Subject of innovation or: how to redevelop 'the patient' with technology
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3 Constructing macro-actors

Conflicting standardisation scenarios

In this second chapter of Part 2, I continue both the theoretical discussion of subjectivation by political attempts to use technology for re-shaping power relations, and the practical discussion of the planning of the infrastructure for the Dutch electronic health record. However, as I indicated before, the approach that I took in the previous chapter has some shortcomings with respect to both these angles. In this chapter, I try to amend them.

Starting with the practical angle, many studies in the domain of science & technology studies (SST) have indicated that technical infrastructures are not made in or around parliament. Without intending to do injustice to the value of this contribution, I hope to have made clear that it would be equally restrictive to not take ‘traditional’ politics into consideration anymore. Following the line of these SST studies, in this chapter I expand the scope of where politics is located. This implies examining what is called ‘subpolitics’, in this case of electronic health record development. While the previous chapter dealt with the political conceptualisation of the infrastructure in general, this chapter focuses on the question of technical standardisation. We will see that this broadening of scope adds a good deal of complexity, not the least in terms of questions of subjectivation. In addition to the fairly ‘straightforward’ account of policy planning that I presented so far, at subpolitical level we are faced with various conflicting scenarios that standardisation experts imagine. A good deal depended on the rather specific perspective I took: looking for neoliberal elements in a broad political debate. Other angles might have brought other points forward as well. In fact, this conflict is often referred to as a ‘standards war’. In interviewing such experts, a much-heard statement was that ‘there is no such thing as the EHR’. On the basis of this, I found four radically different ‘models’ or ‘scenarios’ for future development. Only one of these relates to the image that I sketched in the previous chapter. This underlines one of the main angles of this study once again: the fact that the electronic health record does not exist (yet) implies that different scenarios are still open for discussion. Such a notion is crucial for an ‘analysis of the present’.

Theoretically, I try to remedy the (purposefully chosen) unsophisticated way in which I used the technological script concept so far. I do this by relat-
ing it to what Callon & Latour (1981) have called macro-actors. One of the things that I hope to achieve in this chapter is to show how this concept can help in getting grip on technology-enabled governmentality. In concrete, this denotes that I try to explain how different actors seem to regard the electronic health record as a macro-actor, which has a particular impact on the Dutch health sector. I added the emphasis to make clear that it is not merely a layer of explanation that I have added to the case. Instead, I use Callon and Latour’s concept to make sense of the accounts of others. Obviously, however, a certain degree of re-presentation on my part is inevitable. If we think back to the previous chapter, we can already recognise the macro-actor way of reasoning. The best example is probably that the electronic health record is positioned as a tool to fix macro-level problems. Still, I have only skimmed the surface of such a description. The question is what a macro-actor is. Is it only technology, or do users play a part as well? Instead of performing a re-interpretation of the analysis of the last chapter, I apply this analysis to the added complexity that the focus on the subpolitical level implies. If there are multiple scenarios for a future electronic health record, we should also keep in mind that there are potentially multiple macro-actors as well. An important question is what this implies for subjectivation.

Taking this angle implies that I attempt to make a connection between Foucault’s governmentality studies and Bruno Latour’s ‘sociology of association’. This link has received some scholarly attention over the past decade (for an overview, see: Passoth & Rowland, 2010). The reason for making such a connection in this study is twofold. First of all, I explained before that Foucault’s work is not immediately equipped for grasping the nuances of dealing with technology and ‘things’. The second reason is of more methodological nature. If we take Foucault’s genealogical approach to the study of governmentality, we are likely to study developments with the benefit of hindsight. If we ‘apply’ the perspective of one of his governmentalities, as I did in the previous chapter, we are likely to remain short-sighted. In this study, I am interested in examining governmentality as it is being constructed. Rather than looking for one particular type of governmentality in the present – panoptic or postpantopic (neoliberal) – I study what different types were considered before the discourse stabilises around a particular configuration. The reason for this stems from a more normative angle, or a change perspective. I argue that the best time to challenge undesirable forms of governmentality is when it is still ‘in the making’. I think that the work of Bruno Latour is very suitable to articulate this.
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I start by providing an overview of the conceptual and methodological approach of this chapter. In the second part, I discuss the four EHR scenarios I identified. A particular point of attention is to understand how particular technologies are expected to mediate a particular set of practices. We may ask the question: which of these technologies is deemed most able to mediate postpanopticism? I conclude with a discussion on the question of what we might expect of the future in terms of realising one of these scenarios.

Concepts and methods

I start by discussing the question of how we might imagine the conceptualisation of macro-actor. I articulate this in alignment with Foucault’s ideas on governmentality and subjectivation. As said, the stress is on developing a more sophisticated understanding of the working of technological scripts. Furthermore, I relate the question of multiple macro-actors to multiple subjects, and to the idea of regarding standardisation as subpolitics.

Conceptualising macro-actors

Just like in my discussion of Foucault’s work, in the previous chapter, I start by Latour’s early comments on the social contract. In fact, the paper that he co-authored with Michel Callon on Hobbes’ *Leviathan* (Callon & Latour, 1981) was published only two years after Foucault held his lectures on the topic (published as: Foucault, 2008). Foucault was still alive then. We have seen that Foucault discusses the social contract as a metaphor for thinking about government, in relation to constituting the inhabitants of a particular nation-state as ‘subjects of right’ (Foucault, 2008). Callon and Latour are interested in a different aspect of Hobbes’ work, which suggests a somewhat more literal reading. They pose that Hobbes was the first to articulate the relations between ‘micro-actors’ (individuals) and ‘macro-actors’ (the sovereign). The idea is that individuals conclude a contract to form a macro-actor to which they delegate certain tasks. Callon and Latour pose that their ‘general law of translation’ is more suited for addressing this issue than social contract theory.

