigates on a dynamic, individual and custom made care package 	<ul style="list-style-type: none"> • Provides a standardised process with a clear language usage • Offers a 'road map' which coordinates the support process • The parents and family remain owner of the process and professionals add in and out • Provides the opportunity to zoom in on the capacity and burden of the family • Offers cross domain, 24/7 opportunities • Focus on the ordinary life, with special support where needed • Advises for an appropriate care and educational package • Provides insight into the individuals daily and weekly program • Provides a holistic and integral approach

Curriculum	<ul style="list-style-type: none"> • Advises for preventive, structural and solution-orientated help • Advises for an indication statement • An integral and timely carried out imaging and diagnostics • Get insight into the possibilities and get influence in the decision process 	<ul style="list-style-type: none"> • Focuses on the execution of individual customisation • Built in attention to self-management and participation • Built-in attention for the ordinary life and special support
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Value map

Advice professionals




 Product	 Pain relievers	 Gain creators
Curriculum	<ul style="list-style-type: none"> • Exert influence based on the added information • All information revolving the imaging phase is collected in one place • Advises in the image phase and for an appropriate care and educational arrangement • Clear reference image for care and education for the target group • Maps the support questions of the family • Provides a comprehensive offering for education • Enhanced cooperation based on the choices of a child • Brings coherence in the offered advice 	<ul style="list-style-type: none"> • Assumes a 24-hour arrangement • Focuses on the design, organisation, and execution of balanced day-week programs • Maps information that is collected around an individual and makes it insightful • Gives the individual a central place in the process • Maps the social network of the child and the family in one overview • Makes the specific care and education questions of the child and family insightful • Possibilities to arrange care based on individual preferences

	<ul style="list-style-type: none"> • Provides a clearer picture of the learning question, how to answer it, and the means to do that • Determine the type of care based on the questions • Anticipate on important milestones of what might be needed in the future • Offers cohesion in the educational offering 	<ul style="list-style-type: none"> • Minimises procedural issues through providing a comprehensive overview of the current situation • Offers the opportunity to bring out advice with the help of predefined templates
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Value map

Work professionals

 Product	 Pain relievers	 Gain creators
Curriculum	<ul style="list-style-type: none"> • Facilitates a more efficient planning, execution and evaluation of work • Brings all perspectives together, which enhances the mutual understanding • It focuses on the essentials of work • It makes the complexity insightful and advises for solutions • It limits the amount of goals that have to be achieved in a certain period of time • Advises and focuses on an (individual) qualitative day-week program • Offers inspiration and opportunities for development oriented services (learning lines) 	<ul style="list-style-type: none"> • All involved will get an equal role • That you do what is required, but not more than is necessary • Provides insight into the roles and appointments of all those involved • Work system that provides direction to the activities • Makes the support questions of the person and others involved insightful, before and during the 'care path' • Makes interdisciplinary collaboration possible • All information is available in one central place • Contributes to the organisation and execution of individual customisation

	<ul style="list-style-type: none"> • Organises the collaboration between all those involved • No longer dependent on organisational characteristics but assumes customer preferences • In the dossier, a traceable history is recorded • Relevant information from different reports is merged into one integral lifestyle plan 	<ul style="list-style-type: none"> • The built in systematic follows the customer • Facilitates collaborations based on available information
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Appendix K

Workflow Analysis - Curriculum

This appendix presents the results of the workflow analysis. This section provides an elaborate overview of the processes, user stories, and information objects.

Registration	Intake	Imaging	Advice	Execution
Proces	User story	Information object(s)		
Het aanmelden voor een intakegesprek	Als medewerker van het Quality of Life Centre stuur ik een uitnodigingsmail naar de zorgvrager, zodat deze geïnformeerd en voorbereid naar de intake komt	Uitnodigingsmail <ul style="list-style-type: none"> • Details gesprek • Contactgegevens • Doel gesprek • 'Link' vragenlijst 		
Het ontvangen van zelfmanagement informatie	Als 'intaker' wil ik voor het intakegesprek inzicht hebben in het (huidige) zorgproces van de zorgvrager, zodat ik mij goed kan voorbereiden op het gesprek	Zelfmanagementinformatie <ul style="list-style-type: none"> • Ingevulde vragenlijst 		
Het aanmaken van een nieuw account in Jouw Omgeving voor de zorgvrager	Als 'intaker' wil ik voor het intakegesprek toegang hebben tot een account, zodat er tijdens de intake gelijk gegevens van de zorgvrager geregistreerd kunnen worden	Accountgegevens <ul style="list-style-type: none"> • Inloggegevens 		
Beoordelen van de aanmelding	Als 'intaker' moet ik bepalen of en hoe de gevraagde zorg geleverd kan worden, zodat een eenduidige beslissing genomen kan worden over het vervolgtraject	Zelfmanagementinformatie <ul style="list-style-type: none"> • Ingevulde vragenlijst 		

Registration	Intake	Imaging	Advice	Execution
Proces	User story	Information object(s)		
Het invullen van het intakeformulier	Als 'intaker' wil ik diverse gegevens registreren met betrekking tot de kenmerken, conditie en beperkingen van een zorgvrager en wil ik door middel van gerichte vragen informatie verzamelen, zodat de hulpvragen, levensgewoonten, voorgeschiedenis, leefstijl, knelpunten en wensen inzichtelijk worden	Intakeformulier <ul style="list-style-type: none"> • NAW gegevens • Sociale omgeving • Hulpvragen van betrokken partijen • Problemen van persoon / gezin • Leefstijl huidige en gewenste situatie • Randvoorwaarden 		

Het afnemen van een (nul)meting	Als 'intaker wil ik bij de start van elk nieuw zorgtraject een (nul)meting afnemen en vervolgens op standaard momenten, zodat de effecten van het gebruik van het curriculum objectief geanalyseerd en gevalideerd kunnen worden	(Nul)meting <ul style="list-style-type: none"> Gestandaardiseerde vragenlijsten
Het in kaart brengen van de financiën	Als 'intaker wil ik financieringsbronnen inventariseren en een overzicht maken van beschikbare financieringsvormen, zodat er een begroting kan worden opgesteld voor de zorgvrager en kan worden bepaald of de ondersteuning al dan niet kan worden verleend	Financieel plaatje <ul style="list-style-type: none"> Financiële foto nu Financiële foto benodigd
Het invullen en ondertekenen van een toestemmingsformulier	Als 'adviseur' wil ik (schriftelijke) toestemming van de zorgvrager of diens wettelijk vertegenwoordiger, zodat ik gegevens kan opvragen, verwerken, gebruiken en opslaan	Toestemmingsformulier <ul style="list-style-type: none"> Gegevensgebruik Gebruiksonderzoek Foto en film Opvragen dossiers

