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## **Subject of innovation or : how to redevelop 'the patient' with technology**

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## 4 Immoderate expectations

### *Will the electronic health record behave?*<sup>6</sup>

The subtitle of James Scott's (1998) book *Seeing Like a State* is rather closely related to the stake of Part 3. Not only does it suggest that he studies 'certain schemes to improve the human condition', but also how they 'have failed'. Despite Scott's indebtedness to Foucault's work, subjectivation is not his prime concern. For the following two chapters, I am concerned with the question what the potential of 'failing governmentality' implies for the way the subject is formed. This is a different statement than to say that government has failed, an angle against which Barry (2001) appeals.

The theoretical angle for this part is the question of subjectivation in relation to 'questionable expectations'. I do not wish to suggest that such a point of view is typical for understanding postpanoptical subjectivation. However, I do argue that the expectations that neoliberalism brought forward are likely to relate to a different set of issue than in the case of expectations relating to the impact of a surveillance society. Therefore, in order to understand postpanopticism, we still need to take these particular expectation in account.

The notion of 'questionable expectations' has a variety of dimensions. I focus on two. First of all, there is the angle of 'engineering' technologies of government. When discussing such technologies, Foucault mainly looked at established practices. Considering that I have focused on attempts to create them, we have to take into consideration that such attempts may fail. Latour already warned us that attempted inscriptions may work out differently than planned. The same applies to technologies of government. If expectations fail, another set of practices emerges. If technologies work in a different way than imagined, the practices and relations that they mediate will also take another turn. Macro-actors will not act as they were expected to. And, most importantly, people will be made subjects in different ways, by being embedded in different relations and sets of practices.

A second angle that is important here relates to the expectations with respect to the role, or roles, which are expected of a particular subject-type. With respect to the neoliberal subject, for instance, we have seen that (s)he is

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<sup>6</sup> The fact that this chapter and the following are written in first person plural is due to the fact that the text is based on publications (co-authored by Frans Birrer)

expected to monitor the conduct of care providers, and become a more productive member of society at the same time. These expectations are communicated rather broadly, by political stakeholders, but also in media and probably in individual communications as well. If it turns out that people's subjectivity does not align with what has been communicated, how will this relate to political and societal expectations?

Apparently, expectations matter. However, how can we study them? And, if we study them, can we make any meaningful statements about them before we have the chance of examining the 'reality-effects' of all the projected inscriptions? It seems that the only thing we can do is to take criticism that is voiced against the most important assumptions and expectations into consideration. This is what I do in this part of the study. The two chapters take different approaches, which I explain in more detail later. For now, it suffices to say that this chapter starts in a rather practical way. The next chapter adds a more theoretical layer to these considerations.

The practical issue that is at stake in Part 3 is the critique of some of the crucial expectations underpinning pro-innovation policies in healthcare. Even though the focus is mainly on expectations that relate to subjectivation in the line of what I have discussed so far, a number of other expectations will be discussed as well. Two examples of pro-innovation policy in healthcare are discussed. First of all, I round up the discussion of electronic health record planning, which I started in Part 2. Secondly, however, I introduce another case of pro-innovation policy: the personal budget. This is the topic of the next chapter. In practical terms, we could wonder what healthcare, and innovation in healthcare in particular, will look like if the expectations that are formulated turn out differently. What will this mean for the position of the patient, and the projected restructuring of the healthcare sector?

Starting with the discussion of the electronic health record, it is impossible to take the expectation of all the scenarios I discussed in the previous chapter into consideration. In any case, my main objective has been to 'unpack' the understanding of such a policy that a Foucauldian reading would suggest. Therefore, I mainly restrict myself to the assumptions behind neoliberal reasoning. I do, however, continue the discussion of opposition between the different standardisation organisations that I started in Part 2. I start, however, by providing a general introduction to the theme of expectations in science and technology studies (SST)<sup>7</sup>.

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<sup>7</sup> The text up to here is not part of the publication that constitutes this chapter

The role of expectations in the process of development of technology has received increasing interest in the SST (Science & Technology Studies) community (Van den Belt & Rip, 1995; Van Lente, 1993, and subsequent work; for a recent collection on the subject see Technology Analysis & Strategic Management vol. 18 nos. 3/4, 2006). What is expected of a certain new technology has a strong influence on the direction of the development process. Expectations concerning what is and what is not technically achievable, which functions this new technology could fulfil, and which current problems it could solve are a strong motivator in the development process, with a high impact on the shape the technology will eventually take. Sometimes, these expectations work as self-fulfilling prophecies, with or without unforeseen consequences. On other occasions expectations turn out to be a serious obstruction for actual innovation to take place, or they may lead into completely unexpected directions. In a broader sense, expectations are not confined to the working of the technology per se, but also include expectations of actors concerning their interactions, expected levels of cooperation, strategic considerations, etc. The discussion of expectations of technology and the complexities of the mutual interactions of these expectations fit in what has been called the second or 'reflexive' modernization of society (Beck et al., 1994).

This SST theme of expectations is of course very relevant to innovation studies as well. For innovation, too, expectations will often be a major determinant. In this paper, we will focus mainly on expectations with respect to a specific technology, on what Van Lente (1993) calls the 'promise' of a technology.

