Summary
Future visions of medical neuroimaging  
The challenge of realising responsible research and innovation

Science and technology generate both positive and negative societal implications. On the one hand resulting in for example advances in medical care, automation and options for sustainable energy and on the other had causing problems in terms of safety, privacy, health and responsibility. The challenge is to realise innovations in which the positive impacts are maximised and the negative impacts are minimised.

There is currently general recognition that scientific and technological innovations are socio-technical innovations in which the technologies and their socio-institutional embedding co-evolve. This co-evolutionary approach emphasises that science and technology are influenced by, and co-evolve with, societal demands and events. Innovations development is therefore a dynamic process that involves a wide variety of actors. To manage the embedding science and technology in society, reflexive and participatory approaches have been developed. These approaches aim to create societal benefits while, at the same time, trying to limit the negative side-effects of innovations on society. To this end, the potential impacts a technology may have on society are identified and incorporated into research, technology development and design. These approaches are increasingly captured under the term Responsible Research and Innovation (RRI).

Management of innovations is not a new phenomenon and diverse approaches incorporate RRI-related concepts, such as better foresight, more responsive and adaptive governance and public engagement, aiming to manage innovation process and open them to societal influence. However, incorporating responsible innovation in early, emergent phases of scientific and technological development is still a major challenge. This thesis addresses this challenge by identifying options in the management of neuroimaging technologies in early phases of development in order to facilitate responsible embedding of these innovations in the Dutch health system. Neuroimaging technologies are technologies that produce images of the brain as an intact structure. Technological advances in these technologies and resulting knowledge are expected to lead to the development of improved diagnosis and treatment options and to contribute to novel options for prevention. However, besides potential benefits,
these technologies are also associated with negative effects, such as questions regarding privacy, responsibility and an increase in medicalisation.

The focus in this thesis is on specific approach to RRI: Constructive Technology Assessment (CTA). CTA was developed to establish an optimum balance between desirable positive and questioned negative impacts of innovations. CTA has a long history in aiming for technologies that connect better with societal practices, has already been operationalised, and implemented in practice since the late 1980’s. The research presented in this thesis is the result of a CTA process on neuroimaging in the clinical context conducted in the Netherlands in the period 2010-2013. The process aimed to facilitate broad societal reflection and to guide neuroimaging developments towards more shared desirable developments. In this thesis, the process and its results are presented.

Research design

This thesis was guided by the following principal research question: How can a more responsible process of innovation and embedding of neuroimaging technologies be facilitated in the Dutch health system?

In order to answer this question, the research presented in this thesis aimed to open, shape and manage the innovation process of medical neuroimaging, using a specific operationalisation of CTA, namely the Interactive Learning and Action model (ILA). To tailor CTA to the context of emerging science and technology, implicit long-term directions of the technology development process are a necessary component to function as reference point. Hereto, the ILA model was combined with vision assessment, which has shown to be a suitable method for this purpose. As a result, the focus in this thesis is on desirable future visions which guide the directions of technology development. The premise of this thesis is that visions guide actions of actors in practice and guide interaction between them. In addition, responsible innovation implies accepting the challenge to prospectively identify potential concerns and (systemic) barriers that might hamper innovation development and embedding. To gain understanding of challenges and barriers that might become obstacles when neuroimaging is further developed, and strategies to overcome these, we applied a system perspective.

The approach aimed to provide insights into visions of neuroimaging applications in the Dutch health system and related (systemic) barriers from the perspective of
relevant actors, facilitate dialogue on shared desirable visions and action planning, and contribute to responsible development and embedding of medical neuroimaging applications. With the insights from this process, the research also aimed to contribute to further development of a conceptual and methodological framework of the CTA approach to responsible research and innovation (RRI) of emerging science and technology.

The aim of this thesis is therefore threefold:

I. To gain insight into the (desirable) visions of neuroimaging in the Dutch health system;

II. To identify (systemic) barriers that might hamper, and strategies to realise, a responsible development and embedding of medical neuroimaging applications;

III. To contribute to a further specification of a conceptual and methodological framework for CTA as an approach to responsible research and innovation.