Registration	Intake	Imaging	Advice	Execution
Proces	User story	Information object(s)		
Het opvragen en analyseren van het huidige dossier van een persoon	Als 'onafhankelijk adviseur' wil ik opgevraagde dossierstukken analyseren, zodat de historie van de zorgvrager en zijn en/of haar leefomgeving wordt meegenomen in het leven en de ondersteuning daarbinnen	Dossieranalyse <ul style="list-style-type: none"> Samenvatting 		
Het houden van gesprekken met de verschillende betrokkenen rondom een persoon	Als 'onafhankelijk adviseur' wil ik gesprekken voeren met verschillende betrokkenen, zodat er consensus kan worden verkregen vanuit verschillende perspectieven en gekomen kan worden tot gewenste keuzes	Gespreksverslag <ul style="list-style-type: none"> Aanwezig Gespreksconclusies Tevredenheid gesprek 		
Het observeren van de persoon in zijn (leef/leer) omgeving	Als 'onafhankelijk adviseur' wil ik verschillende observaties van de persoon uitvoeren, zodat vanuit het perspectief van een onafhankelijk adviseur een beeld kan worden verkregen van het kind in verschillende situaties	Media <ul style="list-style-type: none"> Foto Video 		

Het registreren van medicatie van de zorgvrager	Als (werk)professionals en ouder wil ik de medicatie van het kind registreren, zodat iedereen een totaaloverzicht heeft	Medicatielijst
Het analyseren van persoonlijke profielen	Als 'onafhankelijk adviseur' wil ik persoonlijke profielen analyseren, zodat ik de verschillende deelvragen kan ontrafelen en beantwoorden en bepaalde functioneringsgebieden in kaart heb (specialistisch)	Persoonlijke profielen <ul style="list-style-type: none"> • Quality of Life • Gezondheid • Functioneren (ICF)
Het registreren van de (gestelde) diagnose van een persoon	Als 'onafhankelijk adviseur' wil ik de diagnose registreren, zodat ik over de hier aan gerelateerde vervolgstappen voor het dagelijks leven en de in te zetten hulp kan adviseren	Diagnose <ul style="list-style-type: none"> • Medisch • Psychologisch
Het in kaart brengen van het informele en formele netwerk van de zorgvrager	Als (werk)professionals en/of ouder wil ik een netwerkcirkel invullen, zodat ik weet welke personen en instanties er allemaal betrokken zijn (geweest) bij de persoon	Netwerkcirkel
Het schrijven van een holistisch persoonsbeeld	Als 'onafhankelijk adviseur' wil ik een holistisch persoonsbeeld opstellen en vastleggen, zodat ik het totale functioneren van het kind in beeld kan brengen (generalistisch)	Holistisch persoonsbeeld
Het in kaart brengen van het huidige 24/7 arrangement	Als 'adviseur' leg ik het huidige zorg en onderwijs arrangement vast, zodat er inzichtelijk wordt wat de verdeling is van het gewone gezinsleven van een persoon en de speciale ondersteuning die daarbij nodig is	Huidig 24/7 arrangement <ul style="list-style-type: none"> • Voorkeuren • Bevindingen • Leefstijldomeinen • Domeinen speciale ondersteuning

Registration	Intake	Imaging	Advice	Execution
Proces	User story	Information object(s)		
Het in kaart brengen van het gewenste 24/7 arrangement	Als 'onafhankelijk adviseur' leg ik op basis van de resultaten van het huidige 24/7 arrangement, een gewenst 24/7 arrangement vast, zodat er gefundeerde keuzes gemaakt kunnen worden voor een passend dag weekprogramma	Gewenst 24/7 arrangement <ul style="list-style-type: none"> • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning 		
Adviesrapport opstellen	Op basis van de resultaten van de beeldvorming van de persoon wordt door de onafhankelijk adviseur (indicatie) advies uitgebracht over de invulling van een passende route en programma voor de in kaart gebrachte situatie	Adviezen rapport <ul style="list-style-type: none"> • Diagnostiek • Verdere beeldvorming • Passend gewenst 24/7 arrangement • Prioritering doelen • Passend concreet dag-week programma • Aanzet leefstijlplan 		

Registration	Intake	Imaging	Advice	Execution
Proces	User story	Information object(s)		
Het opstellen van lange en korte termijn doelen	Als uitvoerend professional en ouder wil ik op basis van het advies doelen kunnen stellen voor de zorgvrager, zodat er gericht en methodisch gewerkt wordt aan het realiseren van mooi leven van de persoon	Gewenst 24/7 arrangement <ul style="list-style-type: none"> • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning 		
Het invullen van een 'mooi leven' leefstijlplan	Als uitvoerend professional en ouder wil ik op basis van het advies een leefstijlplan kunnen invullen en bijhouden voor de persoon, zodat een passend dag-week programma kan worden ontworpen, gefaciliteerd en gerealiseerd	'Mooi leven' leefstijlplan <ul style="list-style-type: none"> • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning 		
Het aanmaken van een activiteitenlijst	Als professional en ouder wil ik op basis van het advies activiteiten kunnen aanmaken, zodat deze tijdens het opstellen van het dag-weekprogramma ingepland kunnen worden	Activiteitenlijst <ul style="list-style-type: none"> • Activiteiten • Beschrijving 		