Expectations regarding future innovations have the inconvenient characteristic that by their very nature they are not easy to test. It is hard to make sure beforehand whether certain technical barriers will be overcome, or whether customers will adopt a new product. If we were to only act when we are completely sure, there would be no innovation. In fact, some SST researchers have argued from a methodological point of view that such expectations are socially constructed and that we should abandon the idea that objective standards can be found by which they can be compared and evaluated. On the other hand, in practice it would be unwise to categorically ignore any considerations with respect to plausibility or implausibility. There is no point in engaging in completely unrealistic endeavours.

It is precisely the fact that they are so hard to test which makes expectations prone to wishful thinking. Technicians may be prone to excessive enthusiasm concerning what they can achieve. Technical fascination may draw attention away from considering social desirability. Focus on technology can

also lead to unquestioned assumptions of idealised users of the new technology, and to a disregard of the ways real users might use it and what consequences that would have. There have been numerous occasions in the past when experts made immense claims about the potential of certain technologies that, when scrutinised, seemed unwarranted and totally overoptimistic, even taking into account the knowledge available at that time. The consequences of such expectations were sometimes disastrous, or at the very least, they seriously misguided the setting of research priorities. We will just briefly treat one example (see Brown, 2003 for other examples of such 'hypes'). In the 1960s, there were many attempts to build large management information systems that should contain any information relevant to the organisation in question. A manager should have all information, statistics and decision programs at his/her disposal that would be relevant to any decision (s)he would have to make. Rather than starting with experiments with small modules of limited scope, management information systems were designed from a blueprint for an overall system. As a result, these systems never worked – not even in part, because the parts were not conceived such that they could function independently. It took quite some time, and numerous fruitless efforts, before it was realised and accepted that such projects were utterly overambitious, and the term 'management information systems' was changed into the more modest 'management support systems'.

This strongly suggests that, even though up to some point, high expectations are indispensable in innovation, it is also imperative to recognise that such expectations are often intertwined with hidden desires. Technicians may be enticed by the technical fascination of a certain project rather than the feasibility of its promised results; overoptimistic prospects may also be propagated as a means to increase research funding possibilities. Politicians may fancy shiny projects with vast suggested societal benefits as a way to give their constituency the impression that they are actively handling its problems. Companies may be eager not to miss an opportunity, especially when development costs can partly be shifted to governments or other actors. Consumers may be taken in by promises for a better life, which are attractive to believe, and the technical details of which they cannot evaluate by themselves. Often, all actors involved have reasons for indulging in unrealistic assumptions, leading into entanglements like the tragedy of the commons and other social dilemmas ('systems of subliminal enticement' (Birrer, 2000)).

The case we will describe in this article concerns the plans for a national Electronic Health Record system in the Netherlands. This is called a system innovation since it will impact the health care system as a whole, even radi-

cially so, particularly in some of the visions around. While focusing on expectations, our case will be somewhat different from most of what is described in the 'expectations' literature, which usually describes the emergence and development of one particular set of expectations guiding the development of a new technology. In our case, there are two sets of expectations that are to a large extent competing with each other. As for the technology, some small-scale experiments have been undertaken, but an actual Dutch national Electronic Health Record does not yet exist. We will focus on the expectations themselves, rather than on the global political dynamics, of which we are still uncertain where they will lead.

From a constructivist point of view, it might be argued that expectations cannot be evaluated as being realistic or not (cf. Borup et al., 2006, p. 288-289). In this paper, we use a more indirect way to consider expectations, namely by investigating whether or not certain clusters of expectations are substantially defended against relevant counterarguments. Expectations that are not defended in such a way we will call 'immoderate'. We will show that in our case such 'immoderate' expectations can be identified. Sometimes they are even embedded in such broad idealised socio-political perspectives that they get utopian traits.

We use the case of the planning of the Dutch Electronic Health Record to study such 'immoderate' expectations. In a frequently quoted report, commissioned by the then-minister of healthcare<sup>8</sup> (liberal conservative), the CEO of the Dutch telephone provider (KPN) called for regarding the Electronic Health Record and other eHealth projects as radical innovations (Scheepbouwer, 2006). The law that is to regulate the functioning of this record is ultimately to be adopted by parliament. Considering the fact that expectations appear to be crucial here, the first set of empirical materials that we analysed consists of documents that passed through parliament and (could have) influenced decision-making. Obviously, this includes numerous studies and statements by other relevant players, such as the institute that was mandated to prepare the Dutch EHR, as well as medical chambers. We focused on documents that articulate expectations regarding the role that an EHR could play in transforming healthcare, and particularly those that related this to the technical infrastructure. In particular, we have focused on the dynamics of standardisation, even though the expectations that underlie these standards often do not 'reach' parliament. This is in itself an interesting phenomenon, considering that standardisation is usually considered as one of the options for government to advance (or obstruct) innovation (King et al., 1994). We

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<sup>8</sup> By minister of healthcare, we refer to the Minister of Public Health, Wellbeing and Sports.

discuss the assumptions and expectations that are implicitly endorsed by adopting a particular standard. In total, about 150 documents from the period 1994–2009 were surveyed. All documents were coded in two steps: first, we marked any expectations that were voiced, and second, we recoded them according to the main ‘categories’ of expectations that we found. As a second step, we reviewed the existing literature that discussed the type of expectations that we found in the parliamentary documents. We took particular notice of articles that contested these expectations. As such, we consider these articles as empirical material from the Electronic Health Record discourse, in the same way as we consider parliamentary documents. Considering our definition of moderateness, we discuss three major expectations and their underlying assumptions. We then move on to discuss contested issues, showing also that these play only a minor role in the Dutch political debate. We end with a discussion and conclusions.

