Abstract

Insight into public perceptions provides opportunities to take public desires and concerns into account in an early phase of innovation development in order to maximise the potential benefits of innovations for users of the future. Public perceptions of neuroimaging in health care are presented in this article, based on research undertaken in the Netherlands. In six focus groups, citizens articulated benefits, disadvantages and specific concerns regarding future medical neuroimaging applications. Six technological frames of neuroimaging and three frames of the socio-technical system surrounding neuroimaging were found to underlie the arguments used to articulate the degree of desirability of future applications. Depending on the context, individuals use different frames and related lines of argument to discuss the degree of desirability. 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.

Dutch public perceptions of the future of medical neuroimaging technology

6.1 Introduction

Innovations in neuroimaging technologies, such as functional magnetic resonance imaging (fMRI), magnetoencephalography (MEG) and positron emission tomography (PET), make it possible to visualise and study non-invasively the function, connectivity and biochemistry of the brain. Neuroimaging developers consulted in a previous phase of our research, expect that future advances in these technologies will make it possible to obtain more insights into the brain and its disorders, resulting in new and improved preventive, diagnosis and treatment options (reference blinded). They demonstrate a focus on preventive options for which therapeutic options are available. But is this focus also desirable from a public perspective?

To establish an appropriate societal embedding of innovations, it is suggested that societal actors and innovators should engage in an interactive process by which they ‘become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products’ (Von Schomberg, 2011, p.9). Hereto, participatory methods are increasingly applied to ensure that more aspects and more actors, including citizens, are actively engaged in the innovation process (e.g. Broerse et al., 2009; Hagendijk & Irwin, 2006; Rip et al., 1995). Applying these approaches, especially in early phases of technological development, is claimed to improve the translation to applications in which positive impacts are maximised and negative impacts are minimised, and the societal embedding is facilitated (Roelofsen, 2011; Von Schomberg, 2011; Wilsdon & Willis, 2004).

The research described here is part of a project that aims to direct medical neuroimaging developments in the Netherlands in an early phase towards more shared desirable applications and to anticipate negative impacts. In this article, we identify Dutch citizens’ perceptions of neuroimaging applications in health care. In our research, citizens are a potential group of future users. They might use or are affected by neuroimaging in the future, but are no part of the health system yet. In contrast to other future users
(e.g. health professionals, policy-makers), the perceptions of citizens are not resulting from a professional perspective, but rather from a personal perspective. Their knowledge can be considered as ‘contributory expertise’ (Collins & Evans, 2002), and their desires and concerns should also be taken into account in an early phase of innovation research and development in order to maximise the potential benefits of innovations for users of the future. Insight into public perceptions that already exist and which are likely to appear in the public arena in the near future provides insights into aspirations and potential obstacles that might offer opportunities or cause problems in the embedding of future applications at an early stage. This results in understanding how neuroimaging innovations can be shaped in the direction of more shared desirable applications, hence responsible innovations and their societal embedding.

6.1.1 Public perceptions

In this early phase of neuroimaging development, concrete applications on which to reflect are not available and actors might be not fully aware of or familiar with NI. In later phases this situation is reversed, applications and implications are apparent but options to steer the innovation are limited (cf. Collingridge Dilemma of control). As Pickersgill et al(2011) point out, the brain is often regarded as an object of mundane significance and taken for granted until it becomes present as a consequence of its dysfunction. Participants in their research, including potential future users, accounted their emergent interest of neurosciences as a result of some neurological event (i.e. personal experience or familiarity with disorders of the brain). This could imply that citizens not involved with neuroimaging from a professional or personal capacity are not fully aware of or familiar with neuroimaging. However, people often use heuristics in the first stage of perspective formation (Scheufele & Lewenstein, 2005). Perspectives are shaped by an individual’s underlying value orientations, worldviews, knowledge, experiences, and interests (Cuppen, 2009). Perspectives (also known as frames or schemas) are ‘thought organisers’ (Scheufele, 1999), used to perceive, judge and respond. They represent a way of making sense of complex reality and guiding actions (Schön & Rein, 1994). Heuristics are cognitive shortcuts used to make rapid inferences, based on previously acquired information and experiences. They reduce complex problems or questions to simpler problems and questions that can be answered, rather than dealing with the more complex issues (Druckman & Bolsen, 2011; Fiske & Taylor, 2008). Hence, although people might not be fully informed, heuristics make it possible to shape perceptions about new and emerging science and technologies (Roelofsen, 2011).
On the other hand, the ability of neuroimaging to visualise processes in the brain and to generate compelling images has raised public curiosity and expectations regarding neuroimaging uses, at least in the UK (O’Connell, et al., 2011). In a survey among UK citizens of Wardlaw et al. (2011) only 17% of the people indicated to have ‘no awareness’ of neuroimaging uses. In general, UK citizens indicate to have faith in neuroimaging use for medical purposes (Wardlaw, et al., 2011). Our analysis of the Dutch media coverage of neuroimaging research shows that the Dutch media is rather optimistic concerning neuroimaging research, especially regarding potential medical applications (see Chapter 4). This however does not automatically imply that medical neuroimaging applications are considered beneficial regardless their purpose. According to Chilvers & Macnaghten (2011, p. 16) “public attitudes [...] also depend on which technology sector is being discussed as well as on a set of wider contextual and attitudinal factors.” Moreover as Pickersgill et al. (2011) show, neurosciences can be experienced as a threat for those people who perceive neuroscientific concepts to compete with pre-existing ideas about selfhood. In this study, we aim to gain insights into the degree of desirability of potential future medical neuroimaging applications according to Dutch citizens, by obtaining an in-depth understanding of the arguments underlying their perceptions.

6.2 Methodology

To explore medical neuroimaging from a public perspective we used focus groups with citizens (de Cock Buning et al., 2008). The aim of the focus groups was to explore desirable and undesirable neuroimaging applications, and to obtain an in-depth understanding of the arguments underlying the perceptions, involving participants who are not involved in neuroimaging from a professional or personal (e.g. patient) capacity.