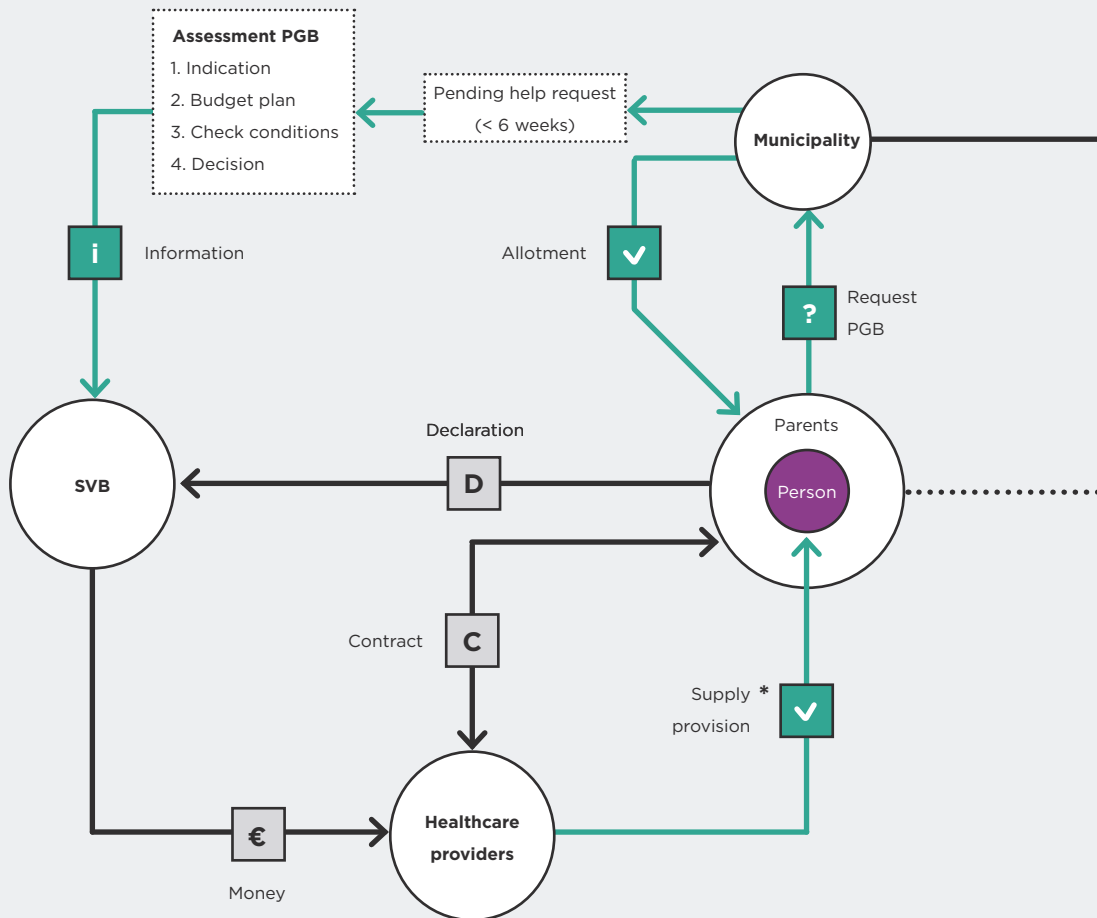
Het vaststellen van het gewenste dag-weekprogramma	Als uitvoerend professional en ouder wil ik activiteiten inplannen die passen bij het advies, zodat ik een betekenisvol en passend dag-weekprogramma kan samenstellen	Dag-weekprogramma
Het rapporteren op activiteiten	Als uitvoerend professional en ouder wil ik kunnen rapporteren op activiteiten, zodat voor iedereen inzichtelijk wordt hoe deze zijn verlopen	Rapportage
Het beoordelen van activiteiten binnen het dag-weekprogramma	Als uitvoerend professional en ouder wil ik activiteiten kunnen beoordelen, zodat voor iedereen inzichtelijk wordt hoe deze zijn verlopen	Evaluatie activiteit
Het evalueren van de gestelde korte en lange termijn doelen	Als uitvoerend professional en ouder wil ik de gestelde doelen kunnen evalueren, zodat duidelijk wordt of deze zijn behaald of niet	Evaluatie doelen

