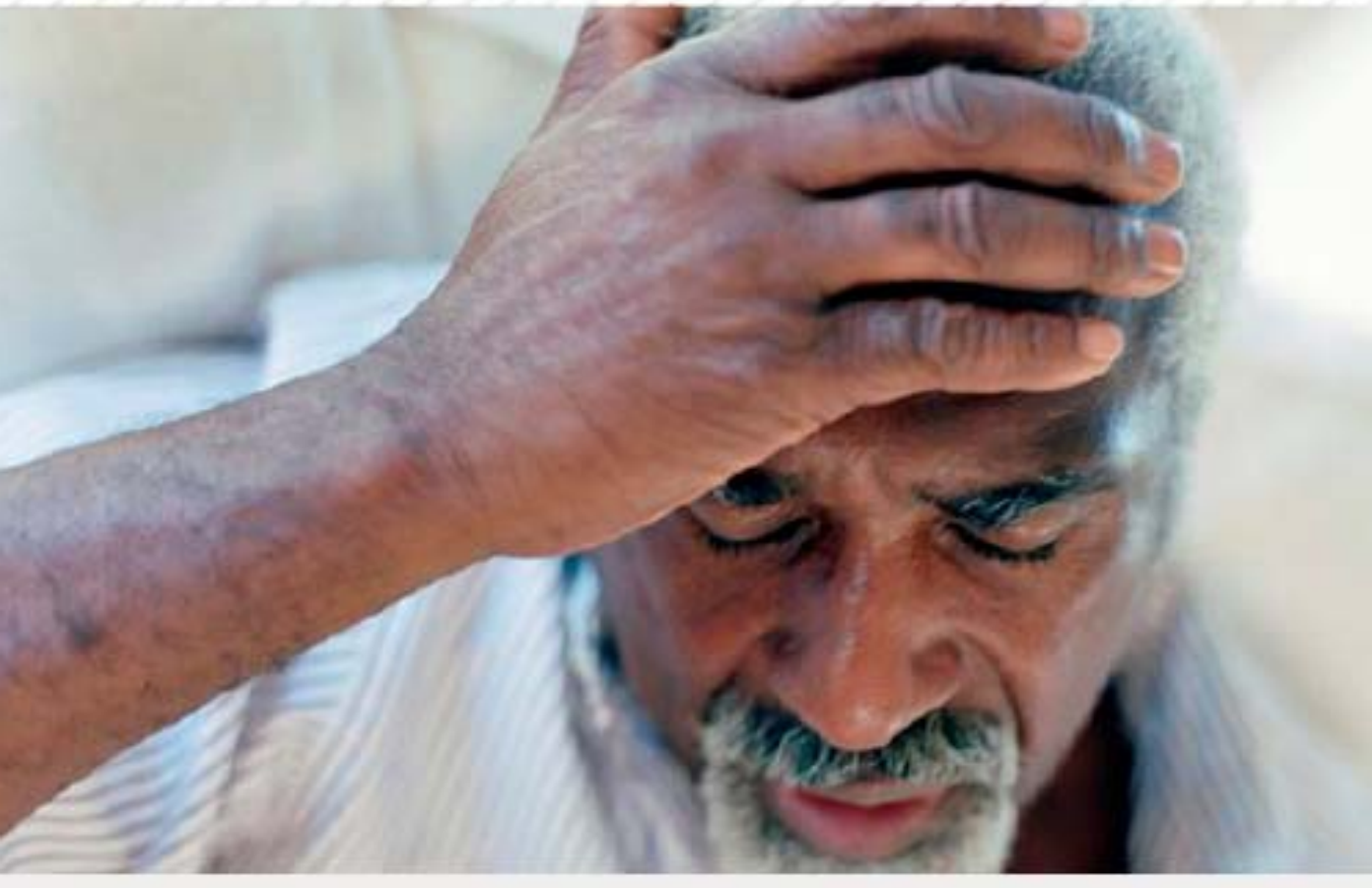
Technology Assessment

Ambient Intelligence

Viable future or dangerous illusion?



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Preface

Ambient Intelligence is an influential vision of the future in which people interact with a digital environment almost as naturally as they communicate with one another. Computers smaller than a postage stamp offer the prospect of a world where the focus is on people rather than technology. As well as bringing convenience and comfort, Ambient Intelligence could also revolutionize the way we look after our health, by providing a basis for personalized health care that is automated wherever possible and desirable.

For the Rathenau Institute, vision development and exploration is a valuable tool for studying the social impact of science and technology. As Werner Siemens said, ‘He who has a vision has a future.’ Siemens grasped that having a vision enables one to move forward with a sense of direction. Ambient Intelligence is a vision with implications for every aspect of daily life. However, it is of course important to consider how realistic a vision it is. Back in 1998, the Rathenau Institute made the point that the digitalization of health information would imply a redefinition of powers and responsibilities. Thus far, this has indeed proved to be a major obstacle to the introduction of electronic medical records.

Ambient Intelligence builds upon the digitalization of health information, but is broader in its visionary scope. Ambient Intelligence envisages not only that we have access to health information wherever and whenever we wish, but also that appropriate health care services are available everywhere. It is a vision that ties in with the idea that individual citizens should have more say in the health care they receive. As such, the Ambient Intelligence vision is very much in line with prevailing thinking on the future of health care.

Nevertheless, it is clear from the content of this report that the use of Ambient Intelligence has potential drawbacks as well as benefits. The report presents a number of case histories and future scenarios, based on the findings of a joint exploratory study by the Telematics Institute (presently: Novay) and the Rathenau Institute. These case histories and scenarios highlight potential obstacles to the use of intelligent health care technologies. The automation of health care services depends upon patients having the competences needed to operate intelligent health care equipment. Furthermore, the health information required to customize health care could also be used by other stakeholders to advance their own interests.

The question at hand is how conflicts of interest may be avoided and whether the promise that patient interest remains central can be kept if Ambient Intelligence is indeed to be the future of health care. Since none of the stakeholders can individually determine what will happen, it is necessary to have a shared vision of how Ambient Intelligence should be employed in practice. For the development of such a vision, all the relevant parties need to engage in debate. This report is intended as the starting point for such a debate.

Jan Staman
Director of the Rathenau Institute

Summary

It is impossible to imagine life today without the computer. We are surrounded by mobile computers that are becoming increasingly smaller, more powerful and more multifunctional. What's more they can increasingly communicate with each other. *Ambient Intelligence* is a future vision on the use of the latest generation of computers. Ambient Intelligence promises that technology will disappear into the background and the *user* will take center stage.

Modern healthcare is also inconceivable without the use of computers. For example, a lot of attention is currently being devoted to the digitization of healthcare information in electronic patient files (EPF). Ambient Intelligence, however, goes a step further. It strives for automated care services at any chosen place at any given time. Over the next few years 'smart environments' will be developed to measure and manage the health of individuals. Smart technology should, for example, enable us to manage our health and possible limitations at home and independently in so far as this is possible. Comfort and optimal ease of use are key aspects of this.

Future of care or concern of the future?

Ambient Intelligence has heightened the discussion about the future of healthcare. In the Ambient Intelligence vision, health care becomes *personalized healthcare:* care that is carefully matched to the person and, where possible, fully automated. Yet Ambient Intelligence alone is not enough to provide personalized healthcare. Always being able to provide individualized care for everyone will require parties in the *care network* around the individual exchanging detailed information about his or her health. Whether that is in the interest of the person concerned depends on which parties gain access to this privacy-sensitive information and for which purposes they may use this. This question is now proving to be a stumbling block for the introduction of electronic patient files (EPF) and this will be no less the case for the use of Ambient Intelligence.

For this study interviews were held with the most important parties from the healthcare sector: care providers, a health insurer, researchers, the Care Insurance Board (CVZ), the Ministry of Health, Welfare and Sport (VWS) and representatives from industry. These parties will all make use of the detailed health information that Ambient Intelligence provides. More importantly, a number of these parties will *have* to have access to this information in order to realize the most important promise

of Ambient Intelligence: the ‘personalization’ of care services. However this gives rise to more possibilities for granting people selective access to care. Further patients and citizens can be more easily directed and influenced in their decisions about their health. In a nutshell: the formation of networks is essential for the personalization of care, yet it is also the biggest threat to it.

Need to debate

Collective agreements are needed to ensure that Ambient Intelligence becomes the *future of care* and not the *concern of the future*. That requires an understanding of the possibilities and problems that the use of Ambient Intelligence will elicit.
With the study *Ambient Intelligence: Viable future of dangerous illusion?* the Rathenau Institute wants to initiate the discussion about these collective agreements. To this end a description is given of Ambient Intelligence and how, in the vision of Ambient Intelligence, smart care technology will be used for our health. The main question continues to be how we can assess this vision in practice and which discussion points this raises.