6.2.1 Focus group participants

In this study, 46 citizens participated in 6 focus groups, geographically divided over The Netherlands. Two focus groups were held in Amsterdam, two in Eindhoven, one in Den Bosch and one in Amersfoort to prevent a regional bias in the results. To develop a rich discussion, a wide variety of personal background was sought among participants, see Table 6.1 which provides an overview of the socio-demographic features of the participants.

To avoid self-selection bias of the participants, the participants were invited from a diversity of public fora, including informal contacts and sport clubs (two focus
groups) and a recruitment agency (four focus groups). To avoid anticipation on the topic (e.g. searching for information), the participants were invited to participate in a ‘discussion meeting of the VU’\textsuperscript{15}.

Table 6.1. Socio-demographic features of the participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Focus group 1 Amsterdam</th>
<th>Focus group 2 Amsterdam</th>
<th>Focus group 3 Den Bosch</th>
<th>Focus group 4 Amersfoort</th>
<th>Focus group 5 Eindhoven</th>
<th>Focus group 6 Eindhoven</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>F 16-30 •</td>
<td>M 45-60 •</td>
<td>F 60-75 ○</td>
<td>M 30-45 •</td>
<td>M 16-30 •</td>
<td>F 16-30 •</td>
</tr>
<tr>
<td>Participant 2</td>
<td>F 30-45 •</td>
<td>F 45-60 •</td>
<td>F 45-60 •</td>
<td>F 16-30 •</td>
<td>M 30-45 •</td>
<td>M 60-75 ○</td>
</tr>
<tr>
<td>Participant 3</td>
<td>F 45-60 •</td>
<td>F 45-60 •</td>
<td>M 60-75 •</td>
<td>M 60-75 ○</td>
<td>F 30-45 •</td>
<td>F 45-60 •</td>
</tr>
<tr>
<td>Participant 4</td>
<td>F 45-60 •</td>
<td>F 45-60 •</td>
<td>M 30-45 •</td>
<td>F 45-60 •</td>
<td>F 45-60 •</td>
<td>F 60-75 ○</td>
</tr>
<tr>
<td>Participant 5</td>
<td>F 30-45 ○</td>
<td>F 30-45 •</td>
<td>M 45-60 •</td>
<td>F 45-60 ○</td>
<td>F 30-45 •</td>
<td>F 30-45 •</td>
</tr>
<tr>
<td>Participant 6</td>
<td>F 30-45 •</td>
<td>M 40-50 •</td>
<td>M 16-30 ○</td>
<td>M 45-60 ○</td>
<td>F 60-75 ○</td>
<td>M 16-30 •</td>
</tr>
<tr>
<td>Participant 7</td>
<td>F 30-45 •</td>
<td>F 45-60 •</td>
<td>F 45-60 •</td>
<td>M 30-45 •</td>
<td>M 45-60 •</td>
<td>M 45-60 •</td>
</tr>
<tr>
<td>Participant 8</td>
<td>F 45-60 •</td>
<td></td>
<td></td>
<td></td>
<td>M 45-60 •</td>
<td>M 30-45 •</td>
</tr>
<tr>
<td>Participant 9</td>
<td>M 45-60 •</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>symbol</th>
<th>explanation</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>female</td>
<td>27</td>
</tr>
<tr>
<td>M</td>
<td>male</td>
<td>19</td>
</tr>
<tr>
<td>16-30</td>
<td>aged between 16 and 30 years</td>
<td>6</td>
</tr>
<tr>
<td>30-45</td>
<td>aged between 30 and 45 years</td>
<td>13</td>
</tr>
<tr>
<td>45-60</td>
<td>aged between 45 and 60 years</td>
<td>21</td>
</tr>
<tr>
<td>60-75</td>
<td>aged between 60 and 75 years</td>
<td>6</td>
</tr>
<tr>
<td>○</td>
<td>Low educational level (e.g. lower general secondary education, lower vocational education)</td>
<td>5</td>
</tr>
<tr>
<td>□</td>
<td>Middle educational level (e.g. higher general secondary education, pre-university and vocational education)</td>
<td>17</td>
</tr>
<tr>
<td>●</td>
<td>High educational level (e.g. higher vocational education or academic degree)</td>
<td>24</td>
</tr>
</tbody>
</table>

\textsuperscript{15} VU is the Dutch abbreviation of ‘Vrije Universiteit’, meaning ‘VU University’. Some participants were familiar with this abbreviation, many were not.
No information about the topic of discussion was provided to participants in advance. The participants recruited by the recruitment agency received a standard financial incentive of €35.00. Those invited via informal contacts and sport clubs received a small diner (soup and bread) prior to the start of the focus group, a Box of chocolates at the end, and reimbursement of travel expenses.

The focus groups were led by a facilitator who guided the discussions and a monitor who observed the group process and took notes. With permission of the participants and based on anonymity, all focus groups were audio recorded after informed consent was obtained. The focus groups lasted for approximately two hours, all with a short break halfway through.

6.2.2 Pilot testing
The methodology was fine-tuned using two pilot focus groups. This fine-tuning involved assessing the use of focus groups to inventory public perspectives of an emerging, rather unfamiliar technology and testing the design. The pilot groups showed that participants were able to articulate desires and concerns regarding future neuroimaging applications. Based on this testing, the focus group design was optimised: exercises were amended to minimise ambiguity and increase consistency between the data of the focus groups. The results of the two pilot focus groups are not included in the results described here.

6.2.3 Structure of the focus groups
The focus groups consisted of the following five steps:

**Step 1** Getting acquainted with neuroimaging. In order to assess the starting level of knowledge, the participants were asked if they had ever heard of a technology named ‘neuroimaging’ and what their first thoughts were on these technologies. Subsequently, all focus groups started with a short presentation describing neuroimaging, providing participants with the same information and thereby the same level of knowledge, see Box 6.1. In presenting the information we aimed not to value the provided example possibilities as either positive (good) or negative (bad).
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Step 2  Inventory of intuitive desirable and undesirable ideas. After the presentation, the participants were asked to write down on post-it notes intuitively two desirable and two undesirable or worrisome ideas they had of medical NIA.