Their main suggestion is that macro-actors are formed by bringing ‘into play associations that last longer than the interactions that formed them’ (1981, p. 283, original emphasis). This implies that the term is used to describe what
sociologists normally call ‘institutions, organizations, social classes, parties, states’ (1981, p. 279). Macro-actors are a composition of humans and ‘things’ – Latour prefers the term nonhumans – that have the capacity to act collectively. Think, for instance, of a statement like ‘the United Nations said that…’ The notion of organisations as actors has received considerable attention in organisational studies. In his later work, Latour continued this discussion under the term ‘collectives’ or ‘hybrids’. This work is more tangible because of the use of practical examples.

The major addition that Callon and Latour make is that associations are not only made of people, but that also materials are included. As examples they name: ‘replacing unsettled alliances as much as you can with walls and written contracts, the ranks with uniforms and tattoos and reversible friendships with names and signs’ (1981, p. 284). This is all very reminiscent of Foucault’s analysis of micro-politics, an influence on Latour’s work which he acknowledges (Crawford, 1993).

The inclusion of nonhumans, or technologies, brings me to the issue that I announced in the introduction as the theoretical stake of this chapter: the development of a more sophisticated understanding of the script concept. So far, I have discussed scripts and inscriptions as pertaining to a particular artefact or technology. However, what happens to the script of a technology, if we regard it as part of a collective, or a macro-actor? If we imagine the electronic health record as such a collective, it is clear that the number of actors that it combines is considerable. It is a system that connects a very large number of humans – doctors, patients and potentially insurance agents, public officials, etc. – and nonhumans – computer boxes, cables, all the screens of a software application, the files that constitute the database, etc. All these parts of the collective also have their own individual goals, even if these are inspired by external stimuli, as Foucault has shown.

Here we get to the core of why I described my usage of the script concept so far as ‘unsophisticated’. When I said in the previous chapter than the electronic health record ‘does things’, I referred to any different things. I said, for instance, that the information that is made available to the patient ‘makes’ him/her behave differently in interaction with a doctor and that it does not ‘allow’ doctors to use their sloppy handwriting for referrals. However, I also implied that people expect the electronic health record to ‘solve’ macro-level problems like waiting lists and the ageing population. In the first two examples, the scripts that are evoked are rather specific ones, relating to a fragment of the entire EHR infrastructure only. In the latter example, however, the suggestion seems to be that the entire infrastructure ‘acts on’ the Dutch
healthcare sector. What is expressed here by actors in the standardisation process is a view of an infrastructure that is both unity and a collection of parts. Another way of formulating this is that the whole is a ‘collection of collectives’. The way in which this is described suggests that both the whole and the collectives of which it is composed have agency of some sort.

The expectation that is voiced by different spokespersons is that it both has a ‘macro-script’ and a set of ‘micro-scripts’. What is of great importance in this respect is that standard-makers seem to pose that the macro-script of the electronic health record is constituted by its set of micro-scripts. In other words, a collection of interconnected functionalities is put together in order to change the behaviour of individuals, in such a way that it contributes to solving macro-level problems. This is somewhat different than Latour’s discussion of collectives, which focuses on the way they form in practice. What I am describing here, is how they are planned and envisioned. This implies that I approach it from the point of view of inscription, i.e. the purposeful attempt to make a technology carry out a particular script.

What is important to realise, however, is that inscription refers to the creation of micro-scripts in this context. Similar to the earlier-mentioned idea of ‘orchestrated synthesis’, the idea seems to be that the macro-scripts will ‘appear to order’ once the micro-scripts are put in place. The assumption is that these inscriptions will succeed in the creation of the ‘smaller’ collectives of which the EHR macro-actor is composed.

If we project this on the case of healthcare, we have to imagine micro-networks of patients, physicians and other parties that are connected by databases, interfaces, standard protocols, etc. These micro-networks are interconnected by a national infrastructure. The different technologies are created for the purpose of prescribing particular behaviour and norms on the different actors in the network. In talking to those involved in the standardisation debate, it is, furthermore, clear that the functioning of a particular standard is regarded in the broader context of people and devices that are connected. Many of them describe the EHR as an actor and in such a way that it reflects the assembled nature that I described above. Practically, this implies that the constellation of physicians, patients and other parties are thought to have a certain collective impact on the functioning of the healthcare sector. I try to show this in more detail in the second part of this chapter.

A final cautionary reminder: no final decision has been made about the different EHR scenarios that I discuss here. In fact, the recent discussion in the Dutch Senate is likely to change the debate completely. Therefore, it is so far only possible to discuss ‘projected inscriptions’. In a sense, all inscriptions are
projections, but in this case this applies to an even greater extent. Latour acknowledges that it is unlikely that the behavioural patterns, tasks, values, duties and ethics that designers try to inscribe will always work as planned. This is obviously of some importance for the case I discuss in this chapter: the different configurations of the EHR will probably not always work as planned, even if one is selected for implementation. I return to this topic in the next chapter, by scrutinising the expectations that underpin EHR development. At the same time, this also shows that the notion of inscription does not imply attributing a ‘God-like status’ to the designer (Latour, 2003). As I indicated in the introduction already, technologies also play a role in design, not only after design. This relativation of constructivism is important from a Foucauldian point of view as well. The idea that subjects are effectively created by a clearly delineable group of designers does not mix well with his ideas about discursiveness. In this respect, the standardisation discussion that I articulate here is clearly part of a longer discussion.

Multiple macro-actors, multiple subjects?

On the basis of the idea that multiple macro-actors are being envisioned, a logical step is to assess to what extent they imply a different subjectivation of the care receiver. Different scenarios imply different collectives, with different human subjects and different technological plug-ins. I related these to different types of governmentality, which all constitute their subjects in a particular way. Therefore, rather than speaking about the ‘neoliberal patient’, as in the previous chapter, I show how different potential configurations relate to different potential subjects. The purpose is explicitly not to scrutinise these configurations, or to confront them with counterevidence from academic literature. This is the topic of the next chapter. I only refer to literature for purposes of clarification.