The phases of the ILA model were used and were slightly adapted for this research domain. The phases provided structure and guided the CTA process described in this thesis. The chapters in this thesis present the subsequent steps of the process.

**Guiding visions of medical neuroimaging (Chapter 4)**

Neuroimaging developers currently shape future directions of neuroimaging developments with their expertise and ideas. In order to identify future neuroimaging technology paths and potential applications, their guiding visions were identified and constructed as a first step in this research. The consulted developers expected that future advances in neuroimaging technologies will make it possible to obtain more insight into the brain and its disorders. They considered that these advances will lead to new and improved diagnosis and treatment options and contribute to realise options for the prevention of brain disorders, which are currently absent. In addition, the visions illustrate what knowledge (for example, how does the ‘normal’ brain function) and technological developments (for example, specific biomarkers and mobile imaging technologies) are required in order to realise the desirable applications, i.e. barriers that need to be overcome. They also indicated who will be potentially affected (e.g. citizens), both positively and negatively, by the implementation of the applications they envisioned and who might be the actual users in practice (e.g. health professionals). The visions show that a shift in health care, from secondary to primary health care, will broaden the range of the envisioned applications.
Summary

Neuroimaging research in Dutch newspapers (Chapter 5)

To gain more insight into neuroimaging visions as portrayed in the media, we conducted a media-analysis regarding how neuroimaging research was presented in the Dutch newspapers published between 1992 and 2012. We explored how neuroimaging research was framed and which influence this might have on the readers. We concluded that neuroimaging research is mainly presented in the Dutch media as providing insights into and solutions for societal problems that should be supported. We were able to identify 13 of the 307 articles that gave multiple framings of neuroimaging research as a practice and its consequences. These articles presented both positive and more negative framings of neuroimaging and resulted therefore in a more or less ‘balanced’ picture. We concluded that if scientists are to strive for a more ‘balanced’ picture of the possibilities and limitations of neuroimaging in the mass media, our results offer opportunities for actors, and neuroscientists in particular, to take this as an example to address and correct current framing.

In addition, we identified and discussed three emerging framings of neuroimaging that are an extension of the border demarcating illness from health. We concluded that future topics of debate concern most likely neuroimaging applications outside the medical realm or medicalisation discussions related to brain-based explanations of social beliefs and phenomena (e.g. religious experiences), and non-medical related behaviours and dysfunctions (e.g. the determination of diminished capacity in the domain of justice).

Vision of neuroimaging from Dutch citizens (Chapter 6)

In focus groups, Dutch citizens articulated benefits, disadvantages and specific concerns regarding future medical neuroimaging applications: diagnosis, treatment and prevention. During the discussions almost all participants employed different frames, i.e. mental images of how neuroimaging is perceived to function and how neuroimaging is developed and used in practice. Neuroimaging technologies were interpreted as 1) objective tools, 2) advancement tools, 3) reductionistic tools, 4) tools that intervenes in naturalness, 5) uncertain tools and/or 6) as a slippery slope to potential negative future situations. The socio-technical system surrounding neuroimaging was framed as a system that can be 1) trusted, 2) accepted and/or 3) should be distrusted and feared. In the discussions, the participants did not restrict themselves to one frame. Depending on the perceived desirability of the application under discussion, they employed different frames in their arguments. Moreover, most participants did not
restrict themselves to either argue in favour or against neuroimaging. They showed individual preferences, but were able to explore multiple frames within the same example. This implies that the acceptability of future neuroimaging applications depends on the context of application and how a person perceives neuroimaging technologies and its socio-technical system.

New and improved *diagnosis* and *treatment* options are considered conditionally desirable by all participants. Freedom of choice, guaranteed privacy, right to know or to be kept in ignorance and informed consent are formulated prerequisites as well as minimum negative social or economic implications for individuals/patients. Neuroimaging use to *prevent* disorders (risk avoidance) is regarded conditionally as highly beneficial, unless the technology outcome is no longer certain, i.e. a predisposition. In this case, the uncertainty of the chance to develop a predisposition outweighs potential risk avoidance for many participants, except for those who are willing to take almost any kind of (technological) option to obtain potential information about their future health.