Step 3  Clarification of ideas. Next, the participants were asked to explain their ideas and why the goal or application written down was desirable or undesirable. During this step, the post-it notes were clustered by the facilitator on instructions of the participants on similarities concerning desirability or undesirability of the ideas. In this way, the articulated ideas were clustered based on a common goal or impact which was seen as important by the participants.

Step 4  Reflection on future applications: 4 cases. In this step, the aim was to reflect on four neuroimaging applications in order to inventory the diversity of perspectives. The cases were derived from a state-of-the-art literature study of medical neuroimaging and interviews with neuroimaging developers. We presented limited information about the applications in order to allow the participants to formulate their own views. Table 6.2 shows the applications and the descriptions used during the focus groups.

Table 6.2. Cases used in the focus groups

<table>
<thead>
<tr>
<th>Case 1: Faster and earlier Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faster and earlier diagnosis with the help of neuroimaging technologies that ‘show’ the disorder. With this, it is imaginable that current tests, such as questionnaires and behavioural tests might become superfluous.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case 2: Determine predisposition</th>
</tr>
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<tbody>
<tr>
<td>Determine an individual’s chance of developing certain brain disorders.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case 3a: Monitor medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Following’ the effect of medication. For example, visualise if the medicine arrives at the intended location in the brain.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case 3b: Monitor development and progression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitor whether a predisposition is developing and/or what the progression of a brain disorder.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case 4: Personalised treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of tailor-made, therapeutic options for individuals</td>
</tr>
</tbody>
</table>

Box 6.1. Description of neuroimaging presented to the participants

**Neuroimaging:** technologies that visualise the brain and brain processes without damaging interventions

**Example:** fMRI which visualises (changes in) brain activity. For example in rest, or when listening to music. To ‘visualise’ if medication works.

**Health care:** contains everything from first complaints to treatment and care
In line with qualitative methodologies, we adapted the design of the focus group as we went along. In the first two focus groups, Cases 3a and 3b were provided as separate cases. When the focus groups showed no large differences in responses to the two cases, with participants arguing spontaneously that targeted treatment was highly desirable, Cases 3a and b were combined as: “Neuroimaging use to monitor the effectiveness of medication and/or the progression of a brain disorder” in the next four focus groups. Furthermore, a new Case 4 was added: “personalised treatment”.

The participants received a red and a green card and were asked to react intuitively to each case by putting a green card in front of them when they thought the example was desirable and a red card when they thought the example was undesirable or worrisome. Thereafter, the facilitator asked each participant why they perceived the case as desirable or undesirable, and stimulated discussion about which prerequisites were important. By using post-its and flip-charts, the discussion was made visual and participants could see what was already mentioned and what was missing from their perspective. The aim of this exercise was not to reach consensus amongst the participants but to inventory all perceptions present in the group. To establish this, an articulated perception was written down and other perceptions that were articulated in response were written down in the same way. When all perceptions were inventoried, the participants were asked if they had obtained a different perspective as a result of the discussion about the case. Subsequently, they were asked, when applicable, to switch the colour of the card in front of them. When participants switched their card, the motivation(s) for the switch was discussed. Then, the next case was presented and step 4 was repeated.

**Step 5  Closure.** At the end of the focus group, the participants were asked whether they had obtained a (different) perspective on neuroimaging during the discussions and how they had experienced the focus group.

### 6.2.4 Data analysis

All focus group discussions were transcribed verbatim. The identities of the participants were anonymised by replacing their names with unique research codes. Data analysis was executed with qualitative data analysis software (ATLAS.ti). Transcripts were coded using an inductive approach. We specifically examined how the participants made sense of neuroimaging and their perceived potential advantages, disadvantages and concerns. We noticed that different interpretations of neuroimaging were employed to argue the degree of desirability. From Orlikowski & Gash (1994) we take the concept of ‘technological frames’ to describe these different interpretations of neuroimaging. We continued by identifying technological frames as they became
apparent in the data and noticed that besides technological frames, different frames of the socio-technical system surrounding neuroimaging (including its actors, rules and policies) determined the degree of desirability. We labelled this ‘socio-technical system frames’ to describe the assumptions, expectations and knowledge of the participants towards this system. This does not imply that the frames are not related to each other. The main difference is that technological frames comprise how neuroimaging technologies are perceived to function and result in consequences for one’s life, and socio-technical frames comprise how actors of the socio-technical system (e.g. health professionals) are perceived to develop and apply neuroimaging and resulting consequences for one’s life. For analytical purposes this distinction is useful to gain an in-depth understanding of the arguments underlying the participant’s perceptions.

The characteristics and interpretations of the frames were constantly discussed between the authors, re-grouped, re-named and verified with the transcripts to assure quality representativeness of arguments brought forwards by the participants and social representativeness, meaning that each frame recurred in multiple focus groups and participants. During this phase of the analysis it became apparent that depending on the context of application different frames were used in a certain pattern to argue the desirability of NIA. This is in line with Orlikowski and Gash (1994, p. 178), who point out that technological frames do not only include “the nature and role of the technology itself, but also the specific conditions, applications, and consequences of that technology in particular contexts”. In other words, different technological frames exist and the context of application combined with the relevant socio-technical frame determines which technological frames are used to argue the desirability. Further analysis of which patterns occurred in which focus group showed that patterns were the same for each case discussed. To assure quality and social representativeness, patterns of argumentation were constantly discussed between the authors and verified with the transcripts.

6.3 Frames of neuroimaging and its socio-technical system

One of the 46 participants indicated to be aware of neuroimaging. Most participants indicated to have no idea what neuroimaging was, and some participants indicated (guessed) that it should have something to do with neurology and visualisation.

