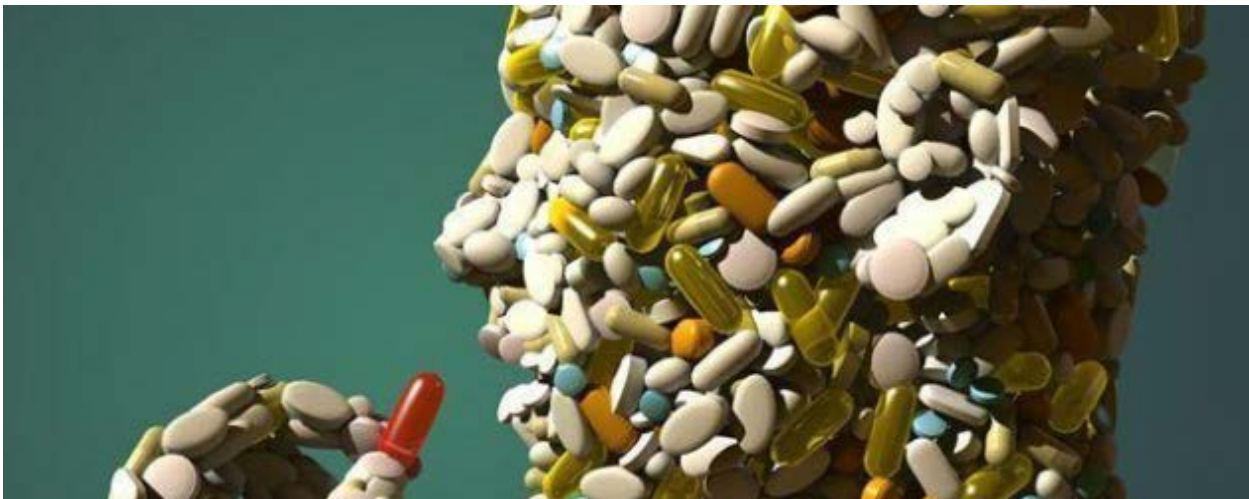# Universiteit Utrecht

Smart governance strategies for the early diagnostics of Alzheimer's disease

An explorative study on the prevention of medicalization

Bachelor thesis

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English summary:

Alzheimer's disease (AD) is one of the biggest health challenges in the Netherlands today. One way of trying to tackle this problem is the development of early diagnostics of AD. However the development of these techniques and its application is controversial since it can enhance a medicalization trend. Medicalization is defined as the process by which nonmedical problems are defined and consequently treated as medical conditions.

To exploit the advantages early diagnostics of AD can offer, while at the same time avoiding medicalization, policy makers should develop smart governance strategies. These smart governance strategies rely on characteristics of Responsible Innovation (RI) that encompasses social, moral and ethical impacts of innovation and implements tools like 'stakeholder collaboration', 'transparency' and 'a bottom-up approach'.

The theoretical background of this research consists of three main areas namely (1) two dimensions of AD diagnosis and treatment: the medical and non-medical approach, (2) technology-push of early diagnostics and demand-pull of patient and societal needs and (3) relevant RI characteristics for developing smart governance strategies.

After executing a systemic literature review and conducting semi-structured interviews with experts in the field, results show that there is a high amount of attention for the medical approach of AD diagnosing and treatment: the development of early diagnostics of AD. An increase in diagnosing or 'labelling' leads to stigmatization of AD patients. This can deteriorate these patients even faster. Secondly it becomes clear that a misbalance between the technology-push and demand-pull can enhance a medicalization trend. Finally, a science-policy gap is identified, due to ineffective implementation of stakeholder collaboration and a bottom-up approach. Transparency in governance in general is also lacking.

Therefore it can be concluded that there are three main fields of advice that form a refined framework for the development of smart governance strategies concerning early diagnostics of AD. These three main areas of advice are: (1) safeguard the balance between a technology-push and demand-pull, (2) prevent stigmatization and (3) improve effective collaboration and communication between scientists and policy makers. Further research into handhelds for the development of these smart governance strategies is necessary.

Nederlandse samenvatting:

De ziekte van Alzheimer is één van de grootste uitdagingen op het gebied van gezondheidszorg in Nederland vandaag de dag. Een manier om dit probleem te lijf te gaan is het ontwikkelen van vroegdiagnostiek van Alzheimer. Echter de ontwikkeling en implementatie van deze vroegdiagnostiek is controversieel omdat het kan bijdragen aan de ontwikkeling van een medicaliseringtrend. Medicalisering wordt gedefinieerd als het proces waarbij niet-medische problemen worden beschouwd en behandeld als een medische aandoening.

Om tegelijkertijd te profiteren van de voordelen van vroegdiagnostiek van Alzheimer en medicalisering te voorkomen, moeten beleidsmakers *'smart governance strategies'* ontwikkelen. Smart governance strategies baseren zich op karakteristieken van *Responsible Innovation* (RI) dat sociale, morele en ethische overwegingen in acht neemt en tools zoals *'stakeholder collaboration'*, *'transparency'* en een *'bottom-up approach'* implementeert.

Het theoretisch raamwerk van dit onderzoek bestaat uit drie delen, (1) twee dimensies van Alzheimer diagnostiek en behandeling: de medische en niet-medische benadering, (2) *tehnology-push* van Alzheimer vroegdiagnostiek en *demand-pull* van patiënten en de

maatschappij en (3) relevante RI karakteristieken die belangrijk zijn bij het ontwikkelen van smart governance strategies.

Na een systematisch literatuuronderzoek en het uitvoeren van semi-gestructureerde interviews met Alzheimer en RI experts, geven de resultaten aan dat er veel aandacht is voor de medische benadering van Alzheimer: de ontwikkeling van vroegdiagnostiek technieken. Het vaker diagnostiseren of 'labellen' leidt tot stigmatisering van Alzheimer patiënten. Dit kan deze patiënten nog sneller achteruit doen gaan. Ten tweede wordt het duidelijk dat een disbalans tussen technology-push en demand-pull de medicaliseringstrend kan vergroten. Tot slot wordt een *science-policy gap* geïdentificeerd. Door ineffectieve implementatie van *stakeholder collaboration* en een *bottom-up approach* vindt er slechte communicatie en collaboratie plaats tussen wetenschappers en beleidsmakers. Ook *transparency* blijkt onvoldoende te worden toegepast door beleidsmakers.

Dit leidt tot de conclusie dat er op drie gebieden advies gegeven kan worden, leidend tot een verfijnd raamwerk voor beleidsmakers. Deze drie gebieden zijn: (1) het bewaken van de balans tussen technology-push en demand-pull, (2) het voorkomen van stigmatisering en (3) het verbeteren van samenwerking tussen wetenschappers en beleidsmakers. Verder onderzoek naar concrete manieren om smart governance strategies te ontwikkelen wordt aangeraden.

Table of contents

Words in text: 7555, excluding: front page, table of contents, inter textual references, tables, reference list and appendix.