Appendix L

Stakeholder networks

Social Support Act

PGB



* Provisions under the Social Support Act

Individual guidance

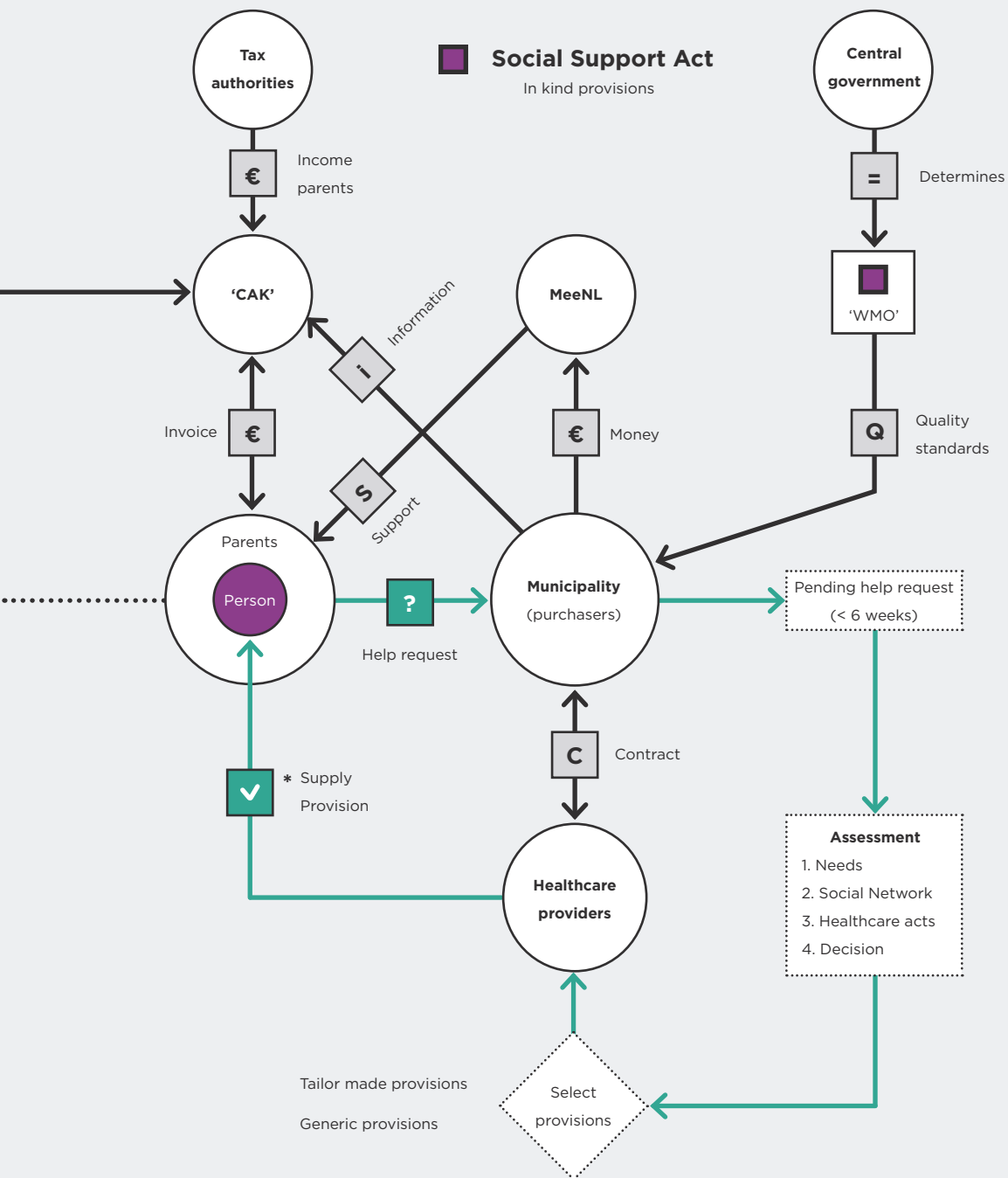
Help in household

Short stay (protected living)