In articulating and discussing desirable and undesirable applications and situations almost all participants (two exceptions) employed different frames. These frames are mental images of how neuroimaging is perceived to function (technological frame)
and how neuroimaging is developed and used in practice (socio-technical frame). Participants interpreted neuroimaging as 1) an objective tool, 2) an advancement tool, 3) a reductionistic tool, 4) a tool that intervenes in naturalness, 5) an uncertain tool and/or 6) as a slippery slope to potential negative future situations. See Table 6.3. for a description of the frames.

Table 6.3. Technological frames of neuroimaging

<table>
<thead>
<tr>
<th>Neuroimaging as</th>
<th>Keywords</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>an advancement tool</td>
<td>not leave options unused; benefit humanity</td>
<td>Knowledge resulting from neuroimaging use and their applications should be used to benefit humanity. Advancements in neuroimaging may provide options to help people stay healthy or to become healthy.</td>
</tr>
<tr>
<td>an objective tool</td>
<td>better than soft measurements; less fraud; fewer mistakes</td>
<td>NIA are an improvement compared to current assessment methods because they cannot be manipulated by the patient, and the results generated by these technologies depend less on insights and interpretations of doctors. Consequently, the generated data is considered to be exact, factual, irrefutable and solid.</td>
</tr>
<tr>
<td>a reductionistic tool</td>
<td>holistic; subjective; ignores nurture, identity and inner strength of people</td>
<td>The brain is a very complicated organ and understanding of how it functions is limited, especially with respect to mental disorders. The brain cannot be seen as a separate part of the body and is influenced, amongst other things, by nurture. The use of neuroimaging reduces the person to a scan, excluding subjective aspects.</td>
</tr>
<tr>
<td>a tool that intervenes in naturalness</td>
<td>not playing God; acceptance of fate; life as it is meant to be</td>
<td>Life is given (by God) which cannot be controlled and this should sometimes be accepted. It is questionable whether it is desirable to ‘play God’, considering that we should let nature determine the progression of life, rather than intervening with, for example, NI.</td>
</tr>
<tr>
<td>a slippery slope</td>
<td>long-term consequences; medicalisation; boundary illness-health needed</td>
<td>NI is part of constantly expanding technological developments and applications in the medical sector. These developments may pave the way for a society which aims to treat, diagnose and prevent any disorder as quickly as possible. In such a society, everyone might be labelled as ill in the search for perfection. The use of neuroimaging to prevent, diagnose and treat diseases is acceptable but a boundary between health and illness needs to be set to prevent the enhancement/treatment of ‘normal’ and healthy people.</td>
</tr>
<tr>
<td>an uncertain tool</td>
<td>distrust in technical reliability and possibilities; potential side-effects; psychological burden</td>
<td>The technical reliability, uncertainty and possibilities of are all questioned. In addition, long-term consequences of neuroimaging are questioned, focusing on potential side-effects and the psychological burden that people could experience as a result of neuroimaging.</td>
</tr>
</tbody>
</table>
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The socio-technical system surrounding neuroimaging is framed as a system that can be 1) trusted, 2) accepted and/or 3) should be distrusted and feared. See Table 6.4 for a description of the frames.

**Table 6.4. Frames of the socio-technical system surrounding neuroimaging technologies**

<table>
<thead>
<tr>
<th>The socio-technical surrounding neuroimaging should be</th>
<th>Keywords</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>trusted</td>
<td>confidence; faith</td>
<td>The acts, competences and knowledge of experts developing and working with neuroimaging can be trusted in terms of doing good and determining the correct treatment plan. Furthermore, science will be progressing towards new medical options and the government is the correct body to regulate and prevent misuse of NI.</td>
</tr>
<tr>
<td>accepted</td>
<td>personal action will not work; take technology as it comes</td>
<td>Future events are inevitable, and that this also applies to NIA. Citizens have no power to influence the future and take a passive stance. Individuals can, for example, live as healthily as possible and take precautions but not all disorders can be prevented (such as brain haemorrhage).</td>
</tr>
<tr>
<td>distrusted and feared</td>
<td>distrust of doctors, commercial parties and government</td>
<td>General distrust of doctors, commercial parties and the government. Distrust of doctors regarding their potentially dubious motives (e.g. screening for lifestyle habits) and their possible preference for a certain diagnosis or therapy. Distrust in the government’s approach to regulate and prevent misuse of NI. In addition, distrust and fear of the use of neuroimaging by commercial parties and the possible consequences when commercial parties gain access to data generated by neuroimaging use</td>
</tr>
</tbody>
</table>

### 6.3.1 Different frames to discuss the degree of desirability depending on the context

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 (44 out of 46 participants). Moreover, most participants (36) did not restrict themselves to either argue in favour or against NI. They showed individual preferences, but were able to explore multiple frames within the same example. Table 6.5 summaries the frames articulated by the participants per case.
<table>
<thead>
<tr>
<th>Example neuroimaging applications</th>
<th>Neuroimaging technological frames</th>
<th>Frames of the socio-technical system surrounding neuroimaging</th>
<th>Total nr participants/ frame/ per case</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>advancement tool</td>
<td>objective tool</td>
<td>reductionistic tool</td>
</tr>
<tr>
<td>Case 1 Focus group 1-6</td>
<td>20</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td>Case 2 Focus group 1-6</td>
<td>19</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Case 3 Together Focus group 1-6</td>
<td>26</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Case 4 Focus group 3-6</td>
<td>17</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total number participants/ frame for all cases</td>
<td>82</td>
<td>23</td>
<td>19</td>
</tr>
</tbody>
</table>
Some participants found it difficult to discuss the desirability of neuroimaging applications without having detailed information regarding the technical aspects and possibilities of neuroimaging and started to critically question the technical reliability and possibilities. As a result, about half of the arguments linked to the uncertain tool frame in Case 1 originated from unfamiliarity with neuroimaging. These decreased to zero in the following cases and are a consequence of the group dynamics: arguments once brought forward will be taken for granted in later discussions. The same applies for arguments from an objective tool frame. These were not constantly repeated, but participants referred back to earlier discussions and arguments were not discussed in-depth again. As a result, arguments derived from uncertain tool and objective tool frames decreased to respectively 1 and zero in Case 4. This implies that, although fewer arguments were brought forward to articulate the desirability, this does not mean that these arguments were less applicable to the case discussed.