1. Introduction

Alzheimer's disease (AD) is a current big health challenge in the Netherlands and is the cause of dementia in over 70% of all patients suffering from dementia (Alzheimer's Association, 2014; Mount & Downton, 2006). Since the 1980's the prevalence of the disease has risen significantly which put AD under the attention of many physicians, policy makers and the public (Scodellaro & Pin, 2011). This rise of the disease's prevalence is caused mainly by the change in definition of AD (Fox, 1989). In 1906 cases of pre-senile dementia (dementia before the age of 65) were described as AD. In the 1970's the definition of AD was extended to cases of senile dementia as well (Scodellaro & Pin, 2011). This has caused a major shift in the paradigm of ageing, namely the fact that dementia was no longer considered to be a symptom of a normal ageing process, but should be treated and diagnosed as a disease (Scodellaro & Pin, 2011).

This shift in the ageing paradigm caused a certain degree of medicalization. Medicalization was first described as early as the 1970's and it is defined as the process by which nonmedical problems are defined and consequently treated as medical conditions (Ballard & Elston, 2005; Barsky & Borus, 1995; Conrad, 1992). The term was introduced to maintain a critical vision on the role of medicine in the management of society (Zola, 1972).

The problem medicalization poses is identified as the excessive and often unnecessary diagnosing of individuals and use of pharmaceuticals (Conrad, 1992). The overuse of pharmaceuticals occurs when pharmaceutical companies play a part in "widening the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments" (Moynihan, 2002: 1). This way pharmaceutical companies can exert an undesired influence on individuals in society (Moynihan, 2002) and a society unnecessarily dependent on medical treatments is created (Conrad, 2008).

Considering the fact that AD is one of the biggest health challenges the Netherlands faces in 2014 (CTMM, 2014), scientists have set out to find solutions for this health challenge. Recently scientists have begun to develop diagnostic techniques that enable screening and in vivo early diagnosing of AD (Cuijpers, 2012). The early detection of AD is one of the most pursued goals in the biomedical industry (Boenink et al., 2011). It can contribute to a better preparation of the

patient on a future with AD, and symptomatic treatments that are available tend to be more effective in an earlier state of the disease. Early diagnostics of AD are therefore considered to be beneficial for AD patients (Moors & Lukkien 2014; Prince et al, 2011). In addition to this, early diagnostics of AD can prevent the use of unnecessary healthcare due to inaccurate treatment (Alzheimer NL, 2012).

However, the development of novel early diagnostics of AD is also being criticized and it is argued that AD diagnosis is misused in elderly people to sell drugs and scare and attract patients thus controlling elderly people (Brown, 1995; Conrad, 1992; Scodellaro & Pin, 2011). This contributes to the medicalization of a normal ageing process because symptoms of senile dementia are diagnosed and subsequently treated as a disease entity rather than a normal and accepted sign of ageing (Clark, 2014).

This constant battle between scientific progress through the development of early diagnostics of AD on the one hand, and the risk of medicalization of a normal ageing process on the other hand, needs to be managed in a proper way. One of these proper ways is implementing so-called smart governance strategies. Smart governance strategies are governance strategies based on the idea of safeguarding a responsible form of innovation (RI) (Kickbusch, 2012). Before going deeper into these 'smart' governance strategies, it is important to first define Responsible Innovation (RI). Pursuing RI has become increasingly important in the last two years in the European Commission's Science in Society programme (Owen et al., 2012). But what makes innovation responsible? Cuijpers et al. (2013) state that in order for innovation to be responsible, the innovation process should entail social, moral and economic concerns. Policy makers that pursue a responsible form of innovation search for the "right" impact of science and technology on society (Von Schomberg, 2012). RI should be an iterative process that is "anticipatory, reflective, deliberative and responsive in its constitution and implementation" (Owen et al., 2013: 46). It is thus not solely innovation in a technical and economic way, but also in a societally responsible way, actively taking the societal impact of innovations into account.

To ensure that the innovations in the healthcare sector develop in such a responsible way, it is important to explore fitting policies for innovations, such as early diagnostics of AD. Bearing in

mind the ideal of responsible innovation, governmental institutions pursue healthcare policies that ensure RI by means of smart governance strategies (Kickbusch et al., 2012).

Before going into detail about what makes governance strategies 'smart', it is important to realize that the term 'governance' is used rather than 'government'. Governance is considered to be a broader concept than government (Lessig, 2009; Rhodes 1996). It is understood as "the interaction of processes, information, rules, structures, and norms that guide behavior toward stated objectives that impact collections of people" (Johnston & Hansen, 2011: 3). It is less rigid than the traditional top-down approach of government.

There has been research performed, by for example the World Health Organization in 2012, concerning smart governance strategies for healthcare and wellbeing (Kickbusch et al., 2012).The WHO defines smart governance as "one way of describing the major institutional adaptations being undertaken in public and international organizations in the face of increasing interdependence" (Kickbusch et al., 2012: 68). Smart governance strategies thus rely more on collaboration and interdependency between different stakeholders than traditional government strategies. What makes governance strategies 'smart' is being more collaborative with different stakeholders, using modern day technology more effectively and being more transparent (Smartgovernance.net, 2014). The American organization 'IDC Government Insights' defines smart governance as "the implementation of a set of business processes and underlying information technology capabilities that enable information to flow seamlessly across government agencies and programs to become intuitive in providing high quality citizen services across all government programs and activity domains" (IDC Government insights, n.d.).

These new smart governance strategies are thus necessary for effective governance in modern day knowledge-based societies that rely largely on new forms of technology and communication (Kickbusch et al., 2012). Another cause for the emergence of smart governance is the rise of modern day challenges that traditional forms of governance are not able to tackle (Scholl & Scholl, 2014).

Medicalization can be seen as one of those modern day challenges that traditional forms of governing lack adequate solutions to, since there is no literature about specific governmental policies concerning medicalization, nor clear definitions or solutions to the problem. Smart governance strategies can be an instrument to provide a possible solution.

The aim of this thesis is to investigate the relation between smart governance strategies concerning early diagnostics of AD and medicalization so that a responsible form of healthcare innovation can be pursued, eliminating the problems medicalization can cause.

The main research question this thesis aims to provide an answer to is as follows:

What are smart governance strategies concerning novel early diagnostics of Alzheimer's disease that prevent medicalization?

Answering this question is theoretically relevant, as it will apply novel knowledge about smart governance strategies to a phenomenon that it has not yet been explicitly applied to: early diagnostics of AD. It will therefore provide new insights into the possible prevention of medicalization possibly caused by these early diagnostics. This simultaneously is of societal relevance, since it aims to provide knowledge that can help prevent negative societal effects of medicalization, such as dependency on pharmaceutical companies and unnecessary high healthcare costs (Conrad et al., 2010).

This thesis first presents a theory section, providing useful theories that lead to a framework on which the exploration of smart governance strategies will be based. It also gives a preliminary answer to the research question. Consecutively the methodology of this research is discussed, leading to the results section. In the conclusion possible ways of developing smart governance strategies that can tackle the medicalization of AD problem will be discussed. The discussion will give advice about relevant further research and demonstrate the difficulties that arose during this investigation.