The argument of multiple subjectivity is not just academic parlour. Actors in the EHR discussion actually use the term subject to evoke different ways of constituting people in their statements. The Public Health Council, for instance, argued that, for one of its studies, it did not only survey healthcare consumers, but also ‘healthy subjects’ (RVZ, 2004, p. 13). Foucault considers such ‘dividing practices’ – between ‘healthy’ and ‘unhealthy’ for instance – as one of three ways of transforming human beings into subjects (1982, p. 777). The other category, ‘healthcare consumers’, does not only subject people to healthcare, but also to consumer society. As a second example,
the institute that was delegated to enable a Dutch EHR refers to a ‘subject of information’ (NICTIZ, 2006, p. 58), which can either be a patient or a patient’s family member. This shows that the gathering, processing and storing of information is understood as a system that has its own subjects. This is different from the definition that the International Organization for Standardization (ISO) maintains of the EHR: ‘a repository of information regarding the health status of a subject of care, in computer processable form’ (quoted in Blobel, 2007, p. 7). Following the ISO line, it is particularly interesting to note that a participant of an expert meeting of the Dutch senate remarked that the ‘human being’ comes up a number of times in an information system: ‘as care provider, as subject and also as patient, which is also referred to as contra-subject’ (Blobel, 2007, p. 8). I hope it is clear that the notion of subjectivity is sufficiently present in the EHR discussion to justify it as a topic of further inquiry.

**Standardisation as subpolitics**

In the previous chapter, I based my analysis exclusively on documents that were discussed in parliament. Since the mid 1990s, scholars in the vein of German sociologist Ulrich Beck have pointed at what is called the ‘subpolitis- sation of society’, or simply ‘subpolitics’ (e.g. De Vries, 2007). This refers to the idea that politics is not restricted to the acts of government, but that it is dispersed over many knowledge-intensive sites. I do not mean to suggest that subpolitics is a postpanoptical phenomenon. In fact, the very notion of panopticism implies that a particular approach to subjectivation is constituted in local micro-politics. Prison guards, school teachers and factory managers were all part of the panoptical apparatus. The creation of the Panopticon was not an act of central government. Nevertheless, in order to understand how subjectivation takes place in the postpanoptical present, we have to study subpolitical sites of the present.

The different platforms on which the standardisation of the electronic health record is discussed may be regarded as examples of such sites. Standards form an important part of the infrastructure that is laid out throughout the country. Using metaphorical terms like AORTA (NICTIZ, 2003), we are made to imagine a body of vessels through which data is pumped around like blood cells, using a ‘National Switch Point’ (Ministerie van VWS, 2005c; European Commission, 2007) to determine what goes where. Given the objectives, standard ways of handling data are needed to assure that all the differ-
ent parts that are connected to the vessels are interoperable. This was labelled as a problematic issue from the outset (RVZ, 1996) and has remained an issue all along (RVZ, 1996b). This is the reason for focusing on standards in this chapter. As I mentioned briefly in the previous chapter, this is mainly due to the opposition between two approaches: the third version of the American HL7 standard and the ENV13606 standard of European origin. This opposition forms the basis for this chapter. I mainly base my analysis on ten interviews with proponents of the different standards, which were conducted in 2008\(^3\).

On top of that, I iterated my analysis by drawing on the analysis of documents that formed the basis of the previous chapter.

Here, I am concerned with the role that standardisation, as a site of sub-politics, plays in the governmentality discourses surrounding the electronic health record. I still consider governmentality as the ‘reasoned way of governing best and, at the same time, reflection on the best possible way of governing’ (Foucault, 2008, p. 2), rather than as the practice of government. This implies that I focus on the way in which experts reflect on the role of standards in their conception of ‘governing best’. This makes particular sense if we take into consideration that the design of the Dutch electronic health record is still under discussion.

This does imply a different orientation than Latour has taken in his work. My intention is not to ‘follow the actors’ (Latour, 2005b) in the process of making the connections and building the networks that would realise their visions. As I am more interested in their reflections on how to ‘govern’ with a health record, I stay close to their narratives regarding the expected operations of the different scenarios they imagine. I use some of Latour’s concepts to make sense of the stories of standard-makers. As such, I don’t discuss the actual formation of macro-actors, and the actual shaping of subjectivity, but only projections of that. Where possible, I do indicate when standard-makers acknowledge the role that nonhuman artefacts play in the design process. I use a separate section for this, considering that this typically applied to the general opposition between standards, rather than to the more specific level of the different scenarios. This is in line with Latour’s (1987) comments that people can act as spokespersons for things. My goal is not to provide a general account of the role that different actors play in the constitution of different visions or scenarios, even though this would certainly be possible, and interesting. It would articulate that also visions and scenarios are constructs, which do not exclusively stem from human imagination. Because of the focus

\[^3\text{Interviews were conducted with Willem de Ruiter}\]
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on governmentality as a reflective phenomenon, however, I am more interested in the ‘content’ of these constructs.

Four ‘projected’ macro-actors

Whittaker describes the contenders of the ‘standards war’ in the EHR discussion as follows:

‘Coming out of the West, waving Old Glory in the setting sun, are the big guns of the HL7 standards organisation. From Down Under we have the openEHR (pronounced ‘open air’) project, and from Europe we have the easy intellectual superiority of the CEN/TC 251 European medical informatics standardisation committee’ (Whittaker, 2002, p. 29).

In the Netherlands, it is mostly the opposition between the American and the European approach that has attracted some attention in politics (RVZ, 2002b; 2005b; NICTIZ, 2003; ICT Zorg, 2007; Ottes & Van Rijen, 2008; TK, 1997/1998b). Both standard organisations have Dutch departments. Nevertheless, it is important not to overlook the impact of the Australian initiative:

‘over the past five years it has had a significant influence on the development of EHR standards by the three main international ehealth standards development organisations, CEN (European Committee for Standardization), HL7 (Health Level 7), and ISO (International Organization for Standardization). In fact, CEN EN13606 [3] is a subset of the full openEHR specification’ (Schloeffel et al., 2006, p. 1).