The Ambient Intelligence vision

Ambient Intelligence literally means that people are surrounded by intelligent equipment. A smart environment not only knows that people are present but also who, and with what characteristics, needs, emotions and intentions. That is made possible by computers and sensors that – continuously or periodically – measure our physical functions, such as our blood pressure, muscle tension, heart rhythm or sugar level. Technology is becoming increasingly smaller and can, in principle, be incorporated anywhere: in appliances, in walls, in clothes or in our body. A smart environment can automatically respond to changing conditions, can give the user advice or transmit a signal to a contact person. An example is a sensor which observes that an elderly person falls, after which a care provider is automatically warned.

Five layers of intelligence

The founding fathers of ambient intelligence are Emile Aarts and Stefano Marzano (Philips). In 2003, they identified five ways in which the environment can be intelligent. Each successive layer builds on the previous one. With this an increasing number of aspects are automated.

1 Embedding

The equipment is incorporated in the person’s environment in such a way that he scarcely notices it (physical embedding) and he can communicate with it in a ‘natural’ manner (social embedding). An example is sensors in sports shoes that provide the

user with information about the distance he has covered and the calories he has used.

2 Context-awareness

The technology links characteristics of the person to characteristics of the environment. An example is a sensor on the body of a heart patient that warns him if he starts to climb too high in the mountains.

3 Personalization

On the basis of a personal profile, the equipment can be adjusted to the needs of the user. An example is a sensor on the body of a person who wants to lose weight and which advises whether or not he can consume certain foods.

4 Adaptation

The technology automatically responds to changing conditions. An example is equipment on the body of a patient that automatically administers drugs if the situation demands this.

5 Anticipation

The technology responds to environmental factors to prevent problems arising An example is a ‘smart plaster’ that measures UV radiation and warns the person if he has been in the sun for too long and risks becoming sunburned.

Smart view: a vision for intelligent care technology

The basic premise of Ambient Intelligence is that the technology disappears into the background and people take center stage. This study discusses the possibilities Ambient Intelligence can provide in this respect for each layer. A View has been developed for this analysis to assess the vision in practice. As well as considering the care functions (see above) that Ambient Intelligence offers, the study also examines which normative questions play a role in this and the extent to which these care functions can be automated. Cases are used to provide examples from current care practice. Existing bottlenecks are discussed, as equally which demands are not sufficiently met at present. Subsequently scenarios are used to show which problems a ‘smart environment’ can solve, but also which questions and points of interest it raises.

The View reveals that as an environment becomes smarter, we increasingly enter the field of human norms and the possible infringement of these. The step from measuring physical functions to performing an intervention requires an interpretation of the health information. Decisions must be correct, prudent and taken at the right moment. Yet who determines when that is the case? Who programs that? Different needs and interests often need to be weighed up against each other in healthcare.

Examples are the costs and benefits of a treatment or the possible side effects of a drug versus the alleviation of pain. These are issues that the smart environment cannot take over from us, or at least not before we have taken a prior decision.

Therefore, when forming an opinion about Ambient Intelligence it is not enough - as often happens now - to highlight the fact that the developments follow on from trends that are already taking place in healthcare. That is because Ambient Intelligence can also *enhance* these trends. And is this indeed desirable? How much care do we want to transfer from institutes to the residential environment of individuals? As care becomes further decentralized, individuals are increasingly dependent on self-care. Yet can you expect everyone to be able to cope with this technology? Which parties will gain access to which health information? And what are they allowed to do with this? To what extent can you expect people to give up their privacy? How are the interests of citizens and patients on the one hand weighed up against those of professional parties on the other? May an increasingly higher price be attached to unhealthy behavior?

All of these issues are basically related to the identity of ‘the user’: patients, but also others who are confronted with the limits of their health. In fact, there are *several* users, with different interests. Even if the term ‘the user’ refers to the individual citizen or patient, it still needs to be asked to what extent they really will take center stage if Ambient Intelligence is introduced into healthcare.

First move to debate: a powerplay with health information

The successful introduction of Ambient Intelligence makes demands on how healthcare is organized. This study from the Rathenau Institute is a first step towards a debate between the different parties in healthcare about this. It is important that care providers and industry ensure the standardization of network security, and draw up protocols for access to detailed medical data and the storage of these. Further a strict medical regime must be developed for intelligent medication and guidelines must be developed for intervention at a distance.

All of these points require a collective approach. Citizens have an important say in this. The question as to how we want to deal with our health, not only refers to setting conditions but also to making a choice about the future of care. In the current arena, the government has an important role to play. A government that takes on too much responsibility for healthcare, risks a policy that is focused on efficiency in order to keep down the costs. However, if the government increasingly shifts the responsibility

for care functions to the citizen, it hands over care and welfare to market forces that it cannot direct. This could lead to key responsibilities of the government coming under fire: guaranteeing equal access to care, maintaining the quality of care and keeping the costs within reasonable limits for citizens and patients.

Contents

1 Background

Just imagine: computers smaller than postage stamps. You can have them anywhere: in every room of your home, in the hems of your clothes, in the soles of your shoes. And they can make life easier in countless different ways. At home and at work, enhancing your leisure time and helping to protect your health: intelligent surroundings that know where you are and what you want. Around the world, billions are being invested into a range of technologies which have the potential to influence the individual, community, culture and economy – in fact, every aspect of human life. But what kind of future may we expect? And will the further miniaturization of computer technology actually make the world a better place? With a view to answering these questions, this report explores a vision of the future that is helping to shape thinking in this field: the Ambient Intelligence vision.

The Ambient Intelligence vision foresees a world in which people live in intelligent surroundings, based upon the latest computer technology. These computers not only know when people are present, but also who they are, what they are like, how they feel, what they want and what they intend to do. Consequently, these intelligent surroundings can respond to, and even anticipate, people's wishes and needs. Ambient Intelligence implies something more than a setting full of 'smart' devices; it implies the presence of intelligence everywhere: it implies social embedding of the latest generation of computers to improve our quality of life. The computer – whether in the form of your laptop or the chip in your mobile phone – is already an integral part of everyday life. However, today's equipment can also be inconvenient or difficult to use and may even impinge on your privacy. But the Ambient Intelligence vision is of a world where people, rather than technology, take centre stage. The vision foresees technology that, while remaining largely inconspicuous, adapts, often automatically, to the user's needs.

Ambient Intelligence: viable future…?

In this report we are concerned with one important application for Ambient Intelligence: health care. Ambient Intelligence could provide a basis for integrating intelligent health care technology into an individual's personal surroundings. Computers around you, on your body and even in your body could monitor your health status at all times and, when the need arose, alert your carer or intervene directly. In this way, vital action could be taken sooner or the need for hospital visits

avoided. In the context of e-health and telemedicine investment programmes, people are already busy experimenting with such systems.

…or dangerous illusion?

Developments in the health care sector are being shaped by the move towards personalized health care: a form of provision that is not supply-driven, but patient-centred and demand-driven. Ambient Intelligence is seen as having the potential to add significant momentum to this movement. But it is important to consider to what extent the potential of Ambient Intelligence will translate into actual benefit for the individual patient. Our health is looked after in the context of a complex process of social interaction, involving professional health care practitioners, lay carers, health insurers, regulators, producers and governmental bodies. It would therefore be premature to assume that the personal needs and preferences of patients will always take precedence.

Ambient Intelligence generates great optimism, but our exploration of the subject highlights a number of paradoxes: the very scope that Ambient Intelligence creates for the personalization of health care services could in fact prove a threat to personalization. Ambient Intelligence promises greater independence for the elderly, yet could also aggravate their isolation. Ambient Intelligence may enable patients to play a greater role in looking after their own health, but will they actually profit, or does it involve a redistribution of costs that does not necessarily benefit the patient? Ambient Intelligence can open the way for the personalization of health care, but when does personalized access *to* health care become selective exclusion *from* health care? In other words, Ambient Intelligence brings the debate on the future of health care into sharp focus.