2. Theory

The theory chapter contains three different sections. The first section focuses on two different approaches of diagnosis and treatment of AD, a medical and a non-medical approach. This section illustrates the different possibilities of further potentially fruitful development of AD diagnosis and treatment outside of the medical approach that focuses mainly on the development of early diagnostics, and the importance of this alternative approach.

The second section describes the two main innovation dynamics at work in the development of early diagnostics of AD: the technology-push of these new techniques and demand-pull of patient and societal needs. A misbalance between these two mechanisms can cause a degree of medicalization.

Lastly, the third section focuses on the three most relevant characteristics of Responsible Innovation (RI) that play an important role in the development of smart governance strategies.

2.1 Two dimensions of AD diagnosis and treatment: the medical and non-medical approach

Developing early diagnostics of AD has as ultimate goal to create a clear diagnosis and better treatment (or maybe someday even a cure) for the disease (Boenink et al., 2011, Mueller et al., 2005; Scodellaro & Pin 2011). This is part of a medical approach of AD treatment.

However the increased and earlier diagnosing of patients also causes a level of stigmatization (Brown, 1995; Conrad & Barker 2010) and a rise of so-called malignant social psychology (Kitwood, 2002). When observing the development of dementia in any patient, it becomes apparent that social and interpersonal factors play an important role (Kitwood, 2002). This indicates that the way people treat other people with dementia or AD in particular, influences the development of the disease in the patient (Conrad & Barker, 2010). Malignant social psychology describes the process of healthy people stigmatizing AD patients by viewing them purely as AD patients or simply dement, an outcast so to speak, and not as other individuals (Kitwood, 2002). One characteristic of malignant social psychology that is considered important in this thesis is *labelling*. Kitwood defines labelling of AD patients as "using a category such as dementia, or 'organic mental disorder', as the main basis for interacting with a person and for explaining their behavior" (Kitwood, 2002: 46). Labelling is of specific importance since it is

closely related to medicalization. Remembering the definition of medicalization (treating a non-medical condition as a medical one) it becomes clear that the process of medicalization, especially when caused by early diagnostics, is based largely on the application of a label. In this case the label is the diagnosis of AD. According to Kitwood (2002) this labelling of AD patients contributes to social malignant psychology which in its place causes a form of patient care that might only speed up the development of the disease.

Increasing the rate of diagnosing by developing early diagnostics can lead to a higher amount of labelling of individuals that are experiencing a normal ageing process. This causes stigmatization of the patient group meaning that individuals with a mental illness are perceived to have undesirable characteristics leading to a devaluation of that person (Brown, 1995; Corrigan et al., 2003; Jolley, 2000). This is the risk of medicalization.

There is however an alternative way of approaching AD diagnosing and treatment. The second perspective taken into account is a non-medical approach that mainly entails the importance of an active and socially integrated lifestyle (Fratiglioni, 2004, Kitwood 2002, Wilber, 2007) and acceptance of the ageing process (Scodellaro & Pin, 2011).

An active and socially integrated lifestyle can protect against dementia by active stimulation of the brain, which keeps the brain functioning well during the ageing process (Fratiglioni, 2004; Kitwood, 2004). Social integration of AD patients can also help improve communication and understanding between them and other individuals in society (Wilber, 2007). Additionally, the importance of the acceptance of a normal ageing process is attributed greater importance in the non-medical approach of AD diagnosis and treatment. Diagnosing becomes less important than the general wellbeing of a person (Cuijpers, 2014) and ageing is viewed as something normal instead of a disease (Scodellaro & Pin, 2011; Clark 2014).

Insights from these studies can help shaping the right lifestyle habits: being physically and socially active (Fratiglioni et al., 2004; Swaab et al., 2002). But adjusting one's lifestyle in order to prevent a medical condition like dementia can also be seen as a form of medicalization. However when advice about lifestyle adjustments goes hand in hand with the promotion of the acceptance of the ageing process, they change from a form of medicalization to simply shaping one's life in a healthy way (Scherder, 2014).

The danger of too much focus on the medical approach of AD treatment is overlooking the importance of 'simple' lifestyle and specialized care advice that avoids the effects of malignant social psychology. This could potentially diminish the problems caused by AD equally or even more than early diagnostics, without necessarily diagnosing elderly subjects. A pivotal part of this is the acceptance that ageing is inevitable and normal. There are ways to slow the process of ageing down, but in the end it is a normal process and not viewed as a disease.

This is an important fact to keep in mind when developing smart governance strategies concerning early diagnostics of AD. On the one hand the advantages of early diagnostics need to be exploited, while at the same time ensuring that the focus of AD treatment does not solely lie on the medical approach thus stimulating the development of a medicalization trend.

2.2 Technology-push of early diagnostics and demand-pull of patient and societal needs

In order to better understand the causes of medicalization due to early diagnostics of AD, two factors that influence the rate of innovation, in this case of early diagnostic techniques, need to be taken into account: technology-push and demand-pull. The technology-push idea argues that advances in technology determine the rate and direction of innovation within a society (Martin, 1994; Nelson & Winter, 1977; Nemet, 2009) and the need to apply know-how to products or services is the driver of development (Brem & Voigt, 2009). In this case it means the influence that the development of early diagnostics of AD have on the rate of innovation. The demand-pull idea argues the opposite, stating that the rate of innovation and its direction is dependent on the need of the market due to inadequate satisfaction (Martin, 1994; Nelson & Winter, 1977; Nemet, 2009), in this case the patient or societal need for early diagnostics of AD.