**Vision of neuroimaging from societal actors (Chapter 7)**

Regarding the visions of neuroimaging from a societal actors’ perspective, we showed how the contextual aspects of potential applications and basic features of the ideal health system determine the desirability of neuroimaging applications. Neuroimaging technologies are envisioned in 1) the current health care practice, 2) in personalised health care in 3) in person-centred health centres. In all three visions the formulated neuroimaging use for new and improved (personalised) diagnostic and treatment tools from a developer’s perspective are considered desirable, when therapeutic options are available in case of new diagnostics. In itself, preventive options to detect brain disorders in an early stage, i.e. early diagnosis, and the determination of a predisposition for groups at risk are perceived desirable when options to delay the progression, stabilise or treat the disorder are available and under the prerequisite of freedom of choice of the client/patient. However, the envisioned desirable contextual aspects and underlying basic features of the desirable states concerning preventive neuroimaging are different. Reasoning from the vision of neuroimaging as applications in person-centred health centres (vision 3), the interviewed actors considered the application in primary care as desirable for preventive options, i.e. collective prevention. Interviewees reasoning from the vision of neuroimaging as applications in the current health care practice (vision 1) or the vision of neuroimaging in a personalised
health care (vision 2) considered primarily the context of secondary care as desirable for the application of preventive options, i.e. individual prevention.

Understanding of the different visions shows thus incongruence between visions of respondents regarding desirable clinical neuroimaging use and potential future conflicting visions regarding the embedding of neuroimaging applications. We conclude that it is important to note that underlying the arguments to discuss the desirability of neuroimaging there are assumptions regarding the basic features of a desirable health system and the functioning of actors within this system. Our results indicate that the position an actor has in the health system and the vision he or she has of the ideal health system (which are interrelated) drives the vision of neuroimaging an actor holds. Neuroimaging can therefore not be viewed separately from its (future) socio-institutional context and external pressures, and might not be the only technology that is perceived as either an optimisation of the health system or as an opportunity to change the health system.

Prospecting responsible neuroimaging paths (Chapter 8)

In analysing the similarities and differences in visions of neuroimaging from different relevant actors, we showed that different visions of neuroimaging resulted in different desirable technology paths, which have their specific concerns and barriers. Articulated concerns relate to medicalisation and the embedding of new preventive and diagnostic application for which no therapeutic options (yet) exist and the potential negative social and economic implications preventive neuroimaging applications might cause. As compared to neuroimaging developers, health professionals, policymakers, patient representatives and citizens expressed more concerns and related prerequisites under which neuroimaging may contribute to solve brain problems. This particularly applies to preventive neuroimaging use.

Different barriers arose as a result of different visions on how neuroimaging should be embedded in the health system, based on different perspectives of how the health system should look like. Respondents holding the vision of neuroimaging in the current health care practice (vision 1) formulated most of their challenges and barriers on a technological, knowledge and financial level. These barriers are formulated by some respondents from a point of view that they are obstacles that need to be conquered, whereupon the neuroimaging artefact can be developed and subsequently be embedded in the health system in order to optimise it. For other respondents, these barriers can be overcome through changes in the science regime. They perceived the science
regime as being in need to adopt another, disease transcending, interdisciplinary structure and practice of research. This perception is shared by all respondents holding the vision of neuroimaging in personalised health care and person-centred health centres (vision 2 and 3) and by some respondents holding the vision of neuroimaging in the current health care practice (vision 1). According to these respondents, professional and financial structures should be changed in such a way that an interdisciplinary structure and practice of research becomes the new ‘business-as-usual’. The government is here the perceived designated point of departure.

Respondents holding the vision of neuroimaging in personalised health care (vision 2) and person-centred health centres (vision 3) articulated, besides challenges and barriers related to the development of artefacts, barriers and challenges related to the health system. These barriers are formulated from a point of view that structural changes in the health system are needed in order to appropriately embed neuroimaging applications and with this establish an optimised health system. They suggested accomplishing this by developing integrated cure and care plans, involving interdisciplinary teams, which have the consumer/client/patient at their heart. To this end, professionals need to be educated to perform new and different tasks in a person-centred context and hence change their behaviour accordingly. New categories of professionals should be developed to apply and interpret neuroimaging in this context, and future patients should be encouraged to change their behaviour and to become responsible for their own health, by, for example, shared-decision making. In conclusion, formulated barriers are indeed systemic in nature.