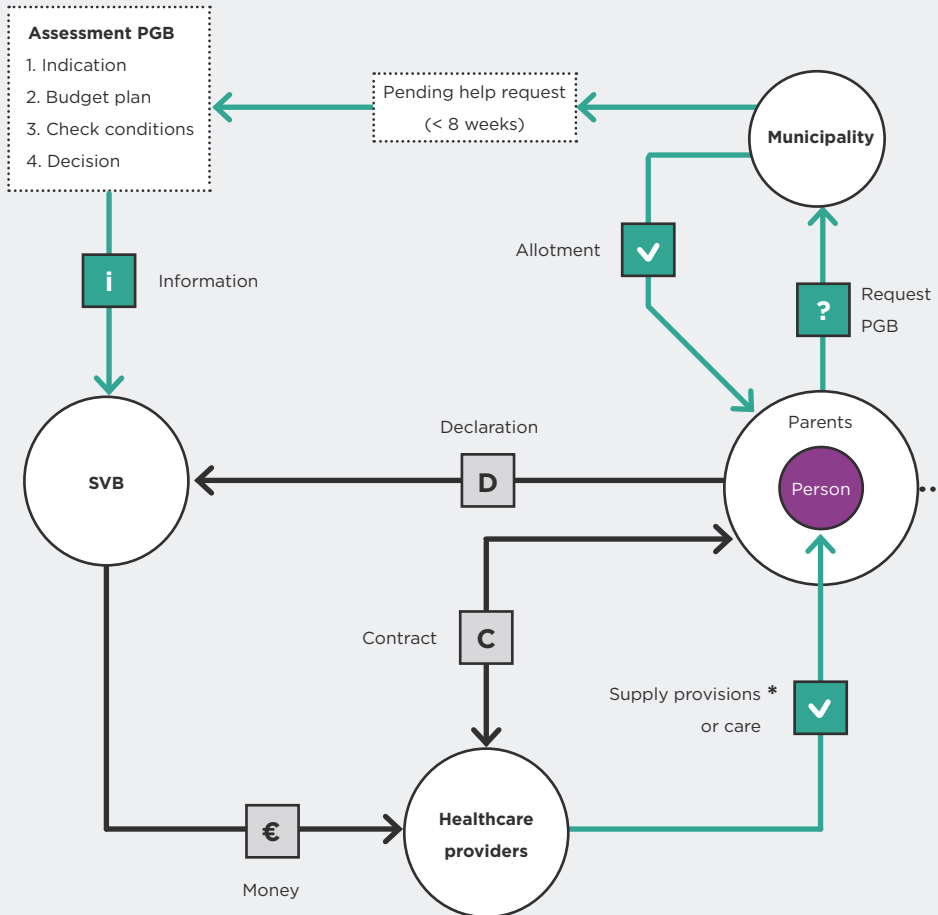
Provisions for transport

Tailor made and generic provisions

Home modifications



Youth Care Act PGB



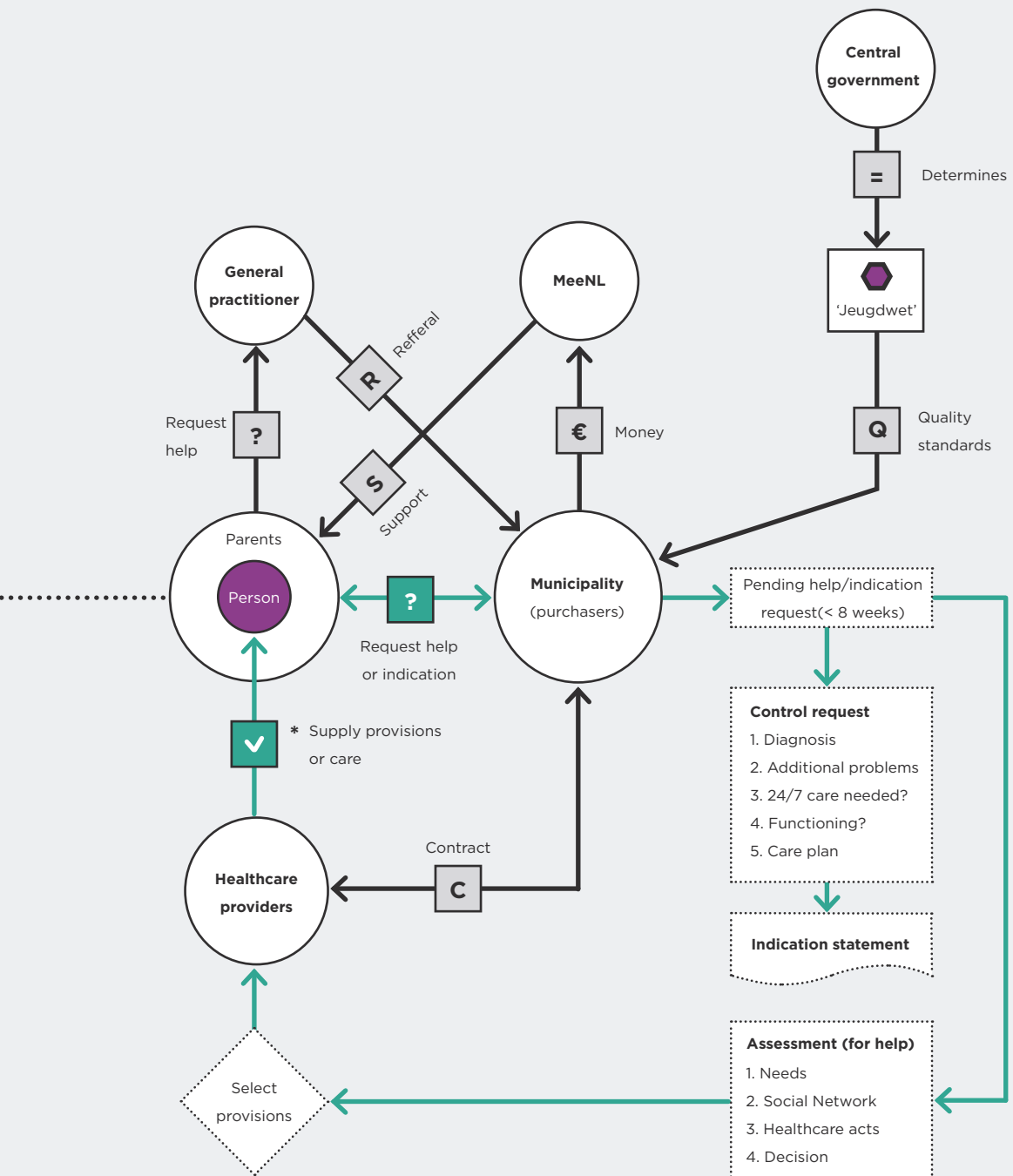
*** Provisions and care under the Youth Care Act**

Individual/group guidance
 Short stay (protected living)
 Personal care

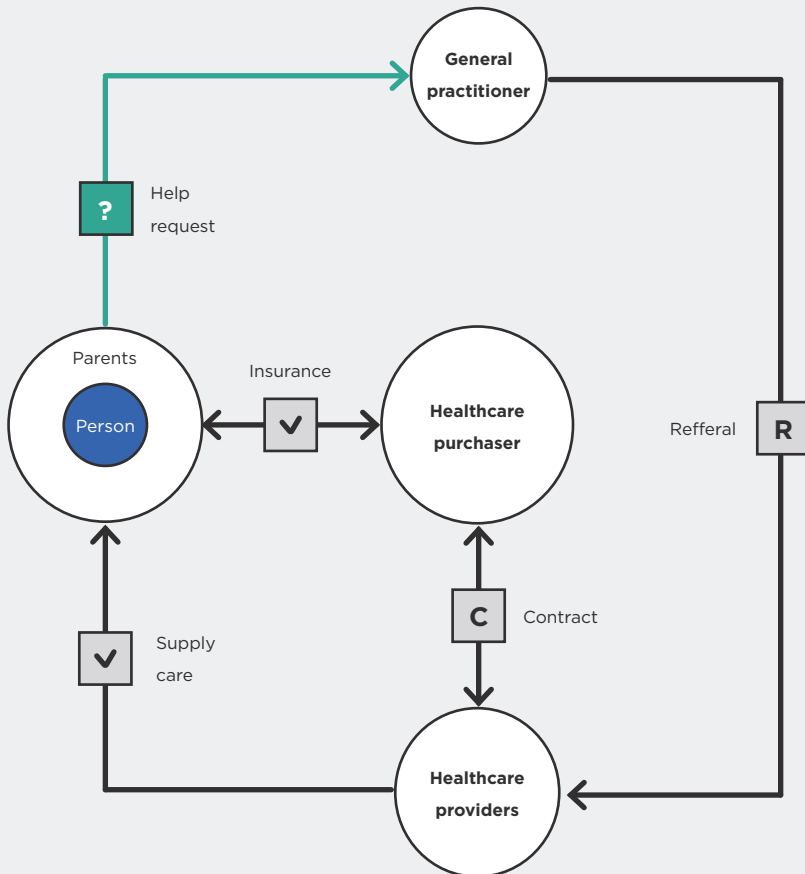
Growth and parenting support

Youth Care Act

In kind provisions



● Health Insurance Act



Appendix M

Design document requirements

This appendix presents the results of requirement specification. This document embodies the minimal set of requirements that are required for the curriculum to function in practice.

Requirement #1	
User story	As parents, I want to invite professionals or family members so they can (temporarily) access (certain parts) of the online environment of my child.
Rationale	In its life, a child moves back and forth between multiple places such as day care, healthcare organisations, schools, etc. Therefore, the data generation and collection should take place at one central space and stay in ownership of the parents (or the Quality of Life Centre) because they are their legal representatives, have a full overview of the situation, and are constantly involved with their child
Value drivers	<ul style="list-style-type: none"> • Parents (and their family) have full ownership during the process and professionals add in/out (ranked 4.59) • Equal partnership between formal and informal network (ranked 3.61)
Information object	Not applicable
Priority score	4.10 (0 = low 5 = high)

Requirement #2	
User story	As a user, I can find all the necessary information regarding a person in one central and safe system through a simple interface.
Rationale	At this moment parents spend a lot of time (re)filling documents for their child, and professionals and other involved parties make decisions based on unavailable, incomplete or outdated information. When the most recent information about a child can be safely accessed, by all involved, from one central place, it facilitates collaborative decision making, and a holistic and integral approach
Value drivers	<ul style="list-style-type: none"> • Provide a holistic and integral approach (ranked 4.88) • Insight into the possibilities and gain influence in the decision process (ranked 4.56) • Provide logistical support in one place (ranked 3.78) • Parents (experience experts) get an equivalent position in the choices that are made for their child (ranked 3.17)
Information object	Not applicable
Priority score	4.40 (0 = low 5 = high)