In the case of early diagnostics of AD, these two factors become essential when understanding the rise of medicalization. The question is whether the new technologies are causing the rate and direction of innovation (the first line in figure 1.), or whether these new technologies are in fact being developed because of an existing demand-pull for early diagnostics by patients or society as a whole (second line figure 1.).
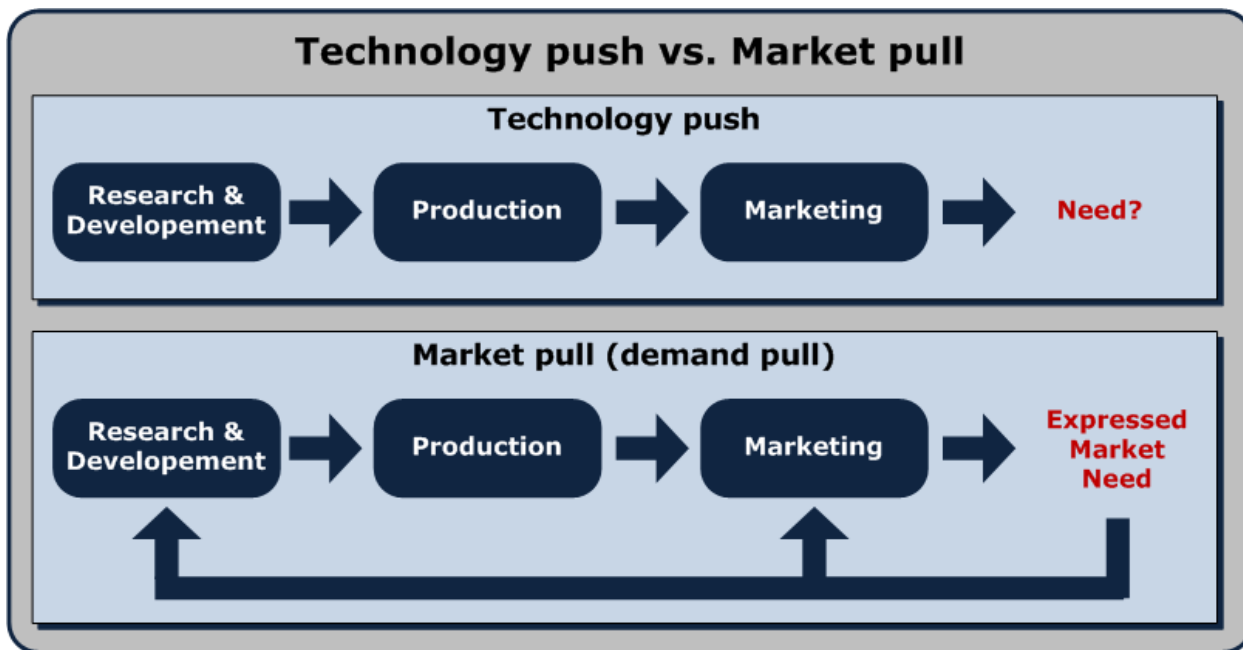
Figure 1. Technology-push vs. Market pull (Martin, 1994)

Medicalization in the introduction of this thesis is defined as "the process by which nonmedical problems are defined and consequently treated as medical conditions". In the case of medicalization of AD, this means that individuals experiencing a normal ageing process define this non-medical problem as a medical problem, namely AD. This conviction can be caused by an early diagnosis and disease mongering (Moynihan, 2002). This way the diagnosing of people can create a demand-pull for further screening, diagnosing and specialized care for AD patients, that may not have had expressed these demands, or had even been labelled as AD patients if it had not been for the early diagnostics in the first place. This way, the technology-push would have created a demand-pull.

Several aspects can be identified within the two concepts of technology-push and demand-pull when they are applied to early diagnostics of AD, based on the definition of the terms and available literature. These aspects are shown in table 1. The identified aspects are relevant because they all provide insight into the dynamics of the two concepts (technology-push and demand-pull) and can help understanding the rise of medicalization.

Table 1. Different aspects of technology-push and demand-pull

Technology-push	Demand-pull
The development of early diagnostics	Patient need for screenings and early diagnosing
The introduction of so-called 'memory clinics' in hospitals	Societal need for better/earlier diagnosing and treatment for AD patients

When designing smart governance strategies concerning early diagnostics of AD, it is essential to determine where technology-push enhances or creates demand-pull in a way that results in negative consequences for society, in the form of medicalization.

2.3 Relevant RI characteristics for developing smart governance strategies

When developing smart governance strategies, as was stated in the introduction, the aim is to incorporate similar characteristics as those of RI. Combining the different descriptions of responsible innovation, in this thesis there is a focus on the following three main characteristics: *stakeholder collaboration*, *transparency* and a *bottom-up approach*. These characteristics have been chosen because they represent characteristics influencing the practical development of smart governance strategies and thus form concrete handhelds or tools for the development of smart governance, as opposed to the general ideals of responsible innovation (such as moral, ethical en economic considerations (Cuijpers et al., 2013)).

In order for smart governance strategies to pursue RI, constant communication and collaboration between stakeholders needs to be present (Willke, 2007). Smart governance strategies concerning healthcare issues have recently been constructed by the WHO bearing in mind the general functioning of a good healthcare system. These strategies were mainly based on the belief in collaboration between different stakeholders as is demonstrated in the following quote:

> "Governance for health promotes joint action of health and non-health sectors, of public and private actors and of citizens for a common interest. It requires a synergistic set of policies, many of which reside in sectors other than health as well as sectors outside government, which must be supported by structures and mechanisms that enable collaboration" (Kickbusch et al., 2012: 9).

Collaboration between stakeholders is thus considered to be an important part of smart governance. In order for a governance program to be smart, it is important to actively involve those who are governed through governance infrastructures, for example by distributed organizations or online communities (Johnston, 2011).

In addition to this stakeholder collaboration in all aspects of the governing process, smart governmental institutions should be transparent when designing governance strategies to be able to meet modern day challenges that surpass traditional ways of governing (Scholl & Scholl, 2014).

In order for governmental institutions to be transparent they must not merely provide government data to third parties, but they should also proactively involve stakeholders in their decision-making processes (Scholl & Scholl, 2014). This way stakeholders get insight into the entire functioning of the institution.

The last RI characteristic taken into account concerning the concrete development of smart governance strategies is the application of a bottom-up approach. This characteristic is closely related to stakeholder collaboration and transparency. A bottom-up approach encompasses the implementation of policies by smaller units than governmental or regulatory institutions, such as firms, organizations or individuals (Fromhold-Eisebith & Eisebith, 2005). The ideas of these smaller units are attributed a greater amount of importance than in a top-down government approach. Naturally this goes hand in hand with stakeholder collaboration when these stakeholders, being firms, organizations or individuals, are involved in the decision-making process of a governmental institution. Taking into account the knowledge and relevant contributions of all stakeholders, a bottom-up approach decreases the risk of an irresponsible form of innovation.

All discussed concepts, the medical and non-medical approach of AD diagnosis and treatment, the dynamics of technology-push demand-pull and the RI based tools for smart governance (stakeholder collaboration, transparency and a bottom-up approach) together contribute to answering the main question of this thesis by providing insight into theories and causes/mechanisms of medicalization that need to be taken into account when preventing medicalization and tools for developing smart governance strategies that aim to do so. The result of this thesis will thus be a refined framework for smart governance strategies concerning early diagnostics of AD that prevent medicalization. This refinement will be achieved through the gathering of information through a systemic literature review and semi-structured interviews.

3. Operationalization

In order to construct a refined framework for smart governance strategies concerning early diagnostics of AD that prevent medicalization, the concepts discussed in the theory section need to be operationalized. The identified indicators remain rather abstract since this research is based on qualitative literature review and exploratory qualitative data from semi-structured interviews.

The amount of focus placed on the medical and non-medical approach of AD diagnosing and treatment will be explored using the indicators visible in table 2.

Table 2. Indicators for medical and non-medical approach of AD diagnosing and treatment

Concept	Indicator
Medical approach of AD diagnosing and treatment	The degree of attention towards the development of early diagnostics of AD and the search for a cure
Non-medical approach of AD diagnosing and treatment	Little focus on diagnosing, focus on lifestyle advice and the acceptance of the ageing process

The different aspects of technology-push and demand-pull mechanisms (see table 1) are operationalized in table 3.