The analysis shows that most (40/46) participants consider Cases 1, 3 and 4 conditionally desirable. With this, they articulated the importance of freedom of choice (the choice to make use of neuroimaging applications), the right to know or to be kept in ignorance and guaranteed privacy. Besides, neuroimaging applications should not have negative social or economic implications for the individual/patient. For example, neuroimaging use to search for additional disorders, life styles and sexual preferences and use and abuse by commercial parties, such as insurance companies and mortgage lenders. Without these prerequisites neuroimaging applications are considered undesirable, regardless the goal of application. Case 2, the use of neuroimaging to determine a predisposition, is regarded undesirable anyhow by seven participants. For the other participants (39), this example is desirable under certain prerequisites which will be described in detail below.

6.4 Patterns of argumentation

The different frames resulted in different patterns of argumentation in each case. Strikingly, despite the different frames, the patterns of argumentation were the same for each neuroimaging application discussed. These are described in detail below.

6.4.1 Case 1: diagnose earlier and faster

The first response to this case was positive for the majority of the participants (37/46). Diagnosis with neuroimaging was seen as clear and evidence-based (objective tool). The participants considered that this application was desirable to detect disorders faster and in an early stage. With this, the desirable assumed implication was delivery
of relevant therapeutic options more quickly, and reducing uncertainty of patients and their social environment (advancement tool). In response, other participants questioned the reliability, accuracy and potential of neuroimaging (uncertain tool). These questions were again rebutted from advancement tool or objective tool frames, as illustrated in the following example from focus group 4. The corresponding frames are added between brackets.

Participant 1: Well I think that for many people the diagnosis of mental disorders is, well, now I finally know what I have. [advancement tool]
Participant 3: Faster diagnosis! [advancement tool]
(....)
Participant 1: But then again, on the one hand yes, but how reliable is it? [uncertain tool]
(....)
Participant 5: Well I think that a lot of suffering, on all fronts, is reduced. If you know what is there and consequently can start treatment quickly. That is only positive. [advancement tool]
[Focus group 4]

This pattern of stating desirable consequences and questioning undesirable consequences resulted in a discussion concerning the differences between neurological/somatic and mental disorders. In five of the six focus groups (except focus group 3), this discussion took place spontaneously. The participants articulated a difference between a physical (neurological) disorder versus a disorder that is in the person him/her self, namely ‘a deviation from the normal’. As explained by one of the participants:

The distinction in certain diseases, I think, is clear in this example. Depression or Parkinson’s disease, I think that is another category I would almost say (...) I have the feeling, but that is just a feeling, that Parkinson’s and Alzheimer’s disease are really just mechanical malfunctions. That there are certain signals that can no longer be transmitted. While depression seems to me a disorder that has not so much to do with the brain, but more with how people live their life, what kind of beliefs they have and things like that.
[Focus group 2, participant 1]

After the distinction between ‘physical’ and ‘mental’ disorders was made, the discussion changed. From then on, the majority of participants considering that setting a diagnosis for neurological disorders was desirable under the prerequisites described above, articulated their arguments from advancement tool or objective tool frames. Regarding mental disorders, participants who considered the diagnosis of
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mental disorder with help of neuroimaging as more specific with lower or no error rate, especially when compared to questionnaires and behavioural tests (which were seen as subjective methods), argued from an objective tool frame. These participants were positive about the fact that patients cannot manipulate a brain scan and that diagnosis is not dependent on the insights and interpretation of a doctor. On the other hand, there were participants arguing that mental disorders are very complicated and that neuroimaging reduces the person/patient merely to an ‘image’ (reductionistic tool). They emphasised the importance of including experiences of both doctor and patient and nurture in setting an appropriate diagnosis. These arguments were frequently combined with questioning the ability of neuroimaging to diagnose a mental disorder (uncertain tool). Consequently, some participants reasoned from different technological frames depending on which disorder was diagnosed, as shown in the following example:

Well, yes, with such a vague complaint like depression I think well, sorry, but what has a machine to do with this? First, talk to the person and then, when that [talking] fails…….[reductionistic tool]
(....)
My father worries about these kinds of issues [memory loss, possible Alzheimer’s disease] and I was at the doctor’s and I asked the doctor if he could determine this somehow. And I was there, during the diagnosis, and then he came with such a pathetic questionnaire and I thought, goodness, I have no confidence in this, frankly. I would much rather that neuroimaging could help him then.
Facilitator: And why is that?
Participant 2: Yes, how it feels, then I suddenly have more confidence in it, oddly enough.
(...) Because, yes, it seems as if it is more the body and less the person. [objective tool]
[Focus group 2, participant 2]

6.4.2 Case 2: determine a predisposition
The first responses to this case were primarily negative (42/46). Participants argued that a predisposition is always uncertain (the onset of the disorder is uncertain) and that knowing a predisposition would result in a psychological burden (uncertain tool). In response, others argued that determining a predisposition offers the possibility of taking precautions, generate scientific knowledge in order to develop therapeutic options, and save health care costs (advancement tool and trust). Compared to Case 1 this is a shift in arguments resulting from uncertain tool frames, which now focus on the uncertainty and psychological burden of neuroimaging applications instead of uncertainty related to neuroimaging technologies.
In the in-depth discussion, arguments were extended to possible negative situations in the future (slippery slope). Moreover, some participants reinforced their own position via this pattern (from slippery slope to advancement tool to slippery slope to uncertain tool). This pattern of argumentation is illustrated in the following example:

Participant 3: So that you can tell at a very early stage whether you get something or not. If you then say, well there is a chance that you will get it and later it appears that you did not get it, what then? That is a dilemma, uh..... [uncertain tool]

Participant 4: I think more about risk groups and that kind of thing. That you have people, where, for example, cancer is a common disease in the family, who then get examined more often, preventively or receive preventive treatments. [advancement tool]

Participant 3: And what if you don’t develop it in the future? [uncertain tool]

Participant 4: Yes, well, I think more about risk groups to check them more often.... [advancement tool]

Participant 3: Oh yeah, that certainly, yes.