Requirement #3	
User story	As user, I want to upload/register information that is collected by means of a physical conversation with the parents, child and family.
Rationale	By making the support questions of all involved insightful at the start, it becomes possible to understand what the involved persons need and what the implications will be in assembling a coherent offering.
Value drivers	<ul style="list-style-type: none"> • Makes insightful who needs what, and at which moment (rated 4.06) • Provide space for the persons story including the values that are of interest to him or her (rated 3.61) • Make the (structural) care and educational questions comprehensible (rated 3.56) • Provide insight in what a child wants, can and does (rated 2.94)
Information object	Intakeform
Priority score	3.74 (0 = low 5 = high)

Requirement #4	
User story	As intaker, I want the possibility to take a baseline measurement on predefined moments
Rationale	By taking questionnaires periodically, the effects of the use of the curriculum can be analysed objectively and validated over a longer period of time
Value drivers	Not applicable
Information object	(Baseline) measurement

Requirement #5	
User story	As intaker, I want to upload information regarding the funding sources of the parents
Rationale	By making the financial situation and the current budget insightful directly at the start, it can facilitate the decision whether or not the support can be granted by the Quality of Life Centre.
Value drivers	Not applicable
Information object	Financial situation

Requirement #6	
User story	As user, I want the possibility to digitally sign or approve specific documents in the dossier.
Rationale	By digitally signing documents, as little as delay as possible will occur between the intake and imaging phase.
Value drivers	Not applicable
Information object	Permission form

Requirement #7	
User story	As advisor, I want the possibility to upload the collected results of the dossier analysis
Rationale	By analysing the current dossier, the history of the care recipient and his / her living environment is taken into account
Value drivers	<ul style="list-style-type: none"> • Map information that is collected around an individual and make it insightful (4.09) • Anticipate on important milestones of what might be needed in the future (3.75)
Information object	Not applicable (external files)
Priority score	3.92 (0 = low 5 = high)

Requirement #8	
User story	As advisor, I want to register the conversations i have with the multiple persons that are involved
Rationale	To reach consensus from different perspectives in order to make choices that are desired
Value drivers	<ul style="list-style-type: none"> • Enhanced cooperation based on the choices for / of a child (rated 4.60) • Make the specific care and education questions of the child and family insightful (rated 3.61)
Information object	Conversation form
Priority score	4.10 (0 = low 5 = high)

Requirement #9		
User story	As user, i want the possibility to upload photo's and videos	
Rationale	<p>The collection of multimedia material has multiple functions:</p> <ul style="list-style-type: none"> • By capturing different emotions of a child, other involved professionals will better know how they need to respond in a certain situation • By capturing different medical procedures, (untrained) professionals can faster learn how and what they need to do to offer the required care • An annual comparison between videos or photos can be made to track the often, small and subtle decline in the health of a child • Parents have more insight in what activities a child has done elsewhere (for example during day care) 	
Value drivers	<ul style="list-style-type: none"> • Equal partnership between formal and informal network (rated 3.61) • Provides insight in what a child want, can and does (rated 2.94) 	
Information object	Not applicable (external files)	
Priority score	3.2	(0 = low 5 = high)

Requirement #10		
User story	As independent advisor, I want to upload (multiple) personal profiles	
Rationale	<p>Personal profiles are meant for people with a (complex) support question to untangle the multiple sub questions and to visualise certain areas of functioning, for example communication or alertness (specialistic). It gives an incentive towards the approach for stimulating well-being and the learning abilities of someone, for deploying help as well as to answer the current questions and to solve problems.</p>	
Value drivers	<ul style="list-style-type: none"> • Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • All information revolving the imaging phase is collected in one place (rated 3.42) 	
Information object	Not applicable (external files)	
Priority score	3.6	(0 = low 5 = high)

Requirement #11		
User story	As independent advisor, I want to register the medication of person	
Rationale	The medication has a big influence on someone's well-being and also involves potential health risks. Providing the users with a list of all medication, more funded choices can be made regarding certain medicine.	
Value drivers	<ul style="list-style-type: none"> • In the dossier, a traceable history is recorded (rated 4.00) • All information revolving the imaging phase is collected in one place (rated 3.42) 	
Information object	Diagnosis	
Priority score	3.71	5 = high 0 = low

Requirement #12		
User story	As independent advisor, I want to register the diagnosis of person	
Rationale	<p>The diagnose serves as important starting point for determining the next steps where questions will be answered, help is deployed and problems are solved.</p> <p>The diagnosis helps to understand the overall health, the reasons behind a persons functioning and the behavior.</p>	
Value drivers	<ul style="list-style-type: none"> • Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • All information revolving the imaging phase is collected in one place (rated 3.42) 	
Information object	Diagnosis	
Priority score	3.60	5 = high 0 = low

Requirement #13		
User story	As independent advisor, I want to register the network of a person	
Rationale	To get an idea of how many people are involved with the individual and his / her living situation. Besides, it is used to gauge the ratio between the informal and formal network. Ideally, this is in balance.	
Value drivers	<ul style="list-style-type: none"> • Equal partnership between formal and informal network (rated 3.61) • Built in attention to self-management and participation (rated 4.25) • Maps the social network of the child and the family in one overview (rated 4.10) • Provides insight into the roles and appointments of all those involved in the care of a person (rated 3.14) 	
Information object	Network circle	
Priority score	3.78	5 = high 0 = low

Requirement #14		
User story	As independent advisor, I want to register a (holistic) personal image based on previously collected information	
Rationale	The personal image is meant for persons with a (complex) support question to query the sum of all questions and to visualise the overall functioning (generalistic). It provides direction for the approach to simulate the well-being and learning questions, for deploying help as well as to answer the current questions and to solve problems.	
Value drivers	<ul style="list-style-type: none"> • Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • Provides space for the child's story including the values that are of interest to him or her (rated 3.61) • Focuses on the ordinary life with special support where needed (rated 4.13) • Brings all perspectives together, which enhances the mutual understanding (rated 4.17) 	
Information object	Holistic personal image	
Priority score	3.92	5 = high 0 = low