Table 3. Indicators for the technology-push and demand-pull

Technology-push	Indicator
The development of early diagnostics of AD	The nature of companies and organizations researching and developing early diagnostics of AD
The introduction of so-called 'memory clinics' in hospitals	The amount of hospitals in the Netherlands that have a 'memory clinic'
Demand-pull	**Indicator**
Patient's need for screenings and early diagnosing	The variety and intensity of patient need for early diagnosis of AD
Societal need for better/earlier diagnosing and treatment for AD patients	The degree of attention for AD diagnostic techniques by the government and organizations.

Lastly, because the aim is to develop a 'smart' and thus 'responsible' form of governance, the most relevant characteristics of responsible innovation that form tools for the development of smart governance strategies should be taken into account. The three main tools used in this thesis are operationalized in table 4.

Table 4: Indicators for the three main characteristics of RI

RI Characteristic	Indicator
Stakeholder collaboration	The nature of inclusion of different stakeholders during the design of smart governance strategies, such as patients, doctors, organizations, hospitals etc.
Transparency	The degree of transparency of the design and implementation of governance strategies by sharing of documents and active involvement of stakeholders in the decision-making process.
Bottom-up approach of governance	The attributed importance of the ideas and contributions of local stakeholders by active implementation of stakeholder collaboration and communication.

In the results section these indicators will be explored providing valuable information for forming an advice for the development of smart governance strategies concerning early diagnostics for AD.

4. Methodology

4.1 Research design

This research was based on qualitative and exploratory research to gather in-depth information on the development of smart governance strategies and create profound understanding of medicalization and its relation to early diagnostics of AD. The theoretical part of the research has the form of a systemic literature review. This systemic literature review serves to gain insight into the current state of knowledge about early diagnostics of AD, smart governance strategies and medicalization (Khan, 2003). The selection of literature is essential when performing a systemic literature review (Bryman, 2008), which is why the collection and selection of data is discussed in detail in section 4.2.

In addition to a systemic literature review approach, the second part of this research has an exploratory nature. This exploration of possible adequate smart governance strategies that can prevent medicalization of AD was based on qualitative data obtained during the systemic literature review and information given by two experts on the subject matter. This was to gain insight into underlying assumptions and refine the conceptual model. This additional information provided by experts of the field was obtained through semi-structured interviews. Due to time limits and availability of experts, information was obtained from two interviews.

4.2 Data collection

The vast majority of collected data is peer reviewed scientific literature concerning responsible innovation, early diagnostics of AD, medicalization and smart governance strategies. This literature was obtained through extensive desktop-research. Several academic databases were consulted such as Google Scholar, PubMed and Scopus. Criteria used to select the literature are the publication year, key words in the title and or abstract, number of citations and field of study. Examples of search terms that were used during the literature search are 'responsible innovation' AND 'governance' OR 'healthcare', 'smart governance', 'medicalization' AND 'Alzheimer's disease' OR 'dementia' OR 'ageing', 'early diagnostics' AND 'Alzheimer's disease'.

To form a relevant and up to date view on smart governance strategies and the medicalization of AD problem, much literature selected is written after the year 2010. Some pivotal works, such as the works of Conrad (2008) on medicalization, were also selected due to the great number of citations and importance of the work.

Articles were selected from different databases, originating from different fields of study. Seeing as this research requires a broad view from different perspectives, it was undesirable to for example only select articles from a medical point of view. This diversity in perspectives is also reflected by the different types of journals that were used during this research. Among the journals that articles were selected from are: *Social Science & Medicine, Journal of health and social behavior, Ecological Economics, American Governance and Science, Public Policy and the Journal of Health and Social Behavior*.

Additional information was gathered by means of semi-structured interviews with experts in the field of AD and innovation studies. The form of the interviews was semi-structured to discover underlying patterns, ideas and opinions about the medicalization of AD and smart governance strategies (Bryman, 2008). I have approached drs. Yvonne Cuijpers, a PHD candidate at the University of Utrecht, who researches responsible innovation. She is also researching the responsibility of early diagnostics of AD. I have also approached prof. dr. Erik Scherder, professor at the Vrije Universiteit in Amsterdam, who is an expert on the treatment of different types of dementia, including AD.

4.3 Data analysis

Both the systemic literature review and the semi-structured interviews have provided qualitative data. Cross-checking data obtained from different articles, and information provided by experts during semi-structured interviews, a degree of triangulation took place. Subjecting theoretical concepts to this process of triangulation has enhanced the internal reliability of these theories (Bryman, 2008).

All data was reviewed systematically, to avoid a personal bias. This has provided a clear overview of the existing knowledge and opinions about the medicalization of AD and responsible and smart governance strategies.

4.4 Research Quality

The three main concepts that need to be taken into account when pursuing a good quality of research are reliability, replicability and validity (Bryman, 2008).

Reliability was pursued during this research by attentive studying of the qualitative data, from both the written literature and the semi-structured interviews. However, due to the fact that there is only one researcher, a colored interpretation of the qualitative data could not be avoided entirely. Using a systematic approach during the review of the literature, this risk of personal bias was decreased.

Replicability entails the detailed description of the methodology, thus ensuring a second researcher could replicate the same research in the exact same manner to for example cross-check the results (Bryman, 2008). This criterion of research quality was met by describing the research process in detail.

Ultimately the validity of this research depends on the fit relation between the collected data and the theory (internal validity), and the degree to which the results will be generalizable (external validity) (Bryman, 2008). Since this is first and foremost a literature research, the internal validity is not applicable to a high degree. A good preparation of the semi-structured interviews will ensure internal validity between the theories used and the data that will be obtained during the interviews. The results of this research will only be generalizable for cases of medicalization in the Netherlands, both of AD and medicalization in other contexts.

5. Results

To answer the research question "what are smart governance strategies concerning the novel early diagnostics of Alzheimer's disease that can prevent medicalization?" the theory section and operationalization have made clear that there are several aspects that need to be taken into account when developing these smart governance strategies. Following the structure of the theory section, these aspects are discussed in the three following paragraphs.

5.1 Dynamics of the medical and non-medical approach of AD diagnosis and treatment

Concerning the degree of attention for the development of early diagnostic techniques, the indicator for a medical approach of AD diagnosing and treatment (table 2), it is deducible that there is a significant amount of attention towards the development of these techniques. This is visible through the large amount of academic papers considering the subject, a variety of which is used in this thesis (Boenink et al., 2011; Mueller et al., 2005; Prince et al., 2011) and research institutions developing these techniques (Scherder, 2014). There is however also a focus in academic papers on the non-medical approach of AD diagnosing and treatment (Kitwood, 2002; Scherder et al., 2005; Scodellaro & Pin, 2011; Swaab et al., 2002), corresponding with the second indicator of table 2: little focus on diagnosing, focus on lifestyle advice and the acceptance of the ageing process. It is important to look at the dynamics between these two approaches in order to give advice for the development of smart governance strategies.