Participant 4: To detect things.

Participant 3: Yes, I completely agree.

Facilitator: Okay, so it [the case] is desirable for risk groups?

Participant 3: Yes, just to check. But suppose that you are going to take medication at a young age, while there is nothing wrong with you......[slippery slope]

[Focus group 4]

This example shows the effect of discussing the desirability of potential neuroimaging applications with other participants: participants gain insights into each other’s frames, reflect on that, agree or disagree with the other participants, change or adjust their frame when applicable, and explore the issue more in-depth.

Knowing an early diagnosis or predisposition. Besides, there was discussion concerning the burden of knowing a predisposition and early diagnosis. Early diagnosis and predisposition were seen by many participants as being more or less the same; a situation in which a symptomless person receives a diagnosis in an early stage or is in the knowledge that he/she has an increased risk to develop a brain disorder. Therefore, this discussion took place when considering Cases 1 and 2. In discussing these situations, two kinds of reasoning can be distinguished. Some participants argue from an advancement tool technological frame that they would like to know a predisposition or early diagnosis in order to live the remaining time of their healthy life as optimally as possible; to take precautions with the intention to stop the development of the disorder, to reduce the severity of the disorder and to have a greater chance of recovery by,
for example, changes in lifestyle and medication; and to take precautions to function as optimally as possible during their life with the disorder. Others argue from uncertain tool technological frame and are of the opinion that they do not want to know the diagnosis because this would influence their life negatively due to the psychological burden (for example, fear and stress) the predisposition or diagnosis would give them. This is illustrated in the following example:

Participant 1: If you want to do that test and then they say to you, well, uh, you have 75% chance that you will get the disease and then... after half a year... would you like to know?
Participant 4: I would like to know. [advancement tool]
Participant 1: Really?! So....
Participant 6: Then the test must be reliable, of course. [uncertain tool]
Participant 1: No, listen! What if you just do that test, and there is nothing wrong with you, you feel good and just do that test, and then they say you have 75% chance that you get that. You are not allowed to smoke anymore. You are not allowed to do this, and that, you must do this. [slippery slope]
(...)  
Participant 6: Well, you can, or try to do all things you want to do in your life, though, if you know in advance... [advancement tool]
Facilitator: So that would be a green card for you?
Participant 6: Yes
Participant 1: Optimist! (...) I think I would be awfully scared. That’s why I would never do such a test, not me. [uncertain tool]
[Focus group 3]

In situations where there are no therapeutic options available, participants who were in favour of taking precautions that would prevent or delay the onset of a disorder (advancement tool), switched to the view of not wanting to know the diagnosis when it would not be possible to take precautions. Then the diagnosis would negatively influence their lives. Participants who valued being able to live their remaining life as optimally as possible and to function as optimally as possible during their life with the disorder, still argued that an early diagnosis and identification of a predisposition would be desirable. Moreover, participants arguing from this technological frame (advancement tool) also valued knowing the cause of future disorders. The implications of knowing would reduce the psychological burden of uncertainty by providing certainty about what is wrong and what disorders could potentially be expected.
6.4.3 Case 3: monitor the effectiveness of medication, the progression of a disorder and the development of a predisposition

All participants (46/46) put a green card or a green and red card in front of them after reading Case 3. The discussions started with articulating the desirable possibilities (advancement tool). Monitoring the effectiveness of medication was expected to give evidence-based insights in order to tailor the treatment towards the patient. Desirable implications of this were considered to be a shorter duration of treatment which, in turn, would decrease the burden on the patient in the following ways: less time spent on finding suitable medication and visiting the doctor; fewer side-effects of medication; and a lighter psychological burden. Moreover, with a shorter duration of treatment, people could return to full functioning in society. Furthermore, monitoring of medication was seen as beneficial in reducing the damage caused by overmedication. Applications to monitor the progression of a brain disorder were seen as desirable when the diagnosis was set in order to adjust the treatment when necessary. Applications to monitor the development of a predisposition were only seen as desirable when the predisposition was determined under the prerequisites formulated.

In the in-depth discussion arguments were not merely related to reliability of neuroimaging (uncertain tool) as in Case 1, but resulted also from reductionistic tool and distrust and fear frames. They relate to the potential harmfulness as a result of frequent neuroimaging use (uncertain tool), the potential use of data outside the health care setting (distrust and fear) and a focus of doctors mainly on medication, which would exclude the patients’ emotions and nurture from the treatment process (reductionistic tool & distrust and fear). Latter was considered to be specifically undesirable concerning mental disorders. This focus, in turn, resulted in the articulation of undesirable future situations (slippery slope) in which neuroimaging was considered to be a Holy Grail. This was contradicted by participants reasoning from advancement tool or objective tool frames. In addition, some participants argued that they trusted doctors and the government to include patient and nurture aspects in the treatment and not to apply neuroimaging when this is harmful (trust). This argumentation pattern is illustrated in the following example:

Participant 7: You can also tailor the treatment or monitor. (...) You can see through imaging if it works, or if the treatment is sufficient for that patient. [advancement tool]
Participant 1: You can also have the placebo effect, that you think it will have an effect and it has effect for everybody else, so it must have effect for me too. And that can give enormous strength which is enough to heal. [reductionistic tool] And suppose that they say it will not work for you and then..... There you go.
Participant 5: At that moment, they can search for a relevant option or a different composition. [advancement tool]

Participant 1: Yes, of course, that is correct. But I wonder, it can help, I believe that too, but it may also be that it is not working and then you become a guinea pig. [uncertain tool + distrust and fear]

(...) Participant 4: Yes, but there are also a lot of people who receive medication that is not working and those people have undergone long periods of trial and error.