## Expectations of the Dutch EHR and underlying assumptions

Even though we would go too far by arguing that the Electronic Health Record is expected to bring about a full-fledged utopia, the EHR discourse does have strong utopian characteristics (Gregory, 2000a; Tully & Cantrill, 2005). Most of the immoderate discourse with reference to the Dutch Electronic Health Record is connected to the Public Health Council (RVZ in Dutch), as well as to a group around the above-mentioned ENV 13606 and related openEHR standards. With respect to the latter: proponents of these standards have explicitly argued for a ‘utopian era’ for ICT in healthcare which, in 2005, was expected from 2010 onwards; this era was characterized as reaching ‘the holy grail, that is, the universal solution for the electronic healthcare record’ (Rossi Mori & Freriks, 2005).

### *First expectation: Increase of cost efficiency and quality of health care*

The basic expectation regarding the role that the Dutch Electronic Health Record is supposed to play is that it will increase (cost) efficiency and quality of care provision. The general argument may be summarised as that automation will lead to cost containment, without compromising the quality of care. This has been clear since the foundational study by the Public Health Council (RVZ, 1996), and has been repeated by every minister of healthcare since. Ever

since a 2003 study of medical information errors for the minister (TNS NIPO, 2003), the major expectation has been that the replacement of a paper-based record by an electronic record will prohibit human errors from occurring. This is what Gregory (Gregory, 2000a) has described as the clinical dimension of utopias around the EHR. Apart from increasing patient safety, it is expected to reduce the (financial) costs that these errors cause to society, as a second report brought forward (TNS NIPO, 2004a). Similarly, the then-minister (Christian democrat) expected the costs of repeated medical procedures to be reduced by automation (TK, 2008/2009a). Academic papers have also voiced the expectation that a fully standardised health record could lead to dramatic cuts in healthcare expenditure, estimated at an annual \$ 77.8 billion for the US only (Walker et al., 2005). For the Netherlands, only the direct costs of medical information errors were estimated to amount to an annual € 1.5 billion (TNS NIPO, 2004a). The Dutch expectation is mainly based on the technical infrastructure that the HL7 standard would enable, considering that this was the imagined standard at the time of the medical information errors study. The focus on cost-containment relates to one of the topics of traditional utopias, i.e. labour. Commissioned by the then-minister (liberal conservative), the CEO of Dutch telecom provider KPN argued that the EHR would play a key role in reducing scarcity on the labour market (Scheepbouwer, 2006). eHealth technologies – amongst which the EHR is shared by the Public Health Council (RVZ, 2002a) – are expected to be able to replace human labour to some extent (RVZ, 2002b). By reducing administrative weight, the then-minister (Christian democrat) expected medical labour productivity to increase, and more time to be available for personal contact with patients (Ministerie van VWS, 2007a). In addition to this, the Public Health Council expected that medical tasks could be delegated to the patient directly (RVZ, 2002a) by the use of information technology. A second, indirect effect that is worth mentioning in relation to labour is that the quality of care, which the EHR is expected to increase, is thought to lead to a healthier population and, therefore, to less exclusion from the labour market, as voiced in the study about medical information mistakes for the ministry (TNS NIPO, 2004a).

#### *Second expectation: Macro use of data*

A second expectation that we identified concerns the role that the EHR is imagined to play in the macro-level management of public health. This involves the 'secondary use' of medical data (Berg & Goorman, 1999; Berg, 1999). Gre-

gory (Gregory, 2000a) calls this the managerial dimension of utopian EHR projects. From the mid 1990s onward, different topical macro-problems have dominated the discourse on the necessity of restructuration, ranging from the then-minister's (social liberal) concern about waiting lists and waiting times for getting medical treatment (TK, 1997/1998b), to questions by MP's about early identification of epidemics and large-scale poisoning (TK, 2000/2001d) and the Public Health Council's proposal for calculating medical norms to be used for decision-support (RVZ, 2005b). Apart from such concrete macro-level challenges, the Council proposed to use the EHR for 'monitoring quality, business coordination, management support, research and statistics and education and policy'<sup>9</sup> (RVZ, 1996, p. 70), to eventually produce 'ultimate strategic management information'. Also evidence-based medicine has been a long-standing objective for them (RVZ, 1996; RVZ, 2002b). Applying EHR data to macro-level challenges requires broad comparison of anonymized data that was generated on the basis of individual patient cases. Following Michel Foucault's (1977) analysis of Jeremy Bentham's model of the panoptical prison, it is common for utopias to continuously observe the totality of the community and all its details with the objective of maintaining discipline (Achterhuis, 1998). The council is fairly precise in describing the type of information that would have to be gathered. In terms of the population, structured storage of data is the method of choice, whereas it is deemed relevant to store highly detailed information on the medical life of individual patients, up to 'a patient's meal' (RVZ, 1996, p. 77). In fact, the institute that was responsible for preparing the Dutch EHR made a distinction between storing individual patient data in natural language and translating it to coded data for secondary use (NICTIZ, 2002a). This brings the discussion back to the issue of standardisation. In fact, the objective of macro-level management was the major argument for the 2005 advice of the Public Health Council to adopt the 13606 standard (RVZ, 2005b). The notion of macro-level management brings up a more controversial element of utopias (or dystopias, according to some): subjecting the individual to the community. Despite an emphasis on balancing the general interest and the interest of the individual patient, potential conflicts of interests were identified at an early stage already by the council (RVZ, 1996). For instance, structured gathering of patient data is not necessarily in the interest of the individual physician (and patient), whereas it is deemed to be in the general interest. The discussion on the notion of a patient-held healthcare chip card was an interesting case in this respect. When discussing the need for a patient to be physically present in order to use data