As was described in section 2.1, a medical approach of AD treatment and a high rate of diagnosing and thus labelling of patients, contributes to the stigmatization of these patients. This stigma goes against the acceptance of the normal ageing process and thus stimulates a medicalization trend. This stigma often causes AD patients to be treated as infantile, incapable and outcasts (Jolly & Benbow, 2000; Kitwood, 2002; De Mendonça Lima et al., 2003). This can lead to deterioration of an AD patient's health because they become inactive and unchallenged.

However, a non-medical approach of AD diagnosing and treatment was also described, shying away from diagnosing and focusing on lifestyle advice and the acceptance of ageing.

Several studies have shown the importance of active neuronal stimulation, for example through physical activity, enriched environments and interactive relationships with other individuals, when pursuing a normal and healthy ageing process (Swaab et al., 2002; Scherder et al., 2005; Kitwood, 2002). A potential cause of neuronal stimulation and reactivation can be an enriched environment. These studies give insight into the importance of lifestyle habits when it comes to the prevention or treatment of AD.

Kitwood suggests another non-medical approach to AD and dementia care, promoting the meeting of main psychological needs of people with dementia by caregivers, which also means an enrichment of the environment of patients by enhancing their social lives. These needs include a feeling of attachment, identity, inclusion, occupation, comfort and love (Kitwood, 2002).

These insights influence the way in which AD patient care should be constructed and resonate the critique of medicalization of "normal" ageing processes since they seem to promote acceptance of ageing and provides advice on how to shape this ageing process in the healthiest way possible, without putting much emphasis on the importance of diagnosing. Avoiding diagnosing or labeling, the chance of stigmatization becomes lower.

However, due to the described advantages of early diagnostic techniques, it is also important to create a more positive view on elderly people suffering from AD to prevent stigmatization while exploiting new technological diagnostic possibilities. Scherder (2014) stated that AD patients and the disease itself are portrayed very negatively in the media which amplifies the stigma that is upon them. Drs. Yvonne Cuijpers also spoke of her conversations with a Dutch doctor that criticizes the form of diagnosing patients, questioning them solely about how often they feel bad or experience negative symptoms, instead of asking them how often they feel good or happy. This negative form of questioning pushes patients more into a negative stigma (Cuijpers, 2014) that also takes the form of self-stigma, pushing patients to think less of themselves and their capabilities (Corrigan et al., 2006; Watson et al., 2007).

There are some initiatives that try to portray dementia/AD and old age in a more positive way, considering books like *'Het nieuwe oud'* (The new old) (Kits & Schut, 2011) and *'de gezichten van dementia'* (the faces of dementia) (Wanders & van Hoogdalem, 2012). There are also movies such as '*I remember better when I paint*' (2009) and *'Alive inside: a story of music and memory'* (2014) that illustrate the importance of neuronal activity (through painting and

music) for AD patients. But we are far away still from a positive view on AD patients, though approaching them in a more positive way, activating them and enriching their environments can slow down the disease and improve their old age. An important conclusion is therefore that stigmatization of AD patients can be an obstacle in the promotion of the non-medical approach of AD treatment, and because this non-medical approach proves to be valuable, stigmatization should be avoided.

5.2 Safeguarding the balance between technology-push and demand-pull

When developing smart governance strategies concerning early diagnostics of AD it is important to look at technology-push and demand-pull in an objective way and pursue a balance between the two.

The first indicator of technology-push (see table 3: the nature of companies and organizations researching and developing early diagnostics of AD) can be explored in the Netherlands.

All eight Dutch academic hospitals and pharmaceutical companies in the Netherlands claim to research early diagnostics of AD (NFU, 2014), and national initiatives like the 'Delta-plan dementie', 'Amsterdam Centre on Aging', 'the Netherlands consortium for healthy ageing' and the 'Internationale stichting Alzheimer onderzoek' are just a couple of examples of organizations researching ageing and dementia (Scherder, 2014). 'Alzheimer Nederland' has five big research locations throughout the Netherlands that focus on many aspects of AD, including early diagnostics (Alzheimer NL, 2014).

The second indicator of technology-push (table 2): the amount of memory clinics in the Netherlands, was established in 2013. There were 123 memory clinics spread throughout the country in 2013 (Novartis Pharma, 2013). Considering there are approximately 352 hospitals in the Netherlands over a third of Dutch hospitals have memory clinics (Novartis Pharma, 2013). These memory clinics represent a technology push because they are based on diagnostic techniques and can cause (elderly) individuals to pay a possibly unnecessary visit to a clinic due the high accessibility of the clinics (Scherder, 2014).

Moving to the demand-pull side of the story, the first indicator to explore is the variety and intensity of patient need for early diagnosis of AD. The rise of memory clinics and the popularity of these clinics (Scherder, 2014) suggest that there is a relatively high intensity of patient need

for early diagnosis of AD. Advantages of an early diagnosis, earlier described by Moors & Lukkien (2014) and Prince et al. (2011) explain the intensity of this patient need. However it remains hard to determine whether or not these expressed patient needs might be caused by technology push.

The tendency of patients not wanting to be diagnosed is also described in academic literature and was mentioned by both Prof. dr. Scherder (2014) and Drs. Cuijpers (2014). This tendency is supported by the fact there is no available cure for AD (Boenink et al., 2011) In addition to this, Wimo et al. (2014) describe how the early diagnostics of AD can cause a period of extra stress and loss of quality of life in patients that have received an early diagnosis of AD. This loss of quality of life consists of uncertainty about the disease's development, hospital visits, a possible loss in terms of sick leaves and productivity and the earlier described effects of being stigmatized (Wimo et al., 2014). Patients also want to avoid a social stigma when denying or not seeking for a diagnosis (Brown, 1995; Conrad, 1992; Scherder, 2014). This difference in patient desires for diagnosing shows the variety of patient need for early diagnosis of AD.

Lastly, the final indicator of table 3: the degree of attention for AD diagnostic techniques by the government and organizations, gives information about the societal need for early diagnostics of AD. This degree of attention is represented by several governmental plans and organizations that have been founded to develop or support early diagnostics for AD and the general worries about the rise of number of patients by 2020 (CTMM, 2014; Horizon2020, 2013). This suggests a high societal need for better treatment of AD.

The demand-pull of AD patients and society as a whole brings certain earlier mentioned advantages of early diagnostics to light, such as an aim for better care for patients and providing diagnosis to patients that can then prepare for the disease (Prince et al., 2011).

In addition to this, Prof. dr. Scherder (Scherder 2014) points out that recent studies are researching the relation between cardiovascular disease and AD. If a clear causal relation can be determined, early diagnostics of AD can make a big contribution in preventing or slowing down the development of the disease by for example prescribing medication against hypertension. These studies show the importance of studying cardiovascular disease alongside presumed neuronal causes of AD (Grammas, 2011; Lorius et al., 2014; Waldstein & Wendell, 2010). This

contributes to the importance of the medical approach of AD by developing early diagnostic techniques and suggests that there could be much to gain in this field in the future.