Ambient Intelligence as a topic of debate

The possible drawbacks identified above do not by themselves justify attempting to halt or even slow the development of Ambient Intelligence; the potential benefits are too numerous. Nevertheless, the good intentions of technology developers are no guarantee that undesirable situations will not arise. The central problem is that the provision of customized health care depends on the availability of detailed information about the patient's health, but the application of such information introduces certain conflicts of interest. Under such circumstances, the patient is not necessarily the beneficiary. Since it is the actors in the health care sector who will settle any conflicts that arise, it is important that they agree on the principles that should govern the use of Ambient Intelligence. The patient's voice especially needs to be heard. But as health care becomes more personalized, it becomes harder for any one party to

dictate what form it should take. If in the future we are able to monitor and regulate physical functions at all times, wherever we are, there will be implications for the way we approach health and welfare issues, individually and collectively.

This report therefore begins by examining Ambient Intelligence's potential as a medium for the delivery of personalized (i.e. patient-centred) health care. We then consider the *collective* arrangements necessary to make such health care possible. To this end, we have carried out a literature study and interviewed representatives of the main stakeholder groups. As part of our introduction, we also clarify the demarcation lines between the fields of study. Ambient Intelligence represents the confluence of two key developments: the emergence of a new generation of computers (section 1.1) and the shift towards personalized health care (section 1.2). The final section of this chapter, section 1.3, defines the questions addressed by our study and describes the content and structure of this report.

1.1 The development of the computer

The first computers were created in the 1940s.[1] In the 1960s and '70s, during the first phase of the computer's evolution, only big businesses and institutions had computers, which were of the kind known subsequently as 'mainframe computers'. The arrival of the personal computer (PC) in the 1980s ushered in the second evolutionary phase, in which computers became available to everyone. The 1990s were characterized by three technological developments that came to touch upon most people's lives: the introduction of user-centred interfaces, the integration of computers into everyday appliances, and the growth of wireless communication. Running parallel to these developments was the rise of the Internet. By the early 1990s, commentators in the USA were already talking about this combination of circumstances as marking a third phase in the evolution of the computer.

The computer in the 21st century

One of the best known proponents of the third phase of the evolution of the computer is Mark Weisser. Weisser was scientific manager of the Xerox Palo Alto Research Center (PARC) in 1991 and introduced the concept of ubiquitous computing. He put forward a scenario for the 21st century in which computers were all around us, in domestic appliances and everyday objects, at home and on the move, surrounding us, on our bodies and even in our bodies. Furthermore he suggested that all these computers, some of them invisible, would be able to communicate with one another:

> *'Long term, the PC and workstation will wither because computing access will be everywhere: in the walls, on wrists, and in 'scrap computers' (like scrap paper) lying about, to be grabbed as needed.'*[2]

Third-generation computers have since appeared in various domains. There are cars that shake the driver awake if he or she closes his/her eyes for too long, cameras that sound an alarm if they record suspect behaviour. It is possible to use sensors to continuously monitor a worker's muscle tension, with a view to preventing RSI, or to have the lighting levels, sounds, and smells in a workplace automatically adjusted to maintain an optimal setting.

The third generation of computers promises to be of particular significance for the health and welfare sector. This is partly because of the way our society is developing: the population is increasingly aging, people are remaining active later into life, citizens are increasingly self-assertive and everyone is encouraged to remain as independent as possible for as long as possible. Third-generation computers can play a role in all of these developments.

Criticism and concern

The evolution of the computer involves the combination of various technical innovations. Information and communication technology (ICT) plays a key role in the ongoing integration of nanotechnology, biotechnology, ICT and cognitive science: the so-called NBIC convergence. The driving force behind this convergence is ICT, a field characterized by ever greater miniaturization, opening the way for innovations such as the combination of technology with biological material. Such developments make it possible for scientists to collect and use information about the body and to draw upon new insights gained in the cognitive sciences. For example, 'wet chips' could be implanted in the body to enable paraplegics to move their limbs again.

However, not everyone is equally optimistic about where such developments may be taking us. In contrast to Weisser's upbeat, visionary predictions, others have expressed grave reservations about the course of 'progress'. In 2000, Bill Joy, editor-in-chief of *Wired*, wrote an article that created quite a stir. One passage of the article read:

> *'We are being propelled into this [21st] century with no plan, no control, no brakes. Have we already gone too far down the path to alter course? I don't believe so, but we aren't trying yet and the last chance to assert control is rapidly approaching.'*[3]

In view of the impact that new technologies can have on our lives, Joy argued that it was important to exercise control over their further development. It is of course

impossible to exercise complete control over technological development. However, in technology, as in health care, prevention is better than cure. Critical reflection on the future these developments promise us is an important step in the right direction.

Health status information, wherever and whenever you want it?

This study takes a critical look at the considerable potential that the new generation of computers have for monitoring and managing individual health. In Europe, Ambient Intelligence has been embraced as a vision of computer evolution.

The concept of Ambient Intelligence, first developed by Emile Aarts at Philips, foregrounds the natural interaction between humans and technology .[4] It envisions an intelligent environment that not only knows when people are present, but is also aware of who they are, what they are like, how they feel, what they want and what they intend to do. Consequently, the intelligent surroundings can respond to, and even anticipate, people's wishes and needs. What is more, the underlying technology works 'invisibly', without the user intentionally doing anything. Such technology has enormous potential for the automation of health care services. Hence, the literature on Ambient Intelligence identifies the health care sector as an important field of application.

1.2 Ambient Intelligence and developments in health care

The Ambient Intelligence vision ties in with recent developments in the field of health care, in particular the movement towards personalized health care. The notion of a world where the individual is at the centre of technological development perfectly complements the health care-sector vision of patient-centred service provision. Figure 1 illustrates how Ambient Intelligence can help to make customized health care possible at any given location, by enabling the creation of a network of health care professionals and mobile health care services.[5] The introduction of electronic medical records (EMRs) assumes straightforward arrangements for the exchange of detailed medical information.

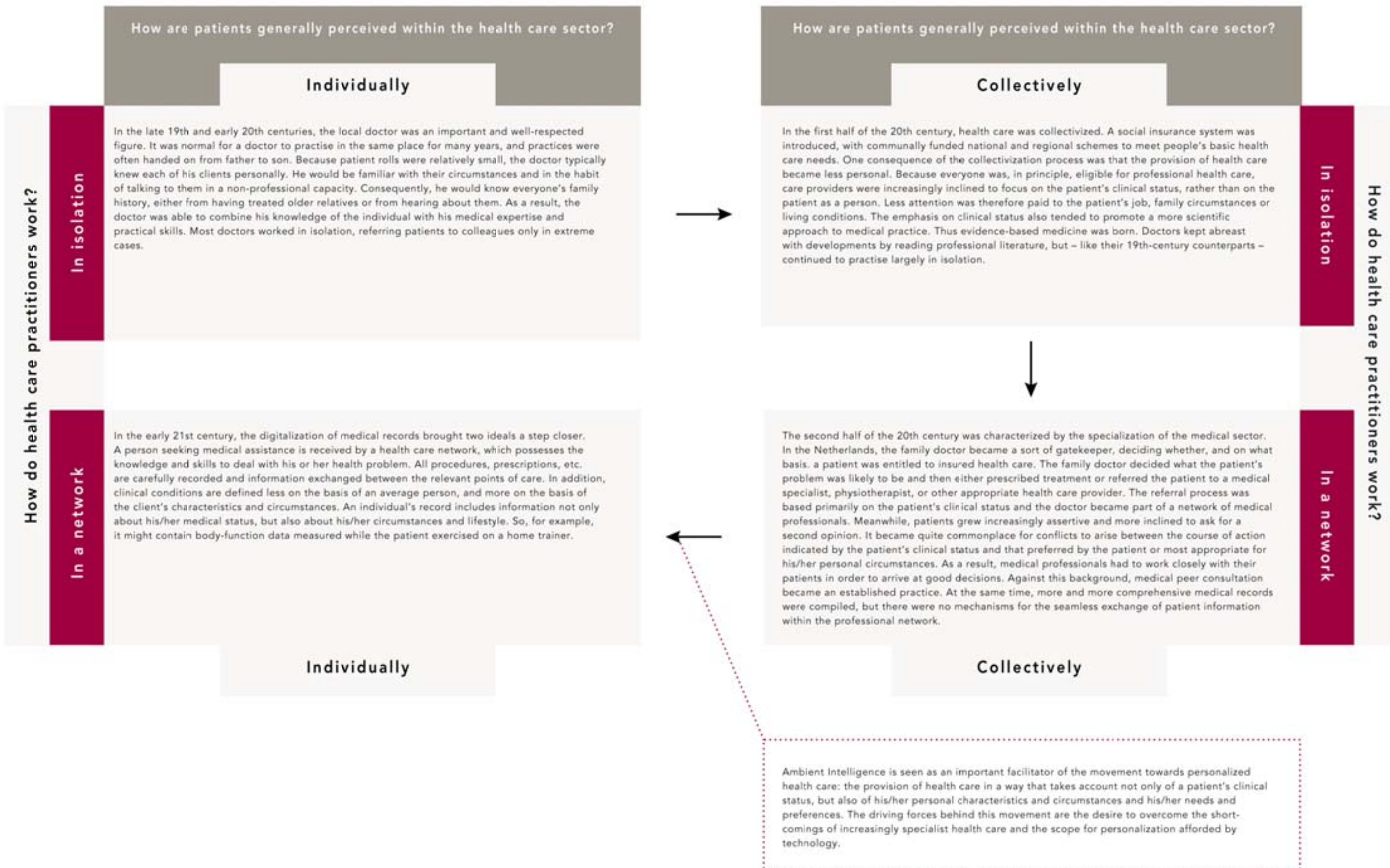
Scientific and technological progress in the medical sector has a significant bearing on what is possible in terms of the organization of health care. As figure 1 shows, any organizational model adopted for the health care sector has its drawbacks. The adoption of a collective supply model, for example, has made a high degree of specialization possible. This in turn has had implications for the powers and