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<sup>9</sup> All translations of Dutch quotations are ours.

for secondary purposes, the Public Health Council argued that: 'for the protection of the privacy of the patient this is of great importance, but for anonymized epidemiological research it forms a major restriction and can thus harm the general interest' (RVZ, 1996, p. 97). The council then argued that privacy regulations were often too restrictive to serve the general interest.

*Third expectation: Transition from supply-driven to demand-driven care*

A third and final expectation of the EHR is that it will contribute to the transition from a supply-driven to a demand-driven care system. The council assumed that, if provided with adequate information, the patient will take up the role of a critical, demanding customer in the healthcare system (RVZ, 2003a). Even though this may seem to be at odds with the earlier-mentioned subjection of the individual to the general interest, we attempt to show here that this is not the case. I.e., the role of the patient as a critical consumer is partially created to serve the general interest of the health system, by holding 'the supply-side' accountable for bad work. Recalling the earlier-mentioned focus on labour, another traditional dystopian/utopian theme comes up: 'purification' (Achterhuis, 1998). Even though the notion of purification has taken a much more destructive form in (partially) realised dystopias, it is interesting to see how the notion of accountability is positioned to 'clean up' the healthcare system. Since the 1970s, the medical institution has often been portrayed as imposing a major threat to our health (Illich, 1976). Increased accountability of doctors to patients is provided as a means of solving this problem. Generally, the notion of demanding more from the patient and giving him/her more responsibilities is also echoed in what the Public Health Council has called 'good patientship' (RVZ, 2007). Starting in 1998, the Council was commissioned to perform a number of studies on this topic, leading to advices such as Towards More Demand-Driven Care (RVZ, 1998a), Between Market and Government (RVZ, 1998b) and From Patient to Customer (RVZ, 2003a). Even though these are not exclusively aimed at the EHR, the health record is named as a precondition for achieving this. Other studies address patient empowerment as an explicit objective of eHealth and the EHR (RVZ, 2002b). Offering a patient-managed health record would give the patient easier access to second opinions (RVZ, 2003a) and enable the patient to have more equal relations to physicians. In spite of these discussions, only at the beginning of 2009 did the then-minister (Christian democrat) request the National IT Institute for Healthcare to propose a design for patient access,

after having been prompted by MPS (TK, 2008/2009e). In order to achieve this, again, the difference between standards is considered crucial. To be able to access patient-centred records, it is considered essential to store medical information in the same way everywhere; the openEHR approach is considered superior to the HL7 approach in this sense (Garde et al., 2007). The much-referenced structured data storage relates to Gregory's (2000a) technical dimension of EHR utopias. Because of this, the Public Health Council recommended the use of a patient-centred record on the basis of the 13606 standard (RVZ, 2005b). In this respect, it is relevant to note that HL7 is moving towards an architecture standard (Garde et al., 2005; Oemig & Blobel, 2005), 'heavily influenced by CEN ENV 13606, openEHR' (Dolin et al., 2006, p. 34).

### *The persistence of expectations*

It seems reasonable to point out that the Public Health Council has explicitly stated that many of the expectations of medical computing that arose in the 1950s and 1960s have not been realised. In spite of that, we have shown that the Council has been one of the main bodies to introduce high expectations from the 1990s onward. It is interesting, therefore, to note their reply to the expectations that were voiced in earlier decades:

'The technology is not the problem in this respect. The current PC that nearly everyone has on their desk is much more powerful than the main-frame computers of the 1960s that filled up an entire room. The problems are rather related to medical content, such as the lack of a communis opinio on, for instance, the (analyses of) facts, standardisations, etc.' (RVZ, 2001, p. 32).

In other words, not meeting expectations has not been due to the expectations themselves, or to the technology, but to 'social factors' like lack of agreement in the field. In this respect, Kaplan's remark seems to give a sharp, albeit somewhat cynical, account:

'When their utopian hopes seemed to have failed, medical computer experts reacted like other 'true believers' (Hoffer 1951). Rather than experiencing cognitive dissonance by abandoning their idea of computer as panacea, medical computer experts shifted their specific goals, thus changing the revolution's precise nature. When the millennium in medi-

cine failed to materialize, they maintained the idea of a computer revolution while changing its characteristics' (Kaplan, 1995, p. 29).