Overall it becomes clear that safeguarding the balance between technology-push of early diagnostics of AD and demand-pull of patients and society for these techniques is important, because technology-push could enhance demand-pull in a way that causes medicalization, but also poses earlier described advantages.

5.3 Three tools for smart governance strategies

In order to achieve the goals described in 5.1 and 5.2 an effective form of policy making is required, through the means of earlier explained smart governance strategies. Three identified tools for this development process are stakeholder collaboration, transparency and a bottom-up approach (see table 4).

The first indicator explored is: the nature of inclusion of different stakeholders during the design of smart governance strategies, such as patients, doctors, organizations, hospitals etc. This indicator describes *stakeholder collaboration* and can be explored by looking at communication between policy makers and different stakeholders.

First of all there are so-called Alzheimer cafés: nationally organized meetings discussing several topics related to AD, amongst which early diagnostic techniques (Alzheimer Nederland, 2014; Cuijpers, 2014; Miesen & Jones; 2004; Morrisey. 2006). These meetings are meant to provide help for AD patients and their family/friends and through their open nature bring different stakeholders together (Cuijpers, 2014; Miesen & Jones, 2004). This is a fruitful initiative that can help policy makers get involved with different stakeholders, such as patients and doctors.

The biggest challenge is to create effective collaboration and communication between scientists and policy makers. Prof. dr. Erik Scherder (2014) talked about his experiences talking to policy makers and stated that understanding of his theories about AD prevention and treatment was often lacking and even if his ideas were heard (promotion of active lifestyles, preventing stigmatization of patients with a form of dementia) they were not put to practice. This shows that collaboration between scientists and policy makers is not yet efficient and should be improved in order for useful scientifically based knowledge about AD to be valuable and implemented in society. This failure of proper communication and collaboration between scientists and policy

makers is referred to in literature as the science-policy gap (Bradshow & Borchers, 2011; Kaufman, 2000; Salomon, 1997), and shows that improvements should be made regarding this indicator.

One thing that needs to be acknowledged is the fact that scientific uncertainty is difficult to translate into policy, since policy requires certainty and clarity (Bradshaw & Borchers, 2000). This uncertainty, in this case about the positive and negative effects of early diagnostics of AD, should therefore be incorporated into policy-making decisions as knowledge and not as ignorance (Bradwhaw & Borchers, 2000). The possibility of the rise of a medicalization trend should thus not be ignored by policy makers but considered to be a possibility based on scientific findings in order to attempt prevention of this problem. This strategy can improve the collaboration between scientists and policy makers and create better understanding plus smart governance strategies that are more anticipatory (Owen et al., 2013) concerning negative as well as positive effects of early diagnostics for AD.

Transparency is another contributor to making governance 'smart'. The focus of the second indicator in table 4 concerns this second tool: the degree of transparency of the design and implementation of governance strategies by sharing of documents and active involvement of stakeholders in the decision-making process. Policy makers should make information about their working methods and decision making process available to stakeholders or the public via for example internet platforms (IDC Government insights, n.d.). Transparency contributes to a higher level of scrutiny, meaning that the governance strategies that are being developed are judged not only by its makers, but also the ones they will affect. This leads to less corruption and a higher level of democracy (Fox 2007; Piotrowski & Van Ryzin, 2007; Von Schomberg, 2012), that will contribute to a level of responsibility of innovation. This transparency is often still lacking in governmental institutions (IDC Government insights, n.d.; Brito, 2007). In the case of early diagnostics of AD, this means that when designing smart governance strategies concerning this matter, transparency needs to be pursued by policy makers. This will increase the level of RI and take social, moral and ethical ideas into consideration.

The last indicator in table 4 concerns a *bottom-up approach* and explores: the attributed importance of the ideas and contributions of local stakeholders by active implementation of stakeholder collaboration and communication. A bottom-up approach eliminates possible pre-existing biases in governmental institutions due to the involvement of other parties (Bang, 2003;

Bond, 2006) and this sharing of knowledge between different parties/stakeholders enhances the value of the system (Landier & Sraer, 2005). Thus during the development of smart governance strategies concerning early diagnostics of AD, it is advisable to apply this bottom-up approach. This entails listening to patients, family and friends of patients, caregivers, doctors, hospitals and scientists (Cuijpers, 2014). Alzheimer cafés are a possibility of implementing this bottom-up approach.

However as the described lack of stakeholder collaboration in academic literature and Prof. Dr. Erik Scherder's described experiences demonstrate, an efficient form of a bottom-up approach and stakeholder collaboration is not yet being applied in the development of most governance strategies. Transparency of governance is also lacking. For governance strategies concerning the early diagnostics of AD to become truly smart, all three described tools need to be applied more effectively.

6. Conclusion

As the literature discussed in this thesis has shown it is clear that AD is a big health problem in the Netherlands that will only continue to grow. The development of early diagnostics of AD is one of the approaches to deal with this problem, but its development is controversial and brings problems of medicalization and stigmatization of AD patients.

To exploit the advantages of early diagnostics of AD while at the same time avoiding medicalization, smart governance strategies concerning early diagnostics of AD are necessary. The most concrete tools for developing these smart governance strategies described in this thesis are stakeholder collaboration, transparency and a bottom-up approach. This research has shown that all three tools need to be implemented more effectively and that some important dynamics such as technology push and demand pull need to be taken into account. This will subsequently help balancing the medical and non-medial approach of AD diagnosing and treatment.

The main question of this thesis was: 'what are smart governance strategies concerning the novel early diagnostics of Alzheimer's disease that prevent medicalization?' This research has identified several strategies that policy makers should take into account.

Being aware of and actively preventing stigmatization of AD patients is a first strategy policy makers should apply. This can improve the situation of AD patients by altering the form of AD care towards promoting a more active and socially integrated lifestyle for AD patients. Policy makers can do so by promoting a more positive view on AD and AD patients. Additionally, the acceptance of a normal ageing process can also be enhanced by making effort to shift the negative view that society now has on ageing. This can decrease the amount of people wanting to get an early screening for AD, which lowers the risk of diagnosing and labeling individuals experiencing a normal ageing process as AD patients. Thus lowering the degree of medicalization overall.

Studying and identifying the technology-push and demand-pull factors concerning early diagnostics of AD is a second important strategy, since gaining insight into these two factors contributes to the understanding of the actual patient and societal demand-pull that exists independently from a technology-push. This is important since this research has shown that too high of an influence from the technology-push, causing a misbalance between the two factors, can contribute to the rise of a medicalization trend.