Even though the then-minister of healthcare (social-liberal) initially focused on European standardisation efforts (TK, 1997/1998b), and the Public Health Council criticised the lack of an underlying data model for the second version of the HL7 standard (RVZ, 2002b), the third version of this standard was adopted for further implementation by the responsible National IT Institute for Healthcare in 2002 (NICTIZ, 2003).^

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^ This paragraph, and the following two, are taken from an earlier publication (Mensink & Birrer, 2010), the remains of which are published in chapter four of this thesis.
The argumentation of the responsible agency was pragmatic: this version was internationally the most developed standard and many Dutch hospitals had already adopted the second version of the standard. The next political incident in relation to the adoption of standards was the negative Dutch vote on the acceptance of four out of five parts of the 13606 standard in May 2007 at the European level (ICT Zorg, 2007), an issue that was not discussed in parliament. However, after a highly explicit advice by the Public Health Council (RVZ, 2005b) and a controversial informal communication by members of the council in a Dutch medical journal (Ottes & Van Rijen, 2008) in favour of the European standard, parliamentarians started questioning the technical shortcomings of the HL7 standard. However, the then-minister (Christian democrat) did not consider the 13606 standard sufficiently mature to be applied on a larger scale, mainly because only four of its five parts had been accepted by then, and because of a lack of existing implementations (TK, 2008/2009e). The minister decided against using the standard in future implementations, as Sweden had done, but did refer to international agreements to move towards harmonisation between HL7 and 13606.

While the HL7 standard traditionally focuses on sending referral messages between the information systems of different healthcare providers, the ENV13606 standard has always put its focus on the coded mapping of medical context. Rather than focusing on basic message exchange, the goal of the 13606 has been to encompass all EHR information at the same time (De Clercq et al., 2004), using the concept of archetypes. Archetypes are defined somewhat cryptically as ‘knowledge level models which define valid information structures’ (Beale, 2001, p. 2) and practically denote models in which all medical information related to a certain procedure is stored. HL7’s Clinical Document Architecture (CDA) concept, which can be seen as ‘conceptually very similar to archetypes’ (Eichelberg et al., 2005, p. 282), is intended ‘to structure the clinical information inside the documents (such as a discharge letter). It does not deal with the meta-information required for structuring (and transferring) the relations between these documents, which may be included in an electronic patient record’ (De Clercq et al., 2004, p. 1028).

I do not want to argue that one standard will lead to ‘system X’, and another will lead to ‘system Y’. Even within the group that supports a particular standard, there are diverging views. In this section of the paper, I focus on four EHR ‘scenarios’, which I conceptualise as macro-actors on the basis of the accounts of my respondents. Two of these, which I discuss first, are attributable to the HL7 network, and two to the proponents of 13606. These scenarios are not fully separable empirically. They are not labelled as distinguished
views within the different groups. Where applicable, I indicate where scenarios overlap. That does not mean, however, that these are completely analytical categories either. They were based on oppositions within the accounts of the respondents.

The virtual record

The term ‘virtual record’ is mostly attributable to the HL7 network. The term was repeatedly used by politicians to describe the EHR project (TK, 2000/2001a; 2008/2009e; Hoogervorst, 2006a). On top of that, it was adopted by the implementing institute in its ‘Masterplan’ (NICTIZ, 2002a). The term ‘virtual’ applies to the idea of a network of healthcare providers (physicians, laboratories, etc.), in which medical data is communicated by means of standardised messages between the local information systems that all members of the network maintain and manage individually, using a ‘National Switch Point’ (NSP) (European Commission, 2007) through which queries can be made to local databases. In other words, local databases are ‘black-boxed’ in this system, in the sense that their contents are not considered. Communication in the healthcare system is thus based on HL7’s message paradigm. The virtual record is clearly positioned to facilitate communication in medical processes, which are not necessarily restricted to branches of the healthcare sector. An HL7 representative referred to this as ‘organisational interoperability’, which is distinguished from more technical forms of interoperability. The first steps have been to create specific messages for medication and laboratory data, making use of the third version of the HL7 standard. It is clear that the virtual record is mainly a tool that facilitates the operations on the supply-side of healthcare.

The micro-script that standard-makers want to embed is to create such applications that would make physicians translate their handwritten referral notes to electronic messages with a limited number of basic parameters. Clearly, this is not a major step compared to the current operations of healthcare. Patients and doctors are not constituted in a fundamentally different way than what is the case now. The setup leaves responsibility for medical data with the physician, as (s)he maintains the ownership of the containing database.

Respondents from the HL7 network voiced the idea that the best way to assure high data quality is to make sure that the physician who creates the data - in a measurement, or consultation for instance – remains the owner of
the data, in such a sense that the data remains at its source. In other words, the ‘collective’ of physician and data should not be broken. This relates to the opinion within the network that physicians fundamentally distrust any data that they did not create themselves. Therefore, in order to make sure that someone is responsible and thus accountable for the quality of the data, local data storage is deemed inevitable. Another political argument for local storage of data is based on the idea of avoiding concentration of data for reasons of security, abuse and potentially centralised power structures.

Standard-makers in the HL7 network base their ideas on a pre-defined conception of the ‘regular patient’. A main assumption that underlies their inscription plans is that patients are not interested in an electronic health record, but in the treatment of their illnesses. Before a greater emphasis was placed on patient-access to their records, the position of certain HL7 stakeholders was to provide the patient with access to the ‘logging screen’ only. This gives an overview of the physicians that have (attempted to) access their data. A much-heard argumentation is that patients currently do not ask their physicians for insight in their medical records either.

Even though the virtual record would operate as a macro-actor, it is highly distributed. Its stability depends on its links to the AORTA infrastructure, the National Switch Points and the logins that patients and physicians use to make queries. Its composition changes from time to time, based on the queries that are made. The ‘macro-script’ of this corresponds to the basic expectations of the EHR that are voiced in political discussions. I name the most important examples. By using the EHR, communication is expected to become more efficient (RVZ, 1996). Quality of care is expected to improve, considering that digital records would overcome human errors, such as sloppy handwriting (TNS NIPO, 2003). As a result, healthcare costs would decrease (TNS NIPO, 2004a; TK, 2007/2008b). These expectations hold for all EHR configurations that I discuss. Each of them adds to this in different ways, however.