Gregory would argue that this is not necessarily problematic, however. She states that '[p]ersistence of belief – in a concept, a design idea, a theory, or an hypothesis for discovery – is crucially important for sustaining scientific practice and technological invention' (2000a, p. 198). From the point of view of innovation as a strategic, yet feasible effort, this point of view can be questioned. On the other hand, particularly for information technology, it is true that attempts to innovate often only work out in a second attempt, such as in the case of Web 2.0.

We take up the two main elements of the Public Health Council's comment for the remainder of this paper: on the one hand, the (partial) non-technical nature of addressing the expectations of the Electronic Health Record, and on the other hand, the expectation of the role of technical standardisation in this.

## Contested issues in the international literature

In this section, we summarize a number of contested issues from the international literature that directly relate to the three expectations described above. Despite their relevance to EHR projects, they either received no attention at all in the discussion on the Dutch EHR project, or the counterarguments were simply not answered.

We will start with two issues which relate to the feasibility of certain EHR approaches as a whole. First, expectations are based on the assumption of 'ideal users'. Physicians are assumed to process medical information in such a way that it suits the creation of a 'container EHR' that allows for secondary use. Similarly, it is assumed that, given 'perfect information', the 'good patient' will operate as a critical consumer, as an ideal user. Second, it is assumed that information can be decontextualised for the purposes of: (i) being centred on the patient and (ii) secondary (macro-level) use. Then we briefly review some additional aspects that were already touched upon in the first two sections. As a third aspect, we discuss the assumption that automation makes medical processes more (cost) efficient; technology is thought to: (i) (partially) replace human labour, (ii) reduce the need for repeated medical procedures, and (iii) enable the transfer of medical tasks to the patient. The fourth and final point is the idea that automation improves the quality of care

by reducing human error, which in turn is assumed to lead to positive externalities on the labour market.

### *Ideal users*

It is well-known that changing work processes tends to be a hard job. Not only have actors developed routines over time that they are unlikely to change, but in addition, these routines constitute a social system (Giddens, 1984). Garfinkel's study of 'Good Organizational Reasons for Bad Clinical Records' is a much-quoted argument that illustrates this point (see e.g. Freeman, 2002). Therefore, even if we assume that work processes can be changed, one should not underestimate the efforts of actors to minimise those elements of working with EHRS that (are perceived to) obstruct their work.

The literature shows many instances of strategic behaviour that results in going around the original intention of the system (Pinelle & Gutwin, 2006; Winthereik et al., 2007). In addition, it appears quite common for medical staff members to keep on using 'shadow' paper records, next to their electronic ones (Saleem et al., 2009). Some physicians are in fact reported to boycott EHR systems (Kaplan, 2001). In this respect, it is important to note the massive objections that physicians have made against the use of their own data in the Dutch EHR (Katzenbauer, 2009).

A second instance of assuming 'ideal users' lies in the idea that, given the 'perfect information' that an EHR would provide, patients will show 'good patientship' and will form principal-agent relations with respect to their care providers. Often, such notions as 'patient centeredness' are reduced to clichés (Berg, 2002). One of the arguments given in favour of the assumption of the 'good patient' is that providing better information on the quality of different care providers will spur well-informed choice. Berg, however, argues that providing all available medical information to the patient will rather lead to overload and will require the interference of family doctors as 'information brokers' (Berg, 2002). In other words, the market does not work effectively in such cases. Currently, information is not produced for the patient, but for fellow physicians.

### *Decontextualisation*

As Berg & Goorman have argued, 'medical information is essentially bound to the context of its production. Even the highly standardized laboratory data that figure in every hospital record cannot be read without knowledge of that particular hospital's normal values' (1999, p. 58). Not being aware of the context of a medical act is still thought by many authors to potentially lead to wrong interpretations by other physicians (Pantazi et al., 2006; Son et al., 2008). Many authors build specifically on the argument of Berg & Goorman (Ellingsen & Monteiro, 2003; Kaplan, 2001; Williams, 2005). Some authors are very explicit in arguing that 'interpretation of imprecision is highly contextual, and, furthermore, that medical data cannot be decoupled from their meanings and their intended usage' (Kwiatkowska et al., 2009, p. 351).

However, as is already implicitly argued in such statements, as well as in De Mul & Berg's research on incompleteness (de Mul & Berg, 2007), the question what the information is needed for is crucial here. Coleman concludes that '[t]he need for translation of physician orders can be handled by computer systems. The challenge of effective communication and interpretation cannot' (2004, p. 282).

The main problem, however, seems to occur when information is supposed to be used for 'secondary purposes', as explained in the second expectation that was mentioned in the previous section (macro-level management), and to some extent in the third as well (patient-centeredness). Even though Berg & Goorman (1999) do not argue that such secondary use is fundamentally impossible, they do question the uncritical assumption that information technology can easily enable this.