responsibilities of medical professionals, who no longer operate separately. The drawback of this approach, which is focused on the patient's medical condition, is that individuals are not viewed in the context of their social setting. Furthermore, the collection of information begins afresh, as it were, at each *point of care* (i.e. the point where patient and health care professional meet). A network of health care practitioners is needed in order to retain a medical overview of a patient's status, yet the ability to take appropriate action is compromised by the difficulties involved in exchanging medical data amongst the professionals.

The Ambient Intelligence vision envisages the resolution of both issues through the application of intelligent health care technology. Information about a patient's clinical status can be supplemented by details of his/her personal circumstances and made available wherever and whenever it is needed. Thus, the future of health care would appear bright. In practice, however, things often prove less straightforward than expected. Our individual and communal approach to health care, health and welfare is influenced by more general developments such as population ageing. Key health care sector actors, such as the government, health insurers and industry, adapt their policies to such developments. As a result, the organization of health care involves the balancing of individual and collective interests. Ambient Intelligence can have a major influence on the balance that is achieved, but is itself also dependent on that balance for its success.

Figure 1: The developing landscape of health care
Following the arrows clockwise around the figure below, we can see how the organization of health care changed in the Netherlands in the period from the late 19th to the early 21st century. At the start of this period, personalized health care was the norm, with each patient being treated on the basis of his or her individual characteristics. However, the introduction of a collective health care system led to the patient's clinical condition becoming the chief determinant of health care, and thus paved the way for the formation of a network of health care practitioners. Ambient Intelligence could make it possible to combine the benefits of the collective system with an individualized and patient-centred approach.

Figure 1 The developing landscape of health care



1.3 Scope and structure of this report

Ambient Intelligence offers considerable scope for the provision of health and welfare services that meet clients' individual needs. With this report, the Rathenau Institute seeks to lay down the basis for a debate regarding the collective arrangements that need to be made in this context. The structure of the report is outlined below.

The Ambient Intelligence vision (chapter 2)

The phrase 'Ambient Intelligence' may be interpreted in various ways. In the vision put forward by Philips, one of the pioneers of the concept, there are five levels of Intelligence. Each level is characterized by the new functions that are introduced or integrated into existing (health care) functions. Being function-based, the Philips vision does not provide a context for critical reflection on the social, community, political and moral issues associated with the use of intelligent health care technology. In chapter 2, we therefore explain what we consider Ambient Intelligence to be and present an analytical framework and tool for the assessment of its practical applications.

Part II: Case histories and future scenarios (chapters 3-7)

Five case histories and future scenarios form the main body of this study. Based on interviews and a literature study, they illustrate stakeholders' expectations of intelligent health care technology. Each of the chapters 3 to 7 deals with one level of intelligence. The case histories and scenarios are used to explore what the use of Ambient Intelligence might mean in practice. What benefits could Ambient Intelligence bring to the various health care domains? And what new issues might the use of Ambient Intelligence introduce? Any reader who wishes to focus on the outcomes, without the detailed analysis, can jump to the final section of each of these chapters.

Part III: Analysis and debate (chapters 8-11)

In Part III, we collate the findings presented in the earlier chapters and consider how Ambient Intelligence may influence developments in health care.

Implications for roles within the health care sector (chapter 8)

Within the health care sector, important roles are played by a variety of actors, including the Ministry of Health, Welfare and Sports (VWS), health care practitioners,

the health care industry, health insurers and the Health Care Insurance Board (CVZ). How is the diffusion of Ambient Intelligence likely to impinge on the field of force created by these players? How will the various actors respond to the ubiquity of individualized health information on demand? And what will that mean for the individual citizen or patient: will he/she become the focal point of the health care process? With a view to formulating answers to these questions, we have interviewed representatives of the stakeholder groups referred to above.[6]

Ambient Intelligence and trends in health care (chapter 9)

Within the health care sector, three important trends are apparent. First, we are seeing the increasing decentralization of health care and the growth of self-care. This implies greater acceptance of personal responsibility. Second, more emphasis is being placed on prevention and comfort. Third, the boundary between making ill people better (therapy) and improving healthy people (human enhancement) is shifting all the time.[7] Chapter 9 examines the significance of Ambient Intelligence in relation to these trends. What scope will intelligent surroundings provide for the individual to monitor and influence his/her health at all times, even when he/she is feeling perfectly well? How comfortable will life be in intelligent health care surroundings?

Ambient Intelligence and the future of health care (chapter 10)

Chapter 10 sets out our conclusions regarding the main challenge that Ambient Intelligence creates for the health care sector: how to collectively organize yet also individualize the provision of services. Consultation amongst the relevant parties is necessary if Ambient Intelligence is to be integrated into daily life and into the health care system in a socially acceptable way.

A starting point for debate (chapter 11)

Chapter 11 is intended to set in motion the debate that we believe is necessary regarding Ambient Intelligence. Using the ongoing debate regarding ICT in health care as our starting point, we present a road map for addressing the central problems associated with Ambient Intelligence, as identified in the case histories and scenarios. In developing this road map, we have taken into account not only the technological developments (as one might expect), but also the needs of the various stakeholders and the collective criteria and administrative arrangements required for fulfilment of those needs.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2 What is Ambient Intelligence?

The Ambient Intelligence vision is a vision of everyday life in the future. This is apparent from the title of the book in which Aarts and Stefano Marzano introduced the concept: *The New Everyday* (2003). Intelligent surroundings promise to bring us comfort and convenience and generally enrich our lives. By harnessing the potential of the latest generation of computers, Ambient Intelligence can increase our individual capacity to organize our lives and make us less reliant on other individuals or on bodies such as health care providers or government agencies. As a result, we should be able to go on living independently in our own homes for longer, even if we have physical and mental ailments. In short, Ambient Intelligence has the ability to revolutionize the way we approach issues of health and welfare.

It is envisaged that the latest generation of computers will enter our daily lives in five stages. At each level, our surroundings will become a little more intelligent, until the point is reached where they automatically anticipate our needs (section 2.1). This will depend on the formulation of increasingly detailed personal profiles (section 2.2). The use of Ambient Intelligence raises a wide variety of social, communal, political and moral issues. Who will instigate the changes? To what extent is it desirable to measure and manage the health and welfare of individuals using Ambient Intelligence? In Part II, the assessment tool described in section 2.3 is used to analyse the potential of Ambient Intelligence by reference to five specimen cases from the fields of health care and welfare.

2.1 The five levels of Ambient Intelligence

Using technology to make our homes, workplaces and the places we frequent socially intelligent: according to the Ambient Intelligence vision, this is the great challenge for the near future. It is envisaged that the physical obstacles to the use of such technology will be removed one at a time.[8] Aarts and Marzano foresee optimal adaptation of the surroundings to the individual being realized on five levels, each involving further automation:

Integration	Equipment is invisibly integrated into your surroundings.
Context awareness	The surroundings recognize you and your particular circumstances.
Personalization	Services are tailored to your needs and preferences.
Adaptation	The surroundings adapt automatically to your needs.
Anticipation	The surroundings automatically anticipate your needs.