The chain integration record

The chain integration record is also mainly attributable to the HL7 network. The term ‘chain integration’, or ‘integrated chain approach’, is the translation of a common Dutch way of referring to what is generally called Supply Chain Management (SCM). The notion that something is considered as a supply chain indicates that a particular process is given a special status. Its shape is more fixed than in the case of the virtual record. That does not necessarily
mean that it is more stable, however. SCM was coined by business consultants in the 1980s and has increased in popularity ever since. This academic concept is often applied in political discussions (e.g. RVZ, 1996; Ministerie van VWS, 2002; 2005d). More colloquial terms as ‘healthcare chain’ or ‘chain care’ are to be found in nearly any document in the EHR debate.

This projected macro-actor is largely the same as the virtual record, but would be designed to pull together all the messages concerning individual patients in relevant medical ‘chains’, in order to create a comprehensive record. Its projected ‘macro-script’ is different. This implies that data is not connected to a medical specialisation, as was the case in the virtual setup, but to a patient in a process. This labelling of chains is an additional form of categorisation. This mainly relates to patients with a chronic illness. In such cases, certain members of the HL7 network voiced the idea that it might be good for the record to ‘follow the patient’. In this sense, it is somewhat more patient-oriented than supply-oriented, compared to the virtual record. This does imply a view significantly different from the virtual record, in the sense that data is no longer necessarily distributed and confined to its source, but can be drawn together around a single patient with a chronic disease.

The main inscription of the chain-integration record is that physicians are prescribed to contribute to the constitution of their patients’ ‘chain record’ by the referral message that they send. They are connected in a more fundamental way than if their data were merely accessed through incidental queries.

The patient-user of this macro-actor is constituted rather differently than in the case of the virtual record. An idea that strongly influenced standard-makers in the HL7 network is the distinction between ‘regular patients’ and ‘expert patients’ that was popularised in political circles since the late 1990s (Wilson, 2001). As the former category is deemed to form the majority, part of the network takes it as the basis for defining the workings of the virtual record. This is an indication that the virtual record and the chain integration record could co-exist. We could imagine a system in which regular patients are enrolled in a system through incidental queries, while expert patients have a more structural engagement in a particular medical chain.

Despite the differences between the associations within HL7 that support the virtual record, or the chain integration record, it needs to be argued that there are also strong overlaps between the two associations. For instance, both approaches are based on a strong resistance against central storage and against the notion of investing in archiving in general. By distinguishing between ‘regular patients’ and ‘expert patients’, data is only drawn together
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around the patient in a few specific medical chains. Because of that, local databases can still be maintained to a great extent.

On top of the expectations that I described with respect to the virtual record, some more are added here. The chain integration record is supposed to partly overcome the perceived fragmentation of the healthcare sector. In an advice, order by the Minister of healthcare, it is argued that:

‘an increase of fragmented care is expected; the number of different care providers that work together for the health of one single patient is growing. These developments call for an accessible and exchangeable record between the different care providers in the chain’ (Squarewise, 2006, p. 9)

Such a ‘restructuring’ according to medical chains would result in a repositioning of ‘expert patients’.

The Personal Health Record

The Personal Health Record is mainly attributable to the 13606 network. Even though the idea of a personal health system already arose before computerization, it has only taken flight in the past decade. Particularly the role of commercial providers like Google and Microsoft has been influential in recent years (Rich & Miah, 2009; Wright et al., 2010). In 2010, the European Commission offered funding for projects that would further the integration between systems for ‘personal health’ and ‘public health’\(^5\). The vision of certain 13606 proponents could be regarded as such an approach.

The personal health record signifies a system in which all information around a medical act is connected to an individual patient, rather than to physicians, treatments or processes. 13606 standardises medical information, rather than messages. This information is stored separately from the actual EHR application. This is called a ‘dual-level approach’ (Beale, 2001). Just like in the case of the virtual record, a mediator is required. Here, the mediator is not meant to connect databases, however, but to connect user interface and database.

By using open standards, applications like Google Health and Microsoft Healthvault can connect to the system. The importance of this extension for this macro-actor lies in the fact that these applications have a rather different

orientation than the public health records that I have discussed so far. For proponents of the 13606 network, personal health systems are mainly focused on monitoring data such as fitness indicators that are measured while doing sports. By this inclusion, this macro-actor is expected to stretch out significantly.

But, what is more, this broadening of the network also implies the constitution of a second additional set of users: what some have called ‘pre-patients’. Whereas the public EHR mainly counts ill people as its users, the personal health record also includes those that do not (yet) have an illness. This is interesting from a Foucauldian perspective, for different reasons. While the virtual record was based on an imagined set of fairly passive patients that only want treatment, and the chain integration record aimed at ‘expert patients’, this macro-actor is based on a category that potentially includes the entire population. First of all, in the previous chapter, I indicated how the population became a unit of governance around the 18th century (Foucault, 2008). In this respect, extending the ‘reach’ of the health record is an interesting development. At the same time, it could be argued that the distinction between health and illness is increasingly blurred. A good part of debate in the medical domain has always turned around the question of defining the boundaries of abnormalities from the condition that is considered healthy. If all citizens have an electronic record, this ‘dividing practice’ is less an issue.

A final set of new users, which 13606 proponents imagine, is the fairly undefined category of organizations that could be hired by patients to manage and maintain their data. 13606 proponents acknowledge that managing your own health may be a trying task. Banks are often referred to as the type of institution that could be trusted with such a task. Particularly because of the interest of corporate players like Google and Microsoft, such intermediary organizations are deemed desirable.

The prime function of the Personal Health Record is to provide people with access to their own data. The clearest motivation for this position was the statement of one 13606 proponent that ‘the patient is just a subject in all those information systems, but does not have his own system’. He proposes to create systems in such a way that the patient is ‘electronically represented’ and states that the EHR should not be about information gathering for the physician, but for the patient. Therefore, the fact that the technology is coded in such a way that data is ‘attached’ to the patient inscribes new patterns of use.
A micro-script that is imagined for this macro-actor is based on the possible connection to applications like Google Health and Microsoft Health-vault. In such a case, a patient is probed by the system to actively add data concerning his/her health. It would go too far to use Latour’s prescription concept to describe the agency of the system, but we might say that someone could be enticed by such a function. Still, both within the 13606 and in the HL7 network, I encountered resistance to such forms of ‘user-generated content’, arguing that it is problematic to mix this with existing, authoritative data sources. In line with the focus on the subject, it is interesting to note that data is described as subjective (Foucault, 2008b).