Requirement #15		
User story	As independent advisor, I want to upload a 24/7 arrangement	
Rationale	A (potential) 24/7 care and education arrangement is created to gain insight into the distribution of the normal (family) life of a person and the special support that is needed during this life. It also helps in making the right choices for a balanced program (balance between care and education, effort and relaxation, active and passive)	
Value drivers	<ul style="list-style-type: none"> • Offers cross domain 24/7 opportunities (rated 4.35) • Advises for an appropriate care and educational package (rated 4.35) • Assumes a 24-hour arrangement (rated 3.61) • Determine the type of care based on the questions (3.82) 	
Information object	Not applicable (external files)	
Priority score	4.03	5 = high 0 = low

Requirement #16		
User story	As independent advisor, I want upload an advice report	
Rationale	Often various and complex questions are intertwined with each other. In addition, there is an emotional process and an ordinary family life. Besides, many people are involved in the situation and everyone often focuses (short-term) on their own part of the care. That's why it is important that someone with vision and expertise looks 'everywhere' and provides advice that fits as much as possible to the support, development and learning questions of a person.	
Value drivers	<ul style="list-style-type: none"> • Makes the structural care and educational questions comprehensible (rated 3.56) • Guides the user towards a more meaningful offering for care and education (rated 3.00) • Advises for preventive, structural and solution-orientated help (rated 3.91) • Brings coherence in the offered advice (3.91) • Anticipate on important milestones of what might be needed in the future (rated 4.09) 	
Information object	Not applicable (external files)	
Priority score	3.70	5 = high 0 = low

Requirement #17		
User story	As user, i want to create short and long term goals	
Rationale	While applying a (professional) intervention, of whatever nature, you have to know what you do, why and what results it has. This requires a goal-oriented and systematic working method. Based on this method one can work gradually towards a more desired situation. In doing so, it gives a grip on a complex situation.	
Value drivers	<ul style="list-style-type: none"> • Provide a standardised process with clear language usage (rated 4.59) • Experience experts will get an equivalent position (rated 3.17) • Bring all perspectives together, which enhances mutual understanding (rated 4.57) • Limit the amount of goals that have to be achieved (3.00) • Make interdisciplinary collaboration possible (4.17) 	
Information object	Goals	
Priority score	3.90	5 = high 0 = low

Requirement #18		
User story	As user, I want to register a lifestyle plan	
Rationale	A plan makes it possible to follow the person as well as the things that are important in his or her life. By focusing on their lifestyle, one stays very close to the person in question. In the lifestyle of someone, the daily things of life are expressed. It is meaningful for one to have a certain lifestyle. It provides influence and direction but also meaning in ones life. By means of the plan, the lifestyle of an individual is constantly monitored and checked if it still matches the needs.	
Value drivers	<ul style="list-style-type: none"> • Offer a 'road map' which coordinates the support process (rated 4.13) • Give the individual a central place in the process (rated 3.61) • Relevant information from different reports is merged into one integral lifestyle plan (2.71) 	
Information object	Lifestyleplan	
Priority score	3.70	5 = high 0 = low

Requirement #19		
User story	As user, I want to fill out a day/week program (agenda)	
Rationale	In a day-week program, just like in an agenda, it is clear what someone is going to do. In the program a connection is sought with the questions and wishes of the person to find the necessary balance between effort and relaxation, activation and experience, etc. By implementing the day/week program into an agenda, it becomes very clear what you do, what is feasible and not, and how activities relate to each other. Besides, not the agendas of professionals are leading, but the agenda (daily life) of an individual.	
Value drivers	<ul style="list-style-type: none"> • Provides logistical support in one place (rated 4.31) • Navigates on the execution of individual dynamic custom made care (rated 4.47) • Work system that provides direction to the activities (rated 4.71) • Focus on the essentials of my work (4.43) • Well-balanced day-week programs for a child (4.27) • Provide an overview of what a child wants, can and does (2.94) 	
Information object	Day/week program (agenda)	
Priority score	4.18	5 = high 0 = low

Requirement #20		
User story	As user, I want to report an activities inside the agenda	
Rationale	If you do activities, you also want to know if they deliver the results that were intended beforehand. It gives the involved persons insight but also inspiration and spirit to continue on the chosen path.	
Value drivers	<ul style="list-style-type: none"> • Map information around a individual and make it insightful (rated 4.00) • All information is available in one central place (rated 3.00) • A 'traceable' history is created of an individual (rated 4.00) 	
Information object	Reportform	
Priority score	3.66	5 = high 0 = low

Requirement #21		
User story	As user, I want to evaluate a work goal	
Rationale	Evaluating work goals is important because a statement is made about what has been achieved and in which specific way. It helps to understand what works, for whom, and under what circumstances. This understanding helps to continuously improve the day/week program of a child and ensures the treatment stays on track.	
Value drivers	<ul style="list-style-type: none"> • Facilitates a more efficient planning, execution and evaluation of work (rated 4.71) • Make the complexity insightfull and advise for solutions (rated 3.29) • Facilitate collaboration based on available information (rated 4.14) 	
Information object	Evaluation	
Priority score	4.04	5 = high 0 = low