Integration

Technology that is largely invisible but present everywhere, with which users interact naturally: that, in a nutshell, is the goal of intelligent technology integration. We are increasingly surrounded by computers, chips and sensors at home, in public spaces, in shops and at work. As they become smaller, it becomes easier to integrate them into all sorts of things and places: walls, objects and clothing can all accommodate the new technology. However, it does not end there: devices can also be placed inside the human body. Biosensors can measure physical parameters, such as our skin resistance, heart rate, blood sugar level or heat emission while running. The physical integration of intelligence is accompanied by its social integration, provided that the mode of operation is user-friendly. Operation may in some instances be manual, or may use more sophisticated systems, such as voice recognition or sensors that are, say, integrated into running shoes and feed calorie consumption data to an iPod.

Context awareness

Once our surroundings, with their embedded technology, are intelligent enough to automatically link personal parameters with environmental parameters, they may be considered to possess context awareness. For example, such awareness might entail a computer knowing that a person is at home and has an irregular heart rate, very high muscular tension, or that he or she is showing other medically significant symptoms. Computers, chips and sensors are everywhere and increasingly interlinked; they form a system.

Personalization

While personalization involves the automatic monitoring of a person's physical functions, the matching of health care services to his or her specific needs is still conducted manually (either by a health care practitioner or by the individual concerned).[9] The individual’s needs are recorded in a static user profile. The technology then needs to be flexible enough to be adjusted to dynamic

circumstances: changes of location, changes in the health status of the person, and so on. This requires manual revision of the user profile, since it cannot be changed automatically. Manual revision allows for recommendations and warnings to be given, such as: 'You should take more medication, otherwise ...' The patient can then decide whether to follow the advice.

Adaptation

Once the adaptation level is reached, the computer becomes an actor in the health care process: the intelligent surroundings independently undertake action on the basis of observed physical parameters. Where appropriate, the user's profile is also automatically revised.[10] An example of dynamic adaptation is given in chapter 6. Medication is automatically given to a cancer patient, and the dose is automatically adjusted. To this end, the health care practitioner and patient have to define the boundaries within which adaptations are permissible. Adaptation means that an individual is less consciously involved in the complex of interactions: between his/her body and the technology (parameter measurement), between different technological devices (communication) and between the technology and the health care practitioner (decision making).

Anticipation

With anticipation, the fifth and final level of the vision, the intelligent surroundings undertake action before a health problem arises. For example, IMEC[11] has developed an intelligent patch that measures UV radiation and warns when it is time to move to the shade, in order to avoid sunburn and the possibility of skin cancer. In other words, anticipation implies an element of prediction. Whereas adaptation involves the technology making adjustments on the basis of observations, anticipation involves adjustment on the basis of predicted changes in the body and/or in the person's surroundings.

2.2 The importance of user profiles

At all five levels of intelligence, user profiles play a key role. A user profile is a personal data record, which not only identifies the individual, but also facilitates file linkage and the exchange of information amongst databanks. A patient's user profile will contain at the very least, his/her unique public service number.

User profiles can vary in their scope and the extent to which they contain privacy-sensitive information. A profile may, for example, contain information about health problems or risks (allergies, susceptibility to heart failure, etc), data on medication

use or insurance details. A profile may also define roles and rights, e.g. whether a patient, health care practitioner, insurer or other party is entitled to access sections of an electronic medical record. In other words, a user profile can be used to regulate access to health care.

2.3 An assessment tool for intelligent health care technology

The Ambient Intelligence vision creates the expectation of a future in which technology will be less conspicuous and processes will become user-centred. With a view to determining the extent to which this scenario is possible and desirable, we have developed an assessment tool, which is used in Part II to analyse the use of intelligent surroundings in the context of various health care procedures.

As far as the Ambient Intelligence vision is concerned, the central question is what technical functions and services are provided by intelligent surroundings that can add to, or be integrated with, those already in place. However the use of intelligent surroundings also raises various normative questions, which are relevant for the assessment of Ambient Intelligence. Finally, it is important to consider what we can expect from computers in terms of automation of the way health and welfare issues are dealt with. Hence, the assessment tool focuses on three areas, as described below.[12]

Functions and relationships

This assessment area ties in with the Ambient Intelligence vision described in section 2.1. A skin patch, for example, can serve as a memory chip, transmitter and/or receiver (additional functions). If the patch were combined with a sensor inside the body that measures a critical physical parameter, such as heart valve function,[13] the user could be kept informed about how his/her heart valves are functioning (integration of functions).

Normative questions

Ambient Intelligence does more than merely introduce new functionality to the life of citizens or patients. It has the potential to improve the setting in which they live, providing greater comfort, anticipating events, making technology more user-friendly, adapting to the user, and thus enhancing quality of life. In other words, Ambient Intelligence is relevant in terms of efficiency, functional effectiveness and values. assumption is that it can enable people to live independently for longer and lead more fulfilling lives, that it can make existing therapies less unpleasant, and so on.

In the Ambient Intelligence vision, the ‘users’ of the technology are generally ordinary members of the public (‘citizens’), patients and consumers. However, health care practitioners, health insurers, government agencies and other such parties may also wish to make use of health information regarding an individual yielded by intelligent surroundings. Such use is not necessarily in the patient’s interest. This introduces all sorts of normative questions concerning matters such as access to or exclusion from health care, greater independence versus new forms of dependency and social isolation, the quality of health care, self-care versus behavioural control, privacy, patients under medical supervision versus health care consumers, and the balance between the benefits that Ambient Intelligence brings to citizens/patients and what intelligent surroundings ask of them. For example, do citizens and patients have the skills needed to make use of intelligent health care technologies?

Automation

The further we progress in the Ambient Intelligent vision, from the integration level to the anticipation level, the more we expect of the technology. Each successive level involves further automation, starting with the monitoring of physical parameters, progressing to the exchange of health information, and ultimately resulting in a situation where intelligent surroundings automatically anticipate potential health problems. Any assessment associated with this vision needs to consider whether it is realistic to expect intelligent technological surroundings to make sensible decisions on our behalf. If it is realistic, what does that imply for human input into health care processes? If not, where does that leave Ambient Intelligence? Who will decide when and how intelligent surroundings intervene in our lives? Are there limits to how far we can or should go with the automation of processes related to health, welfare and comfort? These questions are considered more closely in the following chapters.

Part II Case histories and future scenarios

In this part of the report we use a series of case histories and scenarios to explore the scope that Ambient Intelligence offers for making various health care processes more user-centred (see figure 2). We consider how Ambient Intelligence may be used to assist people of all ages with ailments whether stable or unstable, physical or psychological, acute or chronic, treatable or terminal. Each of the chapters 3 to 7 deals with one level of intelligence, using a case history to illustrate the problems that exist in current practice. The case history is followed by an analysis of the health care, welfare and comfort needs that patients and other parties have, and of the extent to which such needs are not currently provided for. We then present a scenario illustrating how Ambient Intelligence might be used to rectify the current mismatch between needs and provision.[14] Finally, each chapter uses the assessment tool referred to in chapter 2 to examine the advantages and disadvantages of the forecast situation.

Figure 2: Structure of Part II

Chapter	*Health care process*	*Level of intelligence*
3	Residential care zone	Integration
4	The hospital of the future	Context awareness
5	Paediatric physiotherapy	Personalization
6	Follow-up health care for cancer patients	Adaptation
7	Sport	Anticipation


Albert Heijn

3 The residential care zone: the embedding of intelligent health care technology

Dutch society is changing, and as it changes, what people expect in terms of the way they live, work and look after their health is also changing. By 2040, there will be four million people in the Netherlands aged 65 or older. According to the Parliamentary Committee on Policy on Older People, population ageing is a positive development indicative of a high level of medical and social provision. The committee argues that we should take more account of the differences among older people and place more emphasis on their value to society.[15] Dutch policy makers accordingly tend to make increasing use of the term *verzilvering*, rather than *vergrijzing*; although both words can be translated as 'population ageing', the former has positive connotations and suggests the enrichment of society.

Regardless of the terminology used, population ageing is an issue that affects and demands change from society as a whole. Taking more account of the differences among older people – such as in their physical, financial and social self-sufficiency – implies greater variation in the corresponding social adaptations. The principle of using technological support to enable older people with functional ailments to go on living safely and comfortably in their own homes for longer, is of increasing importance. One expression of this principle is the development of so-called 'residential care zones'.

Structure of this chapter

This chapter deals with the integration of health care functions and services into our homes and the places we frequent. At present, such integration is often difficult to achieve, as we will see from the case of Mrs P (section 3.1). Quite a number of Mrs P's main needs are not currently being met (section 3.2). The Ambient Intelligence vision foresees health care functions being invisibly integrated into our homes and the places we frequent (section 3.3). In line with this vision, we present a scenario involving John and his daughter Mina, who are untroubled by some of the problems encountered by Mrs P, because of the intelligent integration of health care technology into their surroundings (section 3.4). Finally, we reflect on the associated normative

issues and on the extent to which health management can be automated (section 3.5).