Participant 5: And, for them, it would be positive. [advancement tool]

(...) Participant 1: But, for example, the case of someone who has a mental disorder, who is depressed and who receives a stimulant. Well, he is nice and cheerful today, but is he happy enough? [slippery slope]

Participant 5: I think this is really a comment, with all due respect, of a layman. We see this in that way, but people in psychiatry look at this very differently. [trust]

(...) Participant 4: But I think that if you use this [neuroimaging], that you can objectively better assess someone, compared with someone who says of himself: I feel better today than yesterday. That is less objective than just such neuroimaging. [advancement tool + objective tool]

Participant 1: Well, I dare to doubt. (....) How reliable is it?” [uncertain tool]

[Focus group 4]

6.4.4 Case 4: personalised treatment

In general, the participants expressed the view that ‘designing’ personalised treatment is highly desirable (30/31)\(^{16}\). The initial discussion resulted in the formulation of desirable options (advancement tool and trust). For example, targeted diagnosis and treatment were perceived to be beneficial for patients, the health care system, and society in general. Later on, some participants articulated undesirable consequences in the long-term (slippery slope). These arguments concerned efforts to prevent and control disorders. This was considered to be the result of a change in the boundary demarcating health from disease, resulting in ‘Brave new world’ societies in which everyone is ‘made average’, and no-one is allowed to be different. Other participants did not articulate concerns about these kinds of potential future consequences and trusted the scientists, doctors and government to prevent these situations (trust).

\(^{16}\) See step 4a methodology. After the first two focus groups showed a tendency towards personalised treatment options, this case is added in focus group 3-6.
6.4.5 Main patterns of argumentation
In general, the initial discussions started with arguments focussing on short-term consequences for one’s own future life. This resulted in discussions in which some participants argued in favour of the technology by emphasising the potential benefits of neuroimaging (advancement tool or objective tool) which evoked response from other participants who questioned the possibility and reliability of the technology and the potentially negative consequences of the technology (uncertain tool or reductionistic tool). Case 4 was an exception to this because, initially, only arguments from an advancement tool frame were formulated. In all in-depth discussions, arguments were added with long-term consequences and perceived implications of the socio-technical system surrounding neuroimaging on people’s future lives. These are mostly arguments against the technology and mainly aimed at creating prerequisites for application.

6.5 Conclusions and discussion
Public perceptions of neuroimaging in health care are presented in this article, based on research undertaken in the Netherlands. This study shows that the consulted group of citizens comprises a heterogeneous group of people that were well able to articulate benefits, disadvantages and specific concerns regarding the future embedding of potential neuroimaging applications. In arguing the desirability of neuroimaging applications different technological frames and socio-technical frames were used. Six technological frames were identified that relate to how neuroimaging is interpreted and perceived to potentially influence peoples future lives on short-term and long-term. Three socio-technical frames were identified and relate to trust, acceptance or distrust of the socio-technical system surrounding neuroimaging. The frames are dynamic and show contextual differences. Depending on the application and its context, different frames were employed and related lines of argument to discuss the degree of desirability of potential neuroimaging application. This implies that the acceptability of future neuroimaging applications depends on the context of application and how an individual frames neuroimaging and its socio-technical system.

Patterns of argumentation were the same for each application discussed. All discussions started with arguments focussing on short-term consequences for one’s own future life, arguing in favour as well as against the applications. In the in-depth discussions, arguments concerning potential long-term consequences and implications of the socio-technical system surrounding neuroimaging were added. Because this study identifies frames and related arguments regarding concerns and desires, it shows both
rather optimistic (positive, hopes) and pessimistic (negative, concerns) framings. In this way, insight is obtained regarding the weighting made by participants and contextual differences. In other words, we identified what is considered as desirable (acceptable) and under which prerequisites, and what is considered undesirable under no condition (unacceptable). New and improved diagnosis and treatment options are considered conditionally desirable by all participants. Freedom of choice, guaranteed privacy, the right to know or to be kept in ignorance, and informed consent are formulated prerequisites. Furthermore, neuroimaging application should not result in negative social or economic implications for individuals/patients, according to the consulted citizens. Preventive applications are considered desirable by most participants (39/46) but not within a future society which aims at preventing, diagnosing and treating potentially anything as quickly as possible.

Discussions regarding neuroimaging use to determine a predisposition provided insights into the differences between preventive and other neuroimaging applications. Arguments related not to the uncertainty of the technology as with other applications, but focused on the uncertainty of the predisposition. In other words, neuroimaging use to prevent disorders (risk avoidance) is regarded conditionally as highly beneficial, until the technology outcome is no longer certain, i.e. a predisposition. In this case, the uncertainty outweighed 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. This indicates that the technological frames are driven by a desire to maximise control of life and related risk avoidance, which resulted in arguments regarding the desirability to prevent one’s own disorders. At the same time, certainty was also considered highly desirable by many participants, resulting in arguments questioning the reliability of the technology and expressions of distrust and fear regarding the socio-technical system surrounding these technologies. The uncertainty of a predisposition conflicts with the desire for certainty. Therefore, options to determine a predisposition might be considered controversial.