We observed that the strategies articulated to overcome the barriers were formulated from within the professional practice of an actor, e.g. policy maker, neuroimaging developer, primary or secondary care professional. They were envisioned to increase or maintain the position and/or status the respondent has, while responsibility for the strategies was primarily handed to actors of other practices and regimes. In other words, actors protect and reinforce the rules of their regime. The strategies are formulated from the actors’ perspective of the problem, without considering other actors’ perspectives of the problem and hence understanding of the differences and similarities between these perspectives. These strategies might therefore fail due to their focus on the individual’s own professional practice and their mismatch with the current structures and practices of the health system. On the other hand, slow changing trends, such as aging and a rise in patients with brain disorders, combined with overcoming barriers, by for example making it financially and technically possible to shift towards person-centred approaches and/or primary care, are potential destabilisers of
the dominant health system. The findings of this thesis indicate that actors who envision neuroimaging in a health system with new structures and practices, might in this case start pushing changes they perceive as necessary. In this case the holders of different visions might be in conflict with each other.

**Multi-actor dialogue as strategy to realise more shared desirable applications**

Dialogue meetings in which actors from different disciplines and regimes meet and learn from each other in a safe environment, contributes in realising more shared desirable technology paths and applications, according to participants of our dialogue meeting. Participants of the dialogue meeting indicated that the meeting resulted in awareness and exploration of potential (systemic) barriers and new areas of innovation by discussing desirable and undesirable applications with actors outside their own practice. However, as indicated by the participants, actors from different disciplines and regimes do normally not make the effort to have a dialogue with each other. As suggested by the participants, these dialogues require facilitation of both bringing people together and to create a safe environment where mutual learning may take place, and should be organised with certain regularity.

With this it is important to note that a multi-actor dialogue is not a ‘final state’ or a consensus goal, but more a guide for responsible monitoring. After all, innovations, applications and their socio-institutional context co-evolve during development, implementation, and use. Our results suggest that processes aiming to establish responsible research and innovation in order to facilitate an appropriate embedding of resulting artefacts, such as the iterative ILA model, could, and perhaps should, have a structural place in any emerging science and innovation which aims to produce societal benefits.

**Main conclusions**

Summarised, the following main conclusions can be drawn:

- By demonstrating how a system perspective can be integrated with a CTA process, the research presented in this thesis further specified a conceptual and methodological framework for CTA processes to responsible research and innovation. We demonstrate that integrating CTA not only with vision assessment but also a system perspective offers opportunities to identify and construct visions of relevant actors, to analyse potential barriers during innovation development
and embedding, and to realise mutual interactions between different relevant actors in order to realise more shared desirable visions;

- Based on the obtained results, incongruences in visions, potential conflicting visions, and factors, mechanisms and dynamics that might hamper responsible medical neuroimaging innovation and development could be analysed prospectively;
- To realise more responsible research and innovation the results presented in this thesis indicate that discussions are needed regarding (systemic) barriers that might hamper responsible innovation development in order to proactively anticipate;
- This research showed that innovations in medical neuroimaging have potential to result in responsible development paths, when systemic barriers related to the development, i.e. science regime, and embedding, i.e. health regime, are addressed in a multi-actor learning process. We propose the development of a shared vision of the future health system as a first step;
- To some extent, the interactions between relevant actors resulted in awareness of different visions, new ideas for future activities and in the formation of new contacts/networks;
- However, the impacts of the CTA process remain moderate on the short term. Initialising action with respect to issues beyond one’s own practice remains difficult without the continued facilitation of meetings where actors have the opportunity to interact with actors from different disciplines and regimes;
- Therefore we suggest further research on whether and how CTA processes taking a system perspective might have a structural place around emerging science and innovation aiming for societal benefits and how these innovations can be managed.