What is a residential care zone?

A residential health care zone is a place with special facilities for older people and people with disabilities, which enable them to go on living independently for longer. The expectation is that if independent living is facilitated, social structures are more likely to remain intact and less hospitalization will be required. Various neighbourhoods in the Netherlands are already experimenting with the concept, with local organizations and actors taking responsibility for setting up the zones.[16]

A residential care zone provides various key services related to housing, care, transport and welfare.[17] The zone's homes are designed to remain suitable for people in the later phases of life and round-the-clock care is made available within the locality, with a view to enhancing safety and removing barriers.[18] Every zone has a local store or post office and its own health care support unit, which has a coordinatory function: if a local resident's personal alarm sounds, it is the health care support unit that initially responds.

3.1 Case history: The night Mrs P disappeared

A typical case is that of Mrs P, who is 85 years old and finding it increasingly difficult to live on her own. To help her cope, the Home Care Service provides Mrs P with various technological aids.

Despite her advanced age and having been widowed some time ago, Mrs P continues to live in her own home. However the point is ultimately reached where Mrs P finds the house too big and too much work. An additional problem is that she has become rather forgetful. It is therefore decided that she should move to a special flat, where a warden is on hand to keep an eye on things and check each morning that Mrs P is up and about. Fortunately, Mrs P can take some of her own things to the new smaller and more manageable home.

The Home Care Service has given Mrs P an alarm system: a wrist band with an alarm button and specially adapted phone. The system means that she can summon help from the Home Care Service at the press of a button – a boon if she falls and is unable to get up again on her own. Whenever a carer drops by, Mrs P is wearing the wristband. Unbeknownst to her carers, however, Mrs P takes it off when no one else is around, because she thinks it is a nuisance.

Mrs P no longer cooks for herself, because she is liable to forget that she has left things cooking or leave the gas on when she has finished. To make sure no more dangerous situations arise, the gas supply to the flat has been turned off. A meals-on-wheels service now caters for Mrs P. In case she wants a cup of tea or a boiled egg, Mrs P is given a small electric hot plate. Unfortunately, after a lifetime of gas cooking, she can't get on with this new gadget, which sometimes 'won't work' (because she hasn't plugged it in) or 'doesn't turn off' (because she hasn't flicked the switch). The unhappy relationship comes to an end when Mrs P burns her hand on the hot plate (there being no warning light to say it is hot) and the device is taken away, to be replaced by an electric kettle. She likes the kettle better because it turns itself off when the water has boiled and has a light to say when it is on.

As time goes by, Mrs P loses her grasp of the difference between day and night. She regularly sets off to the shops with her trolley late at night. Sometimes her neighbours notice and intervene, but on other occasions she has had to be brought home by the police (complaining that all she wanted was to do her shopping, but had found everything shut for some strange reason).

And so the flat in the housing complex for older people also ceases to be appropriate for Mrs P and she is moved to a care home. At the home she has her own room, but everything is done for her: her food and drink are prepared by the staff and housekeepers come in to clean her room. Mrs P is also washed by a carer. Otherwise, she seems to be free to lead her own life, although if she goes out at night she can be followed on camera. But the night nurse can't monitor the video all the time…

One night, Mrs P disappears. She decides to go for a coffee with her son because she hasn't seen him for a long time. Finding the long walk tiring, she decides to flag down a car and ask for a lift. To this end, she tries to climb a bank to reach a main road, but falls and breaks her glasses. A passing motorist sees her lying beside the road and calls an ambulance. By pure good fortune, a member of the ambulance crew is one of her son's in-laws; otherwise it would have been very difficult to identify her and find out where she belonged.

Back at the care home, staff devise the following strategy to prevent further problems. They use a patch to stick a chip to Mrs P's back, which triggers an alarm if she leaves the home at night. However, Mrs P is sharp enough to work out that she can get out undetected by using the staff entrance, where there is no sensor. Even locking the staff entrance whenever possible can't keep her in: she manages to get the chip off

her back and slip through the visitors' entrance when no one is looking. As a result, it track her down.

Right up to the time of Mrs P's death, no adequate solution to her nocturnal wanderings has been found.

(Source: MEE, the South-Holland South Disability Support Organization)

The above case history shows that the integration of support technology into current practice is far from straightforward. Mrs P's ailments affect her in various ways. She finds it increasingly difficult to manage in her own home; she can no longer cook for herself; she develops increasing symptoms of dementia and loses her sense of day and night.

Technological progress cannot entirely make up for her physical and mental deterioration. Despite being provided with more and more practical aids, Mrs P can do less and less for herself. Her dementia turns the gas hob into a hazard. The gas hob is replaced with an electric hot plate, which in turn is replaced by an electric kettle. Mrs P can use the kettle easily enough, but is limited to making tea; she can't cook herself an egg anymore. On balance, Mrs P can do fewer and fewer things for herself.

The one additional automated function that is provided is a personal alarm but that is not properly integrated, either physically or socially. Mrs P does not accept the alarm, thus demonstrating her vitality and independence. She regards the alarm as an infringement of her freedom of movement, which she is determined to defend. The things that Mrs P can no longer do are done for her by other people, not by technology. As time goes by, Mrs P receives more and more social support, from the housing scheme warden, the Home Care Service, the meals-on-wheels service and so on.

To what extent is Mrs P at the centre of the health care process? At no stage does she perceive the support that is provided as being for her benefit. Increasingly direct technological means are used to stop her from doing things for herself. Camera surveillance and a microchip are ultimately employed to prevent her leaving the home unnoticed. A situation is reached where Mrs P is no longer allowed to decide for herself when she will go out visiting. It is also debatable as to what extent Mrs P has a real say in other important decisions such as moving home(s) and disconnecting the gas. Even if all the changes take place with her consent, her quality of life and her independence are gradually eroded. At each turn, Mrs P has fewer options to choose

from, and those that are open to her are less and less attractive. In the end, her worsening dementia inevitably means that she is no longer able to decide things for herself at all.

3.2 What needs are not being properly met?

If the case described above is representative of current practice, there are considerable challenges for Ambient Intelligence to overcome. In discussions with personnel from the Southern South Holland Disability Support Organization, five needs were identified as not currently being met, or at least, not properly. Professional support is often not organized soon enough, health care services are not well integrated and health care functions are not sufficiently adaptable to patients' circumstances and wishes. Technology is often user-unfriendly and insufficient account is taken of resentment on the part of the intended user.

Prompt support

Professional support is frequently not provided soon enough because the seriousness of an individual's problems is not recognized. In dementia cases, the difficulties often arise while a person is receiving only lay care (i.e. informal care provided by relatives and/or friends). As a result, not only does the health care recipient go without appropriate care, but the lay carer is placed under undue pressure. When seeking additional professional support, lay carers often meet obstacles:

> *'(...) it took a long time to get formal support and there were various rules limiting what we were entitled to; then implementing the adaptations took a long time and was a complicated business.'*[19]

But support can sometimes be given *too* soon. If an older person is put into incontinence pants on admission to a care home, he or she will quickly become incontinent and remain so. If responsibility for doing or deciding certain things is taken away from a person, his or her capabilities will inevitably tend to deteriorate as a result. Choosing the right moment to make support available is very important if independence is to be promoted and retained.

The integration of health care services

At present, there is very little integration of the various health care services in a neighbourhood or district. There are problems with system incompatibility and – according to the Disability Support Organization – with competition and the inexperience of, for example, installation personnel. System integration implies high

levels of standardization, which in turn depend on protocols being agreed to or imposed. There is no standardization at present, as the Disability Support Organization reports:

> *'There is no switchboard that can process data from several different domotics systems. Furthermore, not everyone has Internet access at home and a lot of people still use analogue lines. As a result, compatibility problems are common. The day when everyone who needs to, can communicate easily with the support services is still a long way off.'*

Many of the technological aids currently in use may be classed as 'domotics', i.e. telematics for the home.[20] Typical applications include alarm systems, safety systems in and around the home, and systems for monitoring people and property. Some home care organizations and emergency switchboard organizations also offer supervision by CCTV, videophone or intercom. In the Rotterdam region, for example, a one-year experimental remote supervision project was organized involving 600 people with heart conditions who were put in direct contact with their doctors.[21] Another notable scheme is the *ThuiszorgOnline* (Online Home Care) scheme operated by the Netherlands Institute for Telemedicine (NITEL).[22]

The adaptability of health care functions

According to the Disability Support Organization, there is insufficient emphasis on an individual's ailments and needs. Existing technology is not varied or adaptable enough to make this possible. In the case described above, it was difficult to provide safely for Mrs P's wish to be able to boil water for tea, while also enabling her to cook an egg. But there are indications of improvements that can be made:

> *'It should be possible to develop a sort of basic package, from which a selection can be made that is appropriate to the individual case. Things should be organized so that it is easy to add forms of support to the selected package as a client's dementia progresses, and so that everything is fully coordinated. In such a dynamic setting, services and technologies need to be more adaptable.' (Disability Support Organization, 2006)*

A user-centred approach depends on the technology installer having a degree of practical insight. Health care practitioners need to know how the technology works, and also what the client's needs and capabilities are. If, for example, a client's weight needs to be checked every day, it is necessary to decide whether the client should weigh him/herself, and then call a health care practitioner, or whether the carer will call the client. In practice, some clients are reluctant to make calls while others will not answer the phone.