The main agency that the personal health record would have in the healthcare system would be to reposition the patient. Even though the notion of patient empowerment has certainly entered political discussions as a relevant trend (RVZ, 1999b), this is rather regarded in relation to health information on the internet. The notion of patient access to the EHR did get increasing attention in recent years (TK, 2008/2009e). Nevertheless, the patient is not considered as the owner of his/her own data (Ministerie van VWS, 2005b; Ministerie van VWS, 2005a). The agency that is attributed to the potential personal health record stems mainly from 13606 proponents.

The monitoring record

The fourth, and final, macro-actor that I discuss here is closest to the setup that I identified in the previous chapter. In other words, it comes closest to what I described as a neoliberal, postpanoptical setup. Therefore, some arguments will be revisited, but from a different angle. This EHR type is not clearly labelled in the discussion, even though it is often described by 13606 proponents.

This macro-actor is technically the same as the Personal Health Record in terms of infrastructure. As I said in the introduction, the macro-actors that I discuss here are not entirely separable in terms of the technology used. The emphasis is clearly different, however. The main distinguisher is that the agency record comes with a different set of anticipated users and connected applications.

The argumentation that is given by 13606 proponents is that their standard enables monitoring and decision-support for individual patients and populations. The emphasis is put on the adequate mapping of medical context. The technology does not only provide the output data of a blood pres-
sure measurement, for instance, but also further context information. It would record who performed the procedure (doctor, nurse, patient, etc.), which equipment was used, which method was applied, etc. Most importantly, information would be presented in such a way that computers can ‘understand’ it. Referring to HL7’s message-paradigm, one 13606 proponent argued that ‘messages are meant for updating EHR’s; that is not the same as archiving’. From a Foucauldian point of view, it would be interesting to question the rationality behind the decision of what should be archived and what should not, rather than the mere notion that there is an archive (Foucault, 1972). I try to comment on this here.

The expected new functionalities imply different micro-scripts in terms of the constitution of the patient. Not only is the user conceived as a disciplinary actor that will hold doctors accountable for bad work, but at the same time (s)he is entered in a relation in which different medical institutions monitor his/her development. Let me start with the first part. The mere notion that patients will have access to more data leads to the assumption that they will change their behaviour. Most importantly, it will probe them to adopt a more critical position vis-à-vis their doctors. It is a relevant factor to note that this macro-actor is, therefore, thought to go against the interest of physicians, as it would undermine their power. As in the case of the personal health record, this relates to a vision of patient empowerment, but to a different one. Rather than arguing for the emancipatory character of empowerment, the vision related to this script is to empower patients with ‘perfect information’ to hold their physicians accountable for the quality of their service. Basically, this implies the vision of a script that would enforce a principal-agent relation of the patient vis-à-vis physician, or a vision of a disciplinary subject as Foucault (2008) described in his analysis of neoliberalism. As I said before, we might regard this as the neoliberal expectation of an ‘orchestrated synthesis’ in society.

The second part of the constitution of the patient, as the object of monitoring, is based on another micro-script. This implies that the creation of computer-processable data entices physicians and public institutions to monitor individual and (anonymous) population-level data. For instance, applications are expected that would probe doctors to monitor not only the sickness of his/her patients, but also the developments in the patient’s health. The general practitioner would take up the role of ‘health counsellor’. In this sense, also here does the addition of personal health systems like Google Health and Microsoft Health Vault imply an addition of sport clubs and the like. As I have shown in the previous chapter, such ex-
expectations do not only apply to individual physicians. Organisations in the realms of medical science, insurance companies, political organisations and the management of healthcare are expected to draw on large-scale, anonymized datasets that are derived from individual patient data (RVZ, 1996). This script relates to a view of certain standard-makers in the 13606 network to increase the efficiency of healthcare by implementing decision-support, or even fully automated decision-systems.

The projected micro-script of automated storage of context information involves yet another expected change of physicians’ behaviour. The effort to create completely trustworthy information is thought to play a major role in reducing the costs that come with repeated medical procedures. Both standardisation networks argue that physicians tend to distrust data generated by colleagues. Some go as far as saying that 'a surgeon would rather not have a memory'. As it was explained in the section on the ‘virtual record’, the HL7 network uses this as an argument to stress the importance of personal data storage for individual physicians. For actors of the 13606 network, by contrast, such an approach is unsatisfactory, considering that it would lead to repeated measurements, which is considered undesirable from the point of view of cost containment.

The third micro-script is similar to one that I described for the personal health record, even though it is framed differently here. Having a system that is built on open standards is expected to ‘invite’ personal health systems like Google Health and Microsoft Health Vault to link up. The logic behind the script is that open standards change industrial behaviour, in the sense that it ‘invites’ broader adoption. This is in conflict with the HL7 view that standards are best made in collaboration with industry. In such a view, relevant players are invited as members of an association before publishing the standard.

Let me summarise the way the principal-agent record would act within the healthcare system. First of all, it is expected to contribute to cost reduction, for instance by reducing the need for repeated tests. This expectation, however, is voiced in parliament as a general expectation of the EHR (TK, 2007/2008b). This is not necessarily restricted to the scenario discussed here. However, the argument is that only 13606 would offer the means of meeting this expectation. On top of that, patients are expected to adopt a principal-agent relation with respect to their care providers. In political discussions, this opinion of mainly voiced by 13606 proponents (RVZ, 2003a). The same applies to question of decision-support. The expectation is that the addition of information from user-generated personal health systems to a public EHR
will contribute to transforming the current ‘sickness system’ into a ‘health system’. It is argued that the current debate is still too much grounded in a supply-oriented system, in which it is financially attractive for physicians to have a high number of patients with a chronic illness. By allowing the addition of ‘health’ related information, physicians are thought to be stimulated to take greater efforts towards prevention. The main way in which this macro-actor is expected to act, is by breaking open the structure of the healthcare sector.