Some authors have developed approaches to address this problem. A few, in fact, use Berg & Goorman's (1999) argument concerning the problematic nature of decontextualisation as an argument to work on better standards and interoperability (van Ginneken, 2002; Weng et al., 2007). In many cases, the notion of context-dependency in terms of digitalising medical information is presented as a problem related to a different generation of health record systems. A key element in most utopias is the notion of making a radical break with the past. In terms of new starts, it is relevant to note the thinking – by virtually all the major actors in the Dutch discourse – in terms of eras that are thought to end with the introduction of the EHR: the paper era that is followed by the digital era or the information era (NICTIZ, 2006b; TK, 1995/1996; RVZ, 2002b), the data-processing and the IT era that are followed by the network era (Ministerie van VWS, 2002), the pre-eHealth era (RVZ,

2002a) and finally the pre-internet era, and even the Web 2.0 era that are to be overcome by the Web 3.0 era (Ottes & Van Rijen, 2008). The 'utopian era' has already been mentioned (Rossi Mori & Freriks, 2005). Some debate legacy systems, the presence of which clearly makes a new start problematic. Particularly the Dutch 13606 group strongly argues for breaking with the existing infrastructure. The institute that is responsible for preparing the EHR, by contrast, distinctly intends to maintain legacy systems (NICTIZ, 2002a).

Some argue that the presence of 'classical systems' stands in the way of recent, more promising developments (Tange et al., 1997) in terms of transferring contextual knowledge. Essentially, this is the main argument of the ENV13606 group with respect to their criticism of the HL7 standard. The systems that Tange et al. propose, however, are radically different from the current proposals in Dutch EHR implementation, as we will see below. Others present the generational difference in terms of outdated theories of information processing (Pantazi et al., 2006). All in all, this seems to suggest that there is a potential future for sharing context-dependent medical data in the sense of the topic of this paper. Therefore, numerous authors suggest numerous ways of designing approaches to map context more effectively (Pantazi et al., 2006; Son et al., 2008; Tange et al., 1997). By now, there have indeed been some careful suggestions that the openEHR standard is probably able to contribute to 'multi-centred clinical research' on the basis of routinely collected data (Garde et al., 2005). In a later paper, however, Garde et al. argue that even though openEHR 'can provide the common basis for ubiquitous presence of meaningful and computer-processable knowledge and information', it 'cannot overcome all barriers to Ubiquitous Computing' (Garde et al., 2007, p. 334).

A radically different approach to the storing and sharing of medical data is the notion of 'medical narratives'. Tange et al. conclude that 'it is widely accepted that medical narratives are best presented in natural prose' (Tange et al., 1997, p. 24), a notion that is supported by others as well (Pantazi et al., 2004). They do, however, see possibilities for creating such natural prose out of previously encoded data; computer software would translate such codes into natural language. Clearly, such a form would be an intermediate between work with coded and non-coded data. In spite of that, however, the basic manner of storing data is still coded. As such, the latter approach is not necessarily at odds with the approach suggested by the ENV13606 network. Even though the medical narrative approach is not referred to explicitly, the approach is comparable to what Pantazi et al. (2004) have described as Case-

Based Reasoning (CBR) in medical informatics. Here too, however, it is explicitly stated that the approach is still highly experimental.

At the very least, it looks like the debate on decontextualisation in general, and for secondary purposes in particular, has not yet been completed. In spite of this, many governments, including the Dutch government, have committed to an approach (HL7) that is strongly criticised for this very reason. It is still questionable to what extent the major alternative (ENV13606/openEHR) can deal with these issues.

### *Cost-efficiency by automation*

The previous considerations implied serious doubts on the feasibility of more ambitious implementations of an EHR system, which by definition impinge on cost-efficiency. Berg stresses that it often takes years for ICT investments to start producing financial benefits in healthcare, and in many cases there is no gain at all (Berg, 2002). To this effect, Berg & Goorman have formulated a much-quoted new law of medical information, which states that '[t]he further information has to be able to circulate (i.e. the more different contexts it has to be usable in) the more work is required to disentangle the information from the context of its production' (Berg & Goorman, 1999, p. 51). The argument of additional efforts because of EHR's has been pointed out many times (Goodyear-Smith et al., 2008; Pinelle & Gutwin, 2006; Tully & Cantrill, 2005; Vikkelsø, 2005). Still, the link to expectations with respect to cost-containment is hardly made, particularly when it comes to macro-economic considerations in this area.

It has been suggested that the investments that would be required to enable the hypothetical, decontextualised secondary use of medical data are considerable (Berg, 1999; Berg et al., 1998). Berg stresses the point that the benefits of such additional use of data do not fall to actors in the operational process of care delivery, but rather to those involved in research, management, insurance or policy-making. He rightly argues that the costs that would need to be met to assure such benefits should, therefore, not be placed on the primary process. In this respect, it is relevant to note that '[t]he utopia of automatic collection of data from a complete record, when this currently has to be laboriously obtained from paper records, seems to herald a new era for research. However, there is debate as whether research will really be easier with the EPR [Electronic Patient Record], or just as difficult in a different way' (Tully & Cantrill, 2005, p. 436). In this respect, one might agree with Vik-

kelsø's argument for a 'theory of distribution' to understand EHR's, rather than for a 'theory of improvement'.