User-friendliness

As Mrs P's case demonstrates, the search for solutions is not always user-centred: nursing home personnel are inventive in their efforts to prevent the old lady wandering at night, but those efforts are not focused on what Mrs P perceives to be her needs. Similarly, although the Home Care Service provides Mrs P with a personal alarm, she considers this to be a nuisance, rather than a help. As soon as her carers are not looking, she takes it off. For her, the added value is non-existent.

The Southern South Holland Disability Support Organization has encountered quite a few problems with the user-friendliness of equipment that is designed both to track the position of a person and to monitor physical parameters indicative of that person's health status. That has been the case, for example, with equipment that continuously measures a client's heart rate as he or she moves from room to room:

> *'It is possible to make use of a GPS (global positioning system), but the transmission of a sufficiently strong signal requires a battery. And batteries are big, heavy, conspicuous and a nuisance to the user. Consequently, a lot of users take the things off, or don't use them properly, causing damage.' (Disability Support Organization, 2006)*

Users do not always have the skills to operate technical aids. Even changing a battery can be awkward, as anyone who has opened up a mobile phone can testify. If a client lacks the ability to handle modern gadgetry, his or her health care practitioners can record that fact in his or her user profile for future reference.

Making allowance for resistance

People who are by nature particularly curious and adaptable can take easily to modern technology. But some people are nervous or suspicious of technological aids, however helpful they may seem to others. Nervousness or suspicion are no less real for being unfounded in the eyes of others. Frequent explanation over an extended period is often needed to overcome initial aversion and get a client to accept and feel comfortable with a technological aid. Health care practitioners have an important role to play in this context. Research has shown that their input can make a big difference, but as things stand, technological aids are often explained to users only at one-off group sessions.[23]

3.3 The potential benefits of Ambient Intelligence

In the Ambient Intelligence vision, people live amid a system of computers, chips and sensors integrated into their surroundings. The expectation is that the citizen or

patient will experience the benefits of this system, but will not have the bother of operating it. Mrs P did not accept her personal alarm, perceiving it merely as a nuisance. The intelligent integration of technology into surroundings could resolve such a problem by ensuring that the benefits of such technology are provided 'invisibly', i.e. both inconspicuously and in a way that removes the need for operation or interaction. Social integration implies a situation where the interaction between people and their technological aids is more natural, more 'human' and more intuitive. Such integration may be expected to increase user-friendliness and minimize resistance.

Ambient Intelligence promises to radically improve communication between people and supporting technology as well as between technological applications. Residential care zones accommodate not only older people but also young ones, who vary enormously in terms of the support they require. Many present-day domotics applications are not sufficiently flexible to cater for such wide-ranging needs. Furthermore, they are not compatible either with one another or with emergency switchboards or the systems used by professional carers. By contrast, the Ambient Intelligence vision anticipates the full integration of health care functions and health care services and thus implies a high degree of standardization.

3.4 Future scenario: at least John can argue with his daughter

In the scenario below we explore the potential of Ambient Intelligence as a means of resolving the problems identified above. The scenario plays out seven years in the future and concentrates on the memory function support afforded to John, an older man with mild dementia and diabetes.

It is 2016. John, seventy-six, suffers from diabetes and is in the early stages of dementia. His wife Margot died last year, and he is finding it difficult to adjust to life without her. Sometimes he forgets that she is gone. His daughter Mina drops by maybe once a week. The visits mean a lot to John, who is very fond of his daughter.

Lately, John has been forgetting more things: he misses appointments; he doesn't take his medication; he leaves food cooking and he mislays his things. Mina happens to read about a new electronic gadget called My Daily Assistant (MDA). 'If you had one of those,' she says, 'you'd be all set up, dad. It stays on all the time and remembers everything for you, so you don't have to worry. What's more, if you have a fall and knock yourself out, the MDA will realize that something's up, because they fit sensors in all your rooms. You don't notice them, but they're there when you need

them. If you're in the room, but not saying anything, the MDA sends word to say you might need help. You can programme it to call my number, and if it alerts me, I'll come right away.' The idea of being in emergency contact with Mina particularly appeals to John. 'It'll be good for both of us, dad: you'll have help on hand all the time and I won't have to worry whether you're OK.' John was sold.

Since John has had his MDA, he has had fewer problems in his day-to-day activities. He can 'talk to the walls' in any room of his house, and what he says is recorded. If he tells the MDA that he has arranged to visit Mina the next day, the MDA will remind him when it is time to get ready: the walls talk back! At first, John found it all a bit strange, but now he finds a lot of the system's features really convenient. It will tell him where he has put his keys down, for example (the keys have RFID, or radio-frequency identification). He does worry, however, that when he goes out, he is on his own. At such times, he misses his wife particularly keenly. The MDA also helps John to stick to his medication regime. He has a medical patch with an embedded chip that monitors his blood glucose level. If a problem is detected, the system alerts John to the problem. If he doesn't take his medication on time, the MDA can also call in assistance. When Mina arrives to make sure everything's OK, John feels guilty about making trouble for her. 'It's no bother, really,' she says.

John has sensitive skin and the patch makes him itch. The doctor explains that, if he likes, he can have a chip implanted under his skin instead. 'It won't itch, it's more hygienic and it'll tell us more precisely how much medication you need,' the doctor proudly declares. John isn't keen on the idea, however, even if the embedded chip is paid for by his insurance. 'At least when it's on the outside I have control over it,' he says. Unfortunately though, his insurance won't go on paying for patches because they have to be replaced frequently, making them more expensive than an embedded chip in the longer term. After a vigorous debate in the media, a judge rules that insurance companies can't be expected to subsidize freedom of choice, if it is not apparent that clients use it rationally. This ruling is at odds both with the view of the liberal government of the day, and with the advice of the Health Care Insurance Board.

John starts to forget his medication more and more often. Mina sometimes has to come running three times a week after receiving a text message from the MDA. The more often she is called out on these 'emergency' visits, the harder she finds it to make time for 'proper' visits. John notices that when Mina does visit, she is increasingly businesslike, although he is at his most lucid. 'How are things going, Dad? Is there anything else I can arrange for you? All you have to do is ask.' When John says that he feels as though someone is looking over his shoulder all the time,

Mina lets him know that she thinks he is making a fuss: 'You ought to be grateful for those gadgets, dad – it's because of them that I know when you need me!' She doesn't realize how lonely her father sometimes feels. He misses having her around and the fun they have together. John doesn't say anything about it to her, though: Mina has enough on her plate as it is. And, after all, he decided to have the MDA, didn't he?

Once a month, John and Mina talk over his condition with the neurologist. The test results confirm what everyone, including John, already knows: his dementia is getting worse. John finds it increasingly difficult to relate what the MDA tells him to his own recollections and perceptions. As a result, he sometimes gets confused. For example, John is sure that he went to the supermarket yesterday, but the MDA says he didn't. 'I've still got the mud on my shoes,' he says. 'The blessed thing doesn't know what I have and haven't done! I reckon it's that talking wall that's got the problem, not me.' The MDA is not able to establish how far John's dementia has progressed. However, it does provide information that can be used as a basis for providing increasingly adjusted support. As time goes by, though, John feels more and more dependent on the technology, when he would rather be dealing with people. If it were Mina watching over him, at least John could argue about what happened yesterday. As it is, she sides with the MDA all the time.

(The above scenario was inspired by the Embedded Systems Roadmap, 2002.)