Artefacts and conflicting interests

It is interesting to note how actors in this standardisation process discuss conflicts of interest in relation to the role that certain artefacts play. I discuss them in a separate section, considering that they do not particularly apply to the four projected macro-actors. All examples that I discuss here relate to criticism of HL7 by 13606 proponents.

The most polarising issue relates to accusations that HL7 proponents did not dare to ‘put a bomb under legacy systems’. Indeed, the implementing institute, which adopted the HL7 standard, opted for working with existing systems (NICTIZ, 2002a). I have argued before that the databases that contain medical information are ‘black-boxed’ in the messaging paradigm. It is clear that the databases ‘under the GP’s desk’ pushed the process considerably. As I showed before, the explanation is different. HL7 proponents take local storage for granted, arguing that it is the only way of gaining the trust of physicians. Their competitors don’t accept this limitation, and attempt to find other ways of assuring higher level of trustworthiness. This is not all. 13606 proponents point at underlying argumentation on the HL7 side. A number of them pointed at the role of hardware vendors, arguing that black-boxing databases is in their interest. One of the main reasons for building on an existing framework of local hardware would be that many of the members of the HL7 network create proprietary database systems. It is argued that such vendors want to keep control over the ‘database column’ of medical information systems, and only want to standardise the communication between them. Also other IT companies are drawn into this association, according to 13606 proponents, because of the market opportunities for creating software plug-ins that would be needed to keep all the different systems connected. By opting for open standards, 13606 proponents attempt to force (the market for) databases to open up.
There are a number of artefacts of which 13606 proponents have claimed that they have pushed the discussion into a direction favourable to them. The clearest example, even if it is not as ‘material’ as most of Latour’s examples, is the Act on Medical Treatment Agreements (WGBO). This was introduced mid-1990s and is argued to have pushed the political discussion for strengthening the role of the patient with respect to medical data. The act declares that patients have the right to access, modify and destroy their medical data, which, in relation to patient empowerment, is thought to be crucial in terms of self-determination. Interestingly, 13606 proponents themselves discuss the act as an actor: they argue how pleased they are not to have to negotiate with HL7 representatives about patient rights, considering that the act ‘does that for them’.

Something similar may be argued about the earlier-mentioned ‘logging screen’ interface of the future EHR. In fact, it became an artefact that embodied a core issue in the political or visionary discussion around the position of the patient in relation to the question of standardisation. Once it was proposed that patients could monitor who accessed their data, questions arose to what extent patients could have access themselves. Interestingly, what started as an attempt to restrict patient access, in the end probed questions to expand it. Only in 2009, there was a promise by the then-minister of health-care (Christian-Democrat) to look into patient access (TK, 2008/2009e).

Certain authors have coined the idea that, on the basis of Latour’s work, concepts may be regarded as nonhuman actors as well (Underwood, 2002). By showing how concepts are translated between communities, one could illustrate how they can push certain processes. Earlier, I referred to the academic concept of ‘chain integration’, which co-existed with terms like ‘health care chain’ and ‘chain care’ in political discussions. It is not my aim to give a general account of the role of concepts in this discourse, even thought that would certainly be an interesting analysis. I do want to give one example that seems particularly relevant from the point of view of standardisation. The core of the 13606 standards seems to lie in the ‘archetype’ concept (Beale, 2001; Garde et al., 2007). This concept pushes both political discussions around accountability of physicians and, more importantly, pushed HL7 to come with comparable concepts. Scholars have argued HL7’s Clinical Document Architecture (CDA) to be ‘conceptually very similar to archetypes’ (Eichelberg et al., 2005, p. 282).

A final point, which is particularly relevant given the discussion of visions and projected futures, is the role of imagined actors. Throughout the description of the four macro-actors, I have already indicated how different
sets of future users and artefacts are drawn into the argumentation of a particular projection. Different macro-actors would involve ‘expect patients’, ‘ill people’ or ‘pre-patients’, as well as ‘decision-support systems’, ‘logging screens’ or ‘Google Health’. Interestingly, some of these artefacts do not actually occur in concrete discussions on standards or on the implementation of the Dutch EHR. We might refer to them as ‘distant actors’. Despite their non-presence, it is clear that their existence pushes political discussions. For instance, members of parliament

‘see all sorts of initiatives abroad, in which a personal medical record is arranged, as in the case of Google Health and Microsoft Health Vault [...] In case government does not properly arrange the access functionality properly, these members fear a parallel development of the public electronic doctors’ record and a patient data vault in the private sector’ (TK, 2008/2009a).

The minister argues that such personal health records can potentially extend, but never replace the public system from a security point of view.

Discussion and conclusions

The four macro-actors that I discussed above can be presented in a more structured manner by categorising them according to two variables: (i) the orientation to changing the situation of individual care on the one hand and of the healthcare system on the other, and (ii) a focus on streamlining process & communication on the one hand, or structure & information on the other. The four technologies-in-design can then be presented as such:

<table>
<thead>
<tr>
<th>Process &amp; Communication</th>
<th>Emphasis on system</th>
<th>Emphasis on patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Virtual record</td>
<td>Chain integration</td>
</tr>
<tr>
<td>Structure &amp; Information</td>
<td>Monitoring record</td>
<td>record</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal Health</td>
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<tr>
<td></td>
<td></td>
<td>record</td>
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</table>

Such a classification of ideal-typical technologies-in-design can be used to enhance the moral dimension of the discussion on technological develop-
ment. They can serve as analytical tools to be used as discussion cases, or even to increase the predictive power of discussions on these developments. In terms of predictions in this case, I just want to highlight a few important developments can be illustrated by means of the above mentioned macro-actors. First of all, it seems clear that the virtual record was the model for Dutch EHR design for most of the process. The actual term was applied by subsequent ministers of healthcare (TK, 2000/2001a; Hoogervorst, 2006a), as well as by the institute that was delegated to enable the implementation of the EHR (NICTIZ, 2002a). Looking at the table above, however, there seems to be a movement on the horizontal variable to the right, i.e. from a system orientation towards an individual care orientation. By such reports as From patient to consumer (NICTIZ, 2002c), and other political advices by the public health council, it seems that the political discussion is moving towards acknowledging the position of the patient. Particularly parliamentary debates in the first half of 2009 voiced a strong dissatisfaction with the role that had been envisaged for the patient up to then. Only in March 2009 has the responsible minister given his veto for allowing patient-access to the EHR (TK, 2008/2009e).