In addition, when relating our results to the research of Pickersgill et al. (2011), we gain insight into another potential concern/barrier. They showed that in articulating subjectivity the brain is perceived as the locus of identity, and at the same time is perceived as just another body part and not all things can be reduced to brain structures and processes. Some future users in the research of Pickersgill et al. perceived brain research, in certain situations, as a threat to longstanding understanding of selfhood, others as giving more insight into selfhood. This ambivalence was also visible in our
research. Participants perceived the brain as the locus of brain disorders and at the same time the brain was perceived as not all determinative with respect to disorders. Subsequently, most participants perceived disorders in terms of the brain in particular contexts (i.e. certain disorders). The potential resulting perceived threat of neuroimaging becomes specifically visible in discussions regarding neuroimaging applications for mental disorders. Participants who perceived these applications as potentially providing more insight and understanding of mental disorders, i.e. neuroimaging as an objective and/or advancement tool, emphasised the potential advantages of neuroimaging (without stating that neuroimaging is the only possibility to diagnose or treat mental disorders). Participants who perceived these applications as conflicting with their views on how mental disorders are part of a broader process, i.e. neuroimaging as reductionistic tool, felt threatened and emphasised the reductionistic aspects of neuroimaging and the importance of including nurture aspects in the diagnostic and treatment process.

Although participants showed a preference to argue in favour or against neuroimaging applications, they explore multiple frames. This probably relates to the emerging aspect of neuroimaging. Given that the applications under consideration do not (yet) exist, individuals have an intuitive preference for a certain frame but consider easily other frames based on arguments of other participants or because one point of view was dominant in the discussion. This space for manoeuvre provides stakeholders with the opportunity to increase the effectiveness of communication of neuroscientific discoveries to reduce the risk of unrealistic expectations and ethical or social concerns (Racine et al., 2010; O’Connell, et al., 2011)

Substantively, arguments brought forward in this research can be related to arguments in discussions about (prenatal) genetic testing. With respect to the structure, these discussions correspond. In research of de Cock Buning et al. (2008) Dutch citizens regarded prenatal genetic testing conditionally desirable depending on the severity of the disorder and under prerequisites such as right to know or to be kept in ignorance, freedom of choice and informed decision making. In addition, arguments related to a balance between the control of life versus fate of nature. Moreover, comparisons with (prenatal) genetic testing were spontaneously made by the participants in the focus groups on neuroimaging, which might imply that the structure of the discussions surrounding medical neuroimaging will not differ largely from those surrounding (prenatal) genetic testing applications.
6.5.1 Inventory of public perceptions in an early phase of technology development

With respect to the methodology, this study shows that the focus group design of this study is a suitable method to inventory a broad range of public perceptions regarding an emerging technology that is not yet familiar amongst participants. Although most studies examine how individuals ascribe meaning to a novel technology in the initial period of technology adaption (e.g. Orlikowski & Gash, 1994; Gapal & Parsad 2000), we demonstrated that identification of different interpretations of a technology before the institutionalisation is possible and gives insights into potential incongruent technological frames when the technology will be implemented. As Orlikowski and Gash (1994, p. 204) showed, different interpretations of a technology “result unintendedly and unknowingly in misaligned expectations, contradictory actions, and unanticipated organizational consequences.” Identifying different technological frames in an early phase of technology development (and examining ongoing sense-making of a technology) offers thus options to steer towards more responsible innovations (i.e. align frames- shared interpretations).

As a consequence of the focus group design, the participants reflected and reacted critically to the cases provided without detailed input of people concerned with or affected by neuroimaging. Considering that many medical applications are currently implemented without consultation of the general public, the observed frames and patterns of argumentation probably correspond to the situation when the concerns of the general public are not taken into account. With this it is important to note that sense-making is an ongoing process when interacting with the technology over time and new interpretations may emerge (Hsiao et al., 2008). This implies also that the argumentation patterns are not static. In a different context, or at different time-periods when the technology becomes or is institutionalised, different citizens could make new interpretations which may be in contrast to those observed in this research. Therefore we are cautious with generalizing our findings to other countries and periods of time.

Furthermore, some remarks can be made concerning the composition of the participants. Even though we aimed at a balance between genders within one focus group and mixed social-demographic factors, two focus groups (Focus groups 1 and 2) consisted largely of women and all participants were highly educated. The results show no major differences in frames or argumentation patterns employed between these groups and the other groups. Additionally, we were not able to find differences in
applied frames or argumentation patterns related to age, gender or educational level in this research.

It is also important to take into account how values and interests of the researchers might have influenced participant responses and the interpretation of the data. We tried to avoid advocating or opposing to the applications discussed and made effort to value all arguments equally in the analysis. Although, participants might have had the idea that there was a ‘right’ answer we were looking for, and with this formulating arguments which they thought we would like to inventory, the two facilitators received the same arguments from participants, indicating that we most likely minimised influencing the participants responses. Additionally, since almost all participants were not aware of neuroimaging developments prior to the discussion, we probably have contributed to an awareness rising.

### 6.5.2 Towards responsible neuroimaging innovations

Neuroimaging developers, consulted in a previous phase of this research, consider preventive options to be highly desirable under some prerequisites, such as the availability of therapeutic options (see Chapter 4). This study shows that preventive neuroimaging options could be desirable but relate to several concerns of Dutch citizens. To establish more responsible neuroimaging applications, relevant actors need to become mutually responsive (Von Schomberg, 2011), and participants’ concerns should be taken seriously in order to promote responsible embedding of neuroimaging. If these concerns are not taken into account, we argued that current values might clash with some applications, resulting in societal anxiety. In these circumstances, current concerns, such as the concern that neuroimaging will determine autonomously (without interpretation of doctor) whether one has a mental disorder, might develop into a script (see Akrich, 1992). In such a script, neuroimaging could be framed as technologies that ‘visualise’ the brain and personal identity, resulting in discriminating processes and stigmatisation of individuals. Contrarily, Illes and others (2009) showed that patients perceive the potential of neuroimaging to diagnose and treat depression as a means of reducing stigma. Scripts will only develop when the technology is developed. At present only concerns and expectations can be identified which are likely to affect positive and negative scripts of neuroimaging.

In a next phase of our research different actor perspectives are integrated through mutual learning in dialogue meetings with the aim to result in mutual understanding and the identification of more shared desirable future directions of medical neuroimaging. Above sketched potential difference between public and patient perspectives regarding desirable implications shows the importance of these kinds of processes.