### *Overcoming human errors*

An assumption that underlies the expectation of quality increase is that automation is capable of overcoming human errors. That this assumption is not self-evident has already become clear from the previous issues discussed, particularly the issue of decontextualisation. The case for regarding medical errors as a problem of human interference was put on the agenda by the American Institute of Medicine's report, entitled *To Err Is Human* (Kohn et al., 2000). Since then, improved records and new technologies have been proposed for overcoming such errors (TNS NIPO, 2003; 2004a). Contrary to affirmative cases (Mahoney et al., 2007), there are also clear examples that show that the potential of digitalisation was overestimated (Walsh et al., 2008). Even though error rates may sometimes be reduced, this does not necessarily imply a lowering of injury rates. Others have argued for increased risk due to digitalisation as well (Caudill-Slosberg & Weeks, 2005; McDonald, 2006; Ó Scolaí, 2007).

## Contested issues in the Dutch context

As already mentioned earlier, the caveats implied in the international literature summarized above hardly had any traceable impact on the discussion of the EHR plans in the Netherlands. In fact, there is only one significant exception: in 1998, the Dutch Technology Assessment Agency published a critical report (Berg et al., 1998), which discussed several of the above issues in some detail. Among them was the issue of decontextualisation and the additional efforts it would entail. If we examine the shape and style of the report, we could conclude that the authors have 'translated' the message of international academic papers into the context of the Dutch EHR debate: the document was named after a Dutch documentary, was written in Dutch and included pictures and examples.

Upon its release in 1998, the report had virtually no traceable impact on high-level discussions. Only in 2005 was the then-minister (liberal conservative) prompted by Evelien Tonkens, a then-member of parliament of the GreenLeft (GroenLinks) party, to address the importance of the narrative ele-

ment of EHRs for medical work. She was not yet in parliament when the report was first published. In a recent interview (conducted by the authors on May 10, 2010), she remembered she was prompted by two simultaneous developments. First, there was the debate around the interpretation of records in child care during court cases, for instance in relation to rulings about the outplacement of children. It appeared that, for purposes of decontextualisation, recorded data had been standardised to such an extent that judges could no longer interpret it. During interactions with physicians, Tonkens heard similar stories about attempts to decontextualise medical data. The second motivation was the reading of James C. Scott's *Seeing Like a State* (Scott, 1998), in which similar issues were analysed.

The minister replied to Tonkens's question as follows:

'The report [...] concludes that gathered information should remain in its original context for supporting the primary process. I subscribe to that thought. However, the developments in the field of chain-integrated and multidisciplinary care place high demands on record-creation. After all, care providers other than the concerned record-keeper also need to be able to understand the context and deal with this information. The need for care information to circulate has an impact on the design of healthcare records. Agreements as well as international guidelines and standards in the field of records have become necessary. However, there will be space for free text for personal use or for sharing this with others' (TK, 2004/2005b).

How can we interpret this reply? First of all, there is a discrepancy between arguing against decontextualisation in the first two sentences and the following statement that it is necessary and inevitable nevertheless. Second, by stating that there will be space for free text for personal or shared usage, the minister partially undermines his earlier stress on the need to share data: (i) we have seen that physicians use their personal notes as 'workarounds' for electronic records, and (ii) the minister previously argued that the natural language of free text is inadequately structured to enable proper sharing.

Unsurprisingly, this issue was not developed further. Tonkens argues that this is mostly due to the perception by political fractions of an issue like this in comparison to other, more politically pressing ones. In the field of healthcare, there are often cases with 'lethal consequences', which take the attention away from seemingly technical issues like this one. This is even stronger if we take into consideration that Tonkens has a background as an

academic researcher, and was therefore familiar with the reports and studies that were mentioned above, contrary to her fellow MPs.

## Discussion and conclusions

Berg and others (1998) have argued against the much-heard criticism that physicians' work processes are unstructured and unscientific. For this paper we have taken a different direction. Even though it seems that the authors have rightfully pointed out that such criticism is often based on a misconception of the medical context in which these work processes are set, the intention of actors in the immoderate EHR discourse is to change these processes anyway.

Obviously, a vision as described in this paper implies severe consequences for the innovation process. First, immoderate expectations will not be met by delivered results, and may actually impede the innovation process because an unfeasible strategy is chosen. Not only in the Netherlands, but also in other western countries, the progress with EHRs is remarkably slow, in view of the fact that apparently its construction is viewed as relatively unproblematic. One explanation of this slowness lies in underestimated technical difficulties. Strategic considerations of various actors involved represent another potential source of delay. For instance, many physicians feel that their practice cannot be decontextualised. For this reason, or simply because they feel their position is threatened, collaboration in the medical branch may not be easy to get by. Comments by Berg and others show that current conceptions of medical records often obstruct the medical process. The same point is made in another recent collaboration of Berg that discusses EHR's as a 'meaningful audit tool' (Winthereik et al., 2007). Record keeping is an important administrative activity that is likely to place a serious burden on the primary process (Berg, 1999). Even though Berg agrees with the call for increasing accountability, he argues that '[i]n many countries, the pendulum has swung from too much discretionary space for the physician to too little' (Berg, 2002, p. 35). Therefore, accountability can bring about obstructions in the medical process.