Lastly, more effective communication and collaboration between scientists and policy makers should be pursued. This research has shown that there is a science-policy gap that needs to be closed. A strategy for policy makers is using the three described tools of stakeholder collaboration, transparency and a bottom up approach. Implementing a bottom up approach, greater importance is attributed to the ideas of scientists, but also patients, caregivers etc. An example of an adequate tool to achieve this is active participation of policy makers during Alzheimer café meetings. Scientific knowledge and accurate patient and societal need can then be identified and implemented in the development of smart governance strategies. This also encompasses stakeholder collaboration, since all different stakeholders get more influence in the decision-making process of policy makers by getting the chance to contribute their ideas and needs. Stakeholder collaboration and a bottom up approach can be effectively applied and verified by individuals in society when policy makers remain transparent in their activities. All three tools contribute to a responsible form of innovation concerning the early diagnostics of AD.

The answer to the research question thus results in a refined conceptual model for smart governance strategies regarding early diagnostics of AD. The three main areas of advice are summarized in the text-box below.

> **Three main areas of advice:**
>
> 1. Prevent stigmatization of AD patients
> 2. Safeguard the balance between the technology-push of early diagnostics of AD and demand-pull of individuals in society for these early diagnostic techniques
> 3. Improve effective collaboration and communication between scientists and policy makers

7. Discussion

The chosen research question and delineation have permitted this research to explore adequate smart governance strategies concerning early diagnostics of AD, specifically to prevent medicalization. This has been of theoretical relevance since it makes novel combinations between theories on smart governance, early diagnostics and medicalization. It can help create knowledge on the dynamics between all three concepts, which has not been studied before. This creates further possibilities for more extensive research in this subject.

Because the result of this research has the form of an advice for policy makers, it is clear to see the societal relevance of this research. Clear implications are that if policy makers follow the three main areas of advice as they were presented in the conclusion, they can create smart governance strategies that effectively prevent medicalization. Empirical proof for the functioning of these strategies however is not yet available, thus the conclusion of this research remains speculative.

The chosen theories were based on the main recurring themes that were identified during the literature review. However, due to time limitations and the fact this research was executed by one researcher, different theories may come up if the research is replicated due to a different interpretation of literature or personal bias. Potentially relevant theories could have been neglected in this thesis.

Because this research was of a qualitative nature, in depth information and underlying assumptions were identified. However a quantitative approach could be valuable to gain more accurate insight into the technology-push and demand-pull mechanisms. Indicators for these concepts have been rather abstract in this research and thus could have been influenced by a personal bias. A quantitative approach could complement and cross-check knowledge gathered with qualitative data in a valuable way. More qualitative data, such as more interviews with experts would also be an important addition to research in this field.

It is also interesting to take this research out of the context of AD, and explore smart governance strategies to prevent medicalization of other conditions as well, such as ADHD, obesity etc. (Malacrida, 2004; Sobal, 1995). Broadening the delineation of this research can help understand medicalization in general better, and could thus also provide other useful insights for creating smart governance strategies tackling this problem. Additionally, this research has only focused on early diagnostics as a cause of medicalization. It is however important to identify

other factors that stimulate a medicalization trend to incorporate these into research on smart governance strategies. This would increase the societal relevance of research in this field even more.

Another interesting theory that could be used in further research in this subject matter is the multi-level perspective approach (Geels, 2002) since this offers another way to explore new technological developments and its influences on different levels, including societal impact and its consequences. Using this different approach can result in other insights into smart governance and medicalization that combined with this research would create more reliable and valid understanding of the subject.

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Appendix A

General outline of questions of semi-structured interviews:

Beste heer/mevrouw,

Het komende ca. half uur zal ik u interviewen aan de hand van open vragen over de ontwikkeling van vroegdiagnostiek technieken met betrekking tot de ziekte van Alzheimer, medicalisering rondom deze ziekte en de rol van gouvernementele organisaties/overheidsbeleid in deze kwestie. Het doel van dit interview is het verzamelen van achtergrond informatie van experts om mijn thesis te ondersteunen die zich focust op "smart governance strategies for early diagnostics of Alzheimer's disease" met een focus op het voorkomen van medicalisering van het 'normale ouderdomsproces'.

Het interview bestaat uit drie delen. Deel 1 bestaat uit een korte schets van uw achtergrond en huidige functie/onderzoeksgebied. Deel 2 bestaat uit vragen omtrent vroegdiagnostiek van de ziekte van Alzheimer en de relatie tot volgens u al dan niet aanwezige medicalisering van de aandoening. Deel 3 focust op de rol van overheidsbeleid, met het oog op 'responsible innovation'.

Deel 1:

Wat is uw vooropleiding?

Wat is uw huidige functie/gebied van onderzoek?

Hoe is uw huidige onderzoek/werk verbonden aan de ziekte van Alzheimer, vroegdiagnostiek technieken en/of responsible innovation?

Deel 2:

Denkt u dat er vraag is vanuit de samenleving naar de ontwikkeling van vroegdiagnostiek technieken met betrekking tot de ziekte van Alzheimer? Komt deze vraag voort uit de aanwezigheid van technologische mogelijkheden of bestond de vraag al voordat deze nieuwe mogelijkheden ontwikkeld werden?

Denkt u dat er vraag is vanuit patienten naar medicijnen die de ziekte eventueel kunnen vertragen? Ook als hierbij het risico bestaat dat mensen die een 'normaal' ouderdomsproces doormaken onnodig deze medicijnen voorgeschreven kunnen krijgen?

Vindt u het ontwikkelen van early diagnostic techniques voor de ziekte van Alzheimer nuttig? Waarom wel/niet?

In hoeverre denkt u dat er sprake is van medicalisering omtrent de ziekte van Alzheimer? En hoe draagt de verdere ontwikkeling van vroegdiagnostiek hieraan bij?

Denkt u dat er bij de ontwikkeling van zorg voor AD patienten teveel wordt gebaseerd op medische bevindingen en uitgangspunten in plaats van een meer sociaal psychologische aanpak die zich meer richt op de AD patient als individu?

Wat zijn volgens u de belangrijkste focuspunten voor het behandelen of voorkomen van AD?

Is een te grote focus op AD preventie/behandeling een bijdragende factor aan het medicaliseren van een normaal ouderdoms proces?

Deel 3:

Hoe groot acht u de verantwoordelijkheid van de regering om beleid in te stellen om eventuele medicalisering te voorkomen?

Op wat voor manieren zou de overheid medicalisering kunnen voorkomen?

Denkt u dat smart governance strategies een 'responsible' vorm van innovatie kunnen waarborgen met betrekking tot vroegdiagnostiek technieken van AD? *NB: RI: stakeholder collaboration, transparency en een bottom-up approach.*

Denkt u dat de betrokkenheid van verschillende stakeholders belangrijk is bij het ontwerpen van een smart governance strategy voor medicalisering? Welke partijen zijn er volgens u van groot belang?

Hoe denkt u dat gouvernementele organisaties transparant te werk kunnen gaan?

In hoeverre moeten smart governance strategies gebasseerd zijn op lokale of nationale/internationale besluitvormingsprocessen? Ziet u meer heil in een bottom-up of een top-down approach bij het ontwikkelen van governance strategieen, met name met een probleem als medicalisering in gedachten?