At the same time, however, there has been a continuous orientation towards using the EHR for addressing macro-issues in healthcare. As we have seen, this is a crucial point in neoliberal, postpanoptic governmentality. This would imply a ‘shift to the left’ in the table. While in the 1990s the record was positioned for addressing waiting lists and waiting times, attention has shifted towards the societal costs of medical information errors in recent years. In terms of the overlap that was described between the personal health record and the monitoring record, the question is whether patient empowerment is meant to emancipate the patient, or to create a disciplinary patient-subject in the healthcare system.

A third and final development that I have observed seems to be less ambivalent in terms of ‘direction’. It seems to be clear that both standards are moving in the direction of standardising the actual information in medical databases, rather than just the messages that are sent between them. Even international proponents of 13606 agree that ‘HL7 is moving towards an architecture standard’ (Garde et al., 2007, p. 342). In this sense, it seems clear that the future of EHR development is to be expected in the lower line of the table above. The question that remains is whether it will stabilise in the left or in the right column.

At the same time, it also needs to be added that, due to frequent criticism, the then-minister (Christian-democrat) became increasingly careful
about making claims that the EHR would expand beyond the virtual record. Particularly due to worries with respect to privacy, the stress on the virtual character was re-emphasised (Ministerie van VWS, 2007b). This may suggest a more ‘modest’ direction for future developments. This is also in keeping with the recent refusal in the Dutch senate. Particularly a motion requesting not to take any irreversible steps with respect to the EHR is telling (Eerste kamer, 2010).

On the other hand, we should perhaps also consider the option that some of these scenarios will co-exist. A number of these scenarios are not mutually exclusive. We could well imagine that the majority of care receivers would be served by a ‘virtual record’, while ‘expert patients’ would receive an additional ‘chain integration record’. In addition to that, the fact the ‘personal health record’ and the ‘monitoring record’ are technically the same, could imply that an effort could be made to have them co-exist somehow.

On the basis of these diverging perspectives, it is hard to predict the future. Technical developments seem to push in a direction that is different from what is desired by the senate. I conclude here by saying that an overview of scenarios, such as I have provided here, would be beneficial in terms of getting grip on the question what is desired. A further question is: how feasible are these scenarios? This is the topic of Part 3.

We have reached the end of Part 2. The theoretical lens of the pair of bifocals at the past two chapters has been to study how people are made subjects by using technologies to re-shape power relations in society. The study of neoliberal perceptions of reciprocity has helped in the understanding of attempts to create a particular set of power relations. Because of that, it became possible to imagine the ‘neoliberal subject’. This subject type embodied the two-fold subjectivation that we were left with after Part 1. It provided a more holistic view of the way in which neoliberal thinkers imagined the apparent opposition of the original two subject types – ‘principal subject’ and ‘subject of human capital’ – to be actually embedded in a unified subject entity. Relations of reciprocity are imagined to ensure that all this is beneficial to the subject. If we take the discussion of the present chapter into consideration, we should, in fact, go even a step further. Not only could we imagine the political constitution of a neoliberal subject, but in addition to this we could pose that such a subject would in fact be embedded in a macro-actor that would serve as an ‘orchestrated’ agent of neoliberal policy. From such a point of view, the subjectivation of the care receiver is even more complex: (s)he
would in fact be something like a ‘neoliberal micro-subject’, embedded in a complex web of different collectives that make up a larger whole.

By taking the practical lens into consideration, we can add a bit of nuance to this image. In the present chapter, I indicated that there are currently still a number of co-existing options for the future of the electronic health record. The refusal by the Senate is likely to have an impact on this as well. Only one of the four scenarios implies a subject-type that resembles the ‘neoliberal subject’, with all of its reciprocal relations. There are reasons to believe that this scenario reflects future international developments. From the point of view of Dutch politics, others scenarios seem more likely. What is more, it may well be imagined that different scenario will co-exist, if implementation in fact goes through. Next to the ‘neoliberal subject’, we have seen a range of other, potential subject-types. The ‘virtual record’ comes with a subject that is relatively comparable to the patient in the current healthcare system. Apart from that, there are potential subjects that are more applicable to particular sub-groups of the patient population. We have the ‘expert patient subject’, for people with a chronic illness, for instance, and the ‘self-managed subject’, which is more likely to apply to younger people who have enjoyed higher education. In fact, their subjectivity is potentially not even formed by being a ‘care receiver’: as we have seen, some standard-makers have voiced the objective of including ‘healthy people’ as EHR users as well. In all of these cases, connections to government and population are considerably less emphasised, or intrusive, than for the neoliberal subject.

I hope that this gives some indications of the shortcomings of an analysis as I unfolded in the previous chapter (despite some of its advantages). Let me briefly highlight a number of these disadvantages. First of all, the ‘gaze’ on parliamentary politics concealed some rather important aspects of the development of this technology. Second, it forms a relevant point of reflection on Foucault’s methods. Considering his historical approach, the focus is likely to be placed on the rationality and practices of subjectivation that did in fact materialise. I hope to have shown that an ‘analysis of the present’ shows that such processes are a lot less straightforward than they may seem in retrospect. Particularly from the point of view of offering a ‘critique of the present’, something that Foucault advocates, this is rather important.

In order to offer such a critique, however, more has to be done. The stake of Part 3 is, therefore, to examine the account of neoliberal discourse from yet another angle. What I try to do is to look at criticism within these political discussions, mainly trying to understand how they are received.
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Obviously, my aim is to understand how this relates to questions of subjectivation. As said, this is an angle that Foucault never embarked upon.