A second consequence of such immoderate expectations in innovation is that they may lead to wishful thinking. Painting a shiny future might overshadow a critical examination of potential downsides, such as compromising privacy considerations, promoting individualisation, or introducing rigid scientific management. Utopias are known to generally have their dystopian

sides as well. One would hope that the social desirability of such utopias will receive more attention as well.

How could we improve innovation processes in these respects? How can 'unreasonable' expectations be separated from reasonable and fruitful ones? In the previous paragraphs, our purpose was not to define an infallible demarcation criterion between the two. What we have been articulating are issues from the international literature that, despite their relevance to the innovation project in question, are somehow disregarded or remain unaddressed in the general discussions on the EHR project. Within the Dutch case, there has been only one serious instance in which certain contested issues were brought into the arena of political decision-making.

If we were to question the role of expectations in innovation processes like the one we described, we might remark that the 'political' networks in which ambitious expectations are formulated are relatively disconnected from academic networks that critically assess the claims that are made. Even though it is certainly true that numerous critical issues were brought forward by members of parliament for instance, we found these to be of a different nature than the ones offered by academic scholars. Relevant notions, such as the privacy and security of the system, have occupied parliamentary discussions for years, whereas questions we described as 'contested issues' were barely touched upon. Such issues are probably more common in the community of science & technology studies (SST) than in parliamentary circles. On top of that, when a translation from one network to the other did take place, its impact was negligible.

This brings us to the background of different actors that are involved in assessing expectations. For instance, it seems right to assume that Berg & Goorman differ from other authors in medical informatics, by taking a Computer-Supported Collaborative Work (CSCW) perspective:

'In medical informatics, design is seen as a matter of construing a functional technology, and implementation as a matter of gearing the organisation to use the technology optimally. In contrast, the CSCW tradition argues that it is primarily the technology which has to fit work practices' (Vikkelsø, 2005, p. 24).

The latter point of view seems to be echoed in the 1998 report, which we discussed in the previous section. In the case of Evelien Tonkens, her background in academic research enabled her to draw new arguments into the discussion, but at the same time, it did not help her to convince her col-

leagues of the importance of the issue, in view of other developments that were – perhaps understandably – perceived to be more pressing<sup>10</sup>.

Finally, what does all this tell us about subjectivation? Or, to be a bit more specific, what do the above-mentioned critiques mean in relation to the earlier discussion of the neoliberal subject? As said in the introduction to this chapter, there are two ways in which I want to examine this issue. First of all, there is the issue of implications for the way in which care receivers are constituted. If certain expectations with regards to technology-enabled practices and relations turn out differently after implementation, subjectivation is likely to change as well. In this respect, a number of remarks are important here. First of all, the frequent criticism of the idea of ideal users puts serious pressure on all the relations in which the neoliberal subject is assumed to be framed. This already starts with the notion of rational, self-interested and competitive interaction between individuals. Individuals may simply not act this way. Care receivers may not hold their patients accountable because of the data that they receive through an electronic health record, or because of ‘function oriented description’ techniques. In a sense, this is the simplest and most destructive critique of neoliberalism, or on other governmentnalities that are based on purposeful subjectivations. Similar problems arise in relation to other relations of reciprocity – to the population, to government – but these are somewhat less tangible. If we look at the argument around the possibilities of decontextualisation, the relation between individual and collective is put under greater pressure. If data cannot easily be taken out of context, it will be considerably harder to use it for serving macro-level objectives. Likewise, it will be hard to use aggregate norms for serving individual patients. If such technical parameters fail, the grand narrative of competition as an overall beneficial organising construct is also likely to falter. Finally, if digitalisation does not result in overcoming medical mistakes and errors, the impact of the EHR on the health of the population might turn out lower than expected, if there is a positive impact at all. In such a scenario, innovation will hardly make neoliberal subjects more productive.

Also from the point of view of the macro-actor that certain politicians and standard-makers are trying to construct, in line with neoliberal thought, such shaky expectations are rather problematic. I have tried to show that not only the human elements of the macro-actors, but also the (micro-)scripts of the mediating technologies involved are likely to work differently. This does not mean that the whole idea of having a macro-actor becomes meaningless.

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<sup>10</sup> The remained of this chapter is not part of the published article

We can certainly imagine that the impact of a particular institution – as the unification of a network – acts in a particular way on a system such as healthcare. However, it is likely that such macro-agency will turn out quite differently than expected. At this stage, it is hard to predict how this will be. Again, the recent refusal by the Dutch Senate will certainly leave its marks. Moreover, we have to take into consideration that, if we take a macro-actor view seriously, that it is by far not as internally consistent as expected. The assumption that all the goals and action-programmes of the different actants would 'point in the same direction' is most likely wrong.

On the basis of the analysis of this chapter, it is hard to comment on the second subjectivating notion of failing expectations: political and societal expectations of the proclaimed subject. What will reactions be if it turns out that patients will not operate according to the promises of neoliberal subjectivity? In order to get a grip on this question, I turn to another pro-innovation policy in the next chapter: the introduction of a personal healthcare budget. The main reason for this is that, contrary to the electronic health record, it *was* introduced already. This makes it considerably easier to take such reactions into consideration.