References

- Akkersdijk, S. M., Kelders, S. M., & van Gemert-Pijnen, J. (2016). *The Grid, Classification of eHealth Applications Towards a Better re(Design) and Evaluation*. Retrieved June 25, 2017, from: <https://ris.utwente.nl/ws/portalfiles/portal/6157530>
- Beernink-Wissink, J. (2015). *Floreren: Zoektocht naar goed leven voor mensen met een ernstige verstandelijke beperking en ernstige gedragsproblemen*. Eburon Uitgeverij B.V.
- Centraal Bureau voor de Statistiek. (2017). *Zorg: uitgaven en financiering vanaf 1972 [Dataset]*. Retrieved September 15, 2017, from [http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=83075NED&D1=a&D2=0,3,8,13,18,23,29,34,39,\(1-2\)-I&HD=160517-1206&HDR=G1&STB=T](http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=83075NED&D1=a&D2=0,3,8,13,18,23,29,34,39,(1-2)-I&HD=160517-1206&HDR=G1&STB=T)
- de Vries, M., & Kossen, J. (2015). *This is how Dutch healthcare works*. Amsterdam, Netherlands: De Argumentenfabriek.
- Dohmen, D. A. (2012). *De 'e' van e-Health. Juiste energie voor optimale implementatie van moderne technologie in de zorg thuis*. Dissertatie. Enschede: Universiteit Twente.
- Expertisecentrum EMB. (2017). *Wat we verstaan onder EMB?* Retrieved October 17, 2017, from: <https://expertisecentrumemb.sheerenloo.nl/expertisecentrum-emb-/home/doelgroep>
- Girini, A., Gagnoli, A., Vigna, C., & Riva, A. (2008). *Second life for eHealth; prospects for the use of 3D virtual worlds in clinical psychology*. J Med Internet Res.
- Hansen, M. M., Miron-Shatz, T., Lau, A. Y., & Paton, C. (2014). *Big Data in Science and Healthcare: A Review of Recent Literature and Perspectives: Contribution of the IMIA Social Media Working Group*. Yearbook of Medical Informatics, 9(1), 21–26.
- Hoeymans, N., van Loon, A., van den Berg, M., Harbers, M., Hilderink, H., van Oers, H., & Schoenmaker, C. (2014). *A healthier Netherlands: Key findings from the Dutch 2014 Public Health Status and Foresight Report*. National Institute of Public Health and the Environment (RIVM).
- Murray, E., May, C., & Mair, F. (2010). *Development and formative evaluation of the e-Health Implementation Toolkit (e-HIT)*. BMC Medical Informatics and Decision Making, 10, 61.
- Nussbaum, M. (2011). *Creating Capabilities: The Human Development Approach*. Cambridge, MA: Harvard University Press, p.19.

- Ossenbaard, H., Van Duivenboden, J., & Krijgsman, J. (2017). *Evaluatie van eHealth-technologie in de context van beleid*. Retrieved June 20, 2017, from https://www.raadrvs.nl/uploads/docs/Briefadvies_over_de_implementatie_van_e-health.pdf
- Osterwalder, A., & Pigneur, Y. (n.d.). *Business model Generation: A Handbook for Visionaries, Game Changers and Challengers*. Switzerland: OSG.
- Osterwalder, A., Pigneur, Y., Smith, A., Bernarda, G., & Papadakos, T. (2014). *Value Proposition Design: How to create products and services customers want*. New Jersey, America: John Wiley & Sons.
- Raad van Volksgezondheid en Zorg. (2015). *Consumenten eHealth*. Retrieved April 21, 2017, from https://www.raadrvs.nl/uploads/docs/Advies_Consumenten_eHealth.pdf
- Raad van Volksgezondheid en Zorg. (2017). *Implementatie van e-health vraagt om durf en ruimte*. Retrieved June 8, 2017, from https://www.raadrvs.nl/uploads/docs/Briefadvies_over_de_implementatie_van_e-health.pdf
- Raghupathi, W. (2010). *Data Mining in Health Care*. Healthcare Informatics: Improving Efficiency and Productivity, (pp. 211-223).
- Rijksoverheid. (2013). *Zeer grote decentralisatie naar gemeenten*. Retrieved May 12, 2017, from <https://www.rijksoverheid.nl/actueel/nieuws/2013/02/19/zeer-grote-decentralisatie-naar-gemeenten>
- Riva, G., & Wiederhold, B. (2015). *The new dawn of virtual reality in health care: medical simulation and experimental interface*. Annual review of cybertherapy and telemedicine.
- Riva, G., Dakanalis, A., & Mantanovi, F. (2015). Leveraging psychology of virtual body for health and wellness. The handbook of psychology of communication technology.
- Ross, J., Stevenson, F., Lau, R., & Murray, E. (n.d.). *Factors that influence the implementation of e-health: a systematic review of systematic reviews (an update)*. Implementation Science: IS, 11, 146. .
- Satava, R. M. (1994). *Emerging medical applications of virtual reality: a surgeon's perspective*. Artif Intel Med 6 .
- Schalock, R. (2002). *Conceptualization, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts*. Mental Retardation: December 2002, Vol. 40, No. 6, pp. 457-470.

- Schippers, E., & Van Rijn, M. (2014). *Kamerbrief over e-health en zorgverbetering [Kamerstuk]*. Retrieved May 12, 2017, from <https://www.rijksoverheid.nl/documenten/kamerstukken/2014/07/02/kamerbrief-over-e-health-en-zorgverbetering>
- Shapiro, M. A., & McDonald, D. G. (1992). I'm not a real doctor, but I play one in virtual reality: Implications of virtual reality for judgments about reality. *Journal of Communication* 42.
- Srivastava, K., Das, R., & Chaudhury, S. (2014). Virtual reality applications in mental health: challenges and perspectives.
- van Gemert-Pijnen, J., Nijland, N., Ossenbaard, H., Kelders, S., Eysenbach, G., & Seydel, E. (2011). A Holistic Framework to Improve the Uptake and Impact of eHealth Technologies. Retrieved May 2, 2017, from <http://doi.org/10.2196/jmir.1672>
- van Limburg, M., van Gemert-Pijnen, J., Nijland, N., Ossenbaard, H., Hendrix, R., & Seydel, E. (2011). *Why Business Modeling is Crucial in the Development of eHealth Technologies*. Retrieved May 2017, 2017, from <http://doi.org/10.2196/jmir.1674>
- van velsen, L., Wentzel, J., & van Gemert-Pijnen, J. (2013). *Designing eHealth that Matters via a Multidisciplinary Requirements Development Approach*. Retrieved May 9, 2017, from <http://doi.org/10.2196/resprot.2547>
- Vlaskamp, C. (1993). *Een kwestie van perspectief. Methodieontwikkeling in de zorg voor ernstig meervoudig gehandicapten*. Academisch proefschrift. Assen: Van Gorcum.
- World Health Organization. (2002). *International Classification of Functioning, Disability and Health (ICF)*. Fifty-Fourth World Health Assembly, Geneva.