3.5 Analysis

To conclude this chapter, some thoughts on the intelligent integration of technology are presented below. We begin by identifying the functions and services that Ambient Intelligence could add or integrate. We then examine a number of normative questions that are important in relation to the way intelligent integration is viewed. Finally, we specify the health care functions and services that can be automated using Ambient Intelligence.

What functional improvements can Ambient Intelligence provide?

The MDA that John is given both provides a number of additional health care functions and integrates certain functions associated with his two ailments: dementia and diabetes. If John's blood sugar level falls below a predetermined threshold, the medical patch tells him that he needs more insulin. If he does not self-administer the required medication in time, the MDA calls in assistance. Assistance would also be

called if John were to fall and be knocked unconscious. In addition, the MDA serves as a memory support, reminding John about appointments and other important things. Finally, the system helps John to keep track of his possessions: his key fob has an active RFID chip integrated, enabling him to find his keys when he can't remember what he has done with them.

In many ways, John's situation is better than that of Mrs P, whose case history was described earlier in the chapter. Mrs P has to move home twice and loses more and more functions as time goes by. She does not accept the personal alarm that is given to her, and later rejects the chip attached to her back in order to prevent her leaving the care home unnoticed. In her view, the devices are not there for her benefit, but for the benefit of others.

Normative issues raised by the scenario

Needs and interests

Debate about intelligent health care technology should not focus exclusively on needs. Within the health care sector, it is normal to take account of patients' competence to rationally assess their own interests. The fact that Mrs P does not perceive herself to be in need of a chip does not exclude the possibility that the use of a chip – and possibly even the implantation of a chip under her skin, so that she cannot remove it – may be in her interest. As long as Mrs P is competent to appraise her own interests rationally, it is she who should decide what aids she will have, however useful a given device might seem to others.

John's MDA enables him to go on living outside a care establishment longer than would otherwise have been the case. However, John has to contend with the medicalization of his domestic environment: he has to submit to a medical regime within his home. One important issue is whether the medical merits of such functions are tested if they are made available as consumer products. An application such as the MDA might first enter use as a mobile phone application. Thus, medicalization may begin in the consumer sector, where needs inevitably prevail over interests.[24]

Acceptance of technology and of ailments

The responses displayed by John and Mrs P indicate that the acceptance of health care technology depends not only on how cleverly it is integrated, but also on the extent to which the client accepts his or her ailments and the extent to which the technology can prevent or correct those ailments. Mrs P's personal alarm and back chip were, physically speaking, just as intelligently concealed as John's MDA, sensors and medical patch. Yet Mrs P responded in a very different way from John.

That is not surprising, given the gradual loss of function experienced by Mrs P. Her technological aids were not well integrated in social terms.[25]

Social relationships

John's use of the MDA has implications for his relationship with his daughter Mina. He initially decides to have an MDA partly so that his daughter won't worry about him, but is concerned about being a burden on her (if he forgets his medication, thus causing the MDA to alert Mina). His fears prove to be justified: Mina visits her father less often and is increasingly businesslike in her dealings with him. John's grumbles about his technological aids are in fact an expression of his increasing loneliness. John admits to having mixed feelings about the technology: he chose to get an MDA, but he didn't choose the consequent change in Mina's attitude towards him. He is glad that Mina comes when he needs her, but he regrets their relationship becoming more businesslike. Although both of them benefit from the technology, both of them lose something too.

More independent or more isolated?

It is not easy to say whether Ambient Intelligence makes John more independent. Like Mrs P, John becomes increasingly isolated in social terms. The hypothetical decision to remove medical patches from the package of insured items illustrates how citizens and patients have little influence on the regulatory process. Such decisions have a bearing on freedom of choice regarding the provision of medical support.

Automation

In both the case history and the scenario, the measurement and registration of physical parameters – such as John's glucose level and ability to remember things – is partially automated. In addition, John's daughter Mina is automatically sent a text message if John has a serious fall or fails to take his medication at the right time.

This highlights the first limitation on what can be automated using Ambient Intelligence. As time goes by, John finds it more difficult to reconcile his own perceptions and recollections with what the MDA tells him, and consequently becomes increasingly confused. It is therefore pertinent to ask whether things could be handled differently. Memories are not distinct entities that are acknowledged as one's own as soon as they are retrieved; the human memory does not work like a computer's hard drive. A memory is significant only in the context of other experiences and recollections. The MDA registers only isolated memories; it does not record their context or the links between them. If the MDA reminds John about something, it is uncertain in what context he will place the information; it may be the case that his dementia will have corrupted that context.

4 The hospital of the future: context awareness

The Netherlands has more than eighty-five hospitals. These include eight university medical centres (UMCs) and nineteen specialist clinical centres; the remainder are general hospitals. Hospitals of the first two types undertake a great deal of research and training. They possess high-level clinical expertise and are able to undertake complex treatments. Specialist clinical centres play an important role in the training of doctors and specialists. Regional hospitals are not involved in research or training, but do provide specialist curative health care. Curative health care is care that is focused on curing medical conditions, rather than recuperation from illness or coping with chronic illness.

Developments

Health care in the Netherlands is increasingly organized on the basis of 'care chains'. A patient who is referred by his/her general practitioner (GP) to a specialist in a hospital, for example, typically enters a chain, made up of a series of connected health care processes, from admission and diagnosis to treatment and rehabilitation. A health care chain will often include several specialisms.[26]

Over the coming fifteen years, hospitals will increasingly take on the character of specialist treatment centres. The Nuffield Trust, which (amongst other things) monitors health care in the United Kingdom, links this expectation to the growth of so-called telehealth services. Telehealth services are monitoring and health care advice services, which help people to recover and recuperate at home as far as possible.[27]

A trend towards the decentralization of health care has been established for some years.[28] One manifestation of this trend is the rise of outpatient clinics, a phenomenon made possible by the fact that many medical procedures have become less invasive than they once were.[29] The World Health Organization (WHO) has emphasized the importance of being able to provide health care, particularly for the chronically ill, at any given point of care.[30] A point of care is a location where care is provided. This is not necessarily a formal health care institution, as with the reanimation of a heart attack victim at the place where he or she suffers the attack (see the case of Mr Algra, below).

Structure of this chapter

In this chapter, we outline what we expect the hospital of the future to be like. We pay particular attention to the provision of health care through the outpatient clinic, after which the patient often goes straight home. The emphasis is on context awareness, which entails computers making associations between locations and personal characteristics. The case history (section 4.1) involves an older couple. Mr Algra has a heart condition, while Mrs Algra has diabetes. Following a brief analysis of current practice and of the needs that are not being properly met (section 4.2), we consider how Ambient Intelligence might be used to improve things (section 4.3). Drawing upon our conclusions, we present a scenario (section 4.4). Finally, we describe the functions and relationships necessary for context awareness, we set out the associated normative issues and we indicate the extent to which the association of locations and personal characteristics can be automated (section 4.5).

4.1 Case history: The house is very quiet when Mr Algra comes home

Mr and Mrs Algra live in a suburb of Enschede. Mrs Algra is seventy-three years old and her husband eighty-one. They have been together for nearly fifty years. Last year, Mr Algra had a heart attack. He was working in the garden, preparing it for winter: a job he had found more demanding each year. 'Before long, I'll have to begin in the summer,' he joked on one occasion. The Algras' son suggested increasing the paved area and having fewer seasonal plants. The heart attack forced the issue: Mr Algra just about managed to call his wife when he developed the tell-tale chest pains. 'It's my heart. Call an ambulance.'

Mrs Algra almost pulled the plug out of the wall, trying to get to her husband while carrying the phone. Because the phone cord wasn't long enough to allow her to be with him while making the 999 call, she stood by a window overlooking the garden as she spoke to the emergency services. Mr Algra was lying motionless on the ground, right in front of her, yet out of reach. She had never felt so powerless. The ambulance was there in eight minutes, but it seemed like an eternity. They came round to the back of the house, as requested. By the time the paramedics arrived, Mrs Algra was exhausted from her mouth-to-mouth resuscitation and heart- massage efforts. Even under normal circumstances she tends to feel very tired because of her diabetes, which she has had for thirty years.

Since the incident, Mr Algra has worn a heart monitor at home. The device tells Mr Algra what his heart rate is and records any abnormalities. Every Tuesday, Mr Algra's

son takes him to the hospital for a check-up. At the outpatient clinic, the data from the heart monitor are discussed. It's not nice having to wait, but the nurse and the doctor are friendly and give good advice. Don't eat too much fatty food, and exercise regularly. 'Do you enjoy gardening?' the nurse had asked Mr Algra on his first visit. She was very embarrassed when the full circumstances were explained, but Mr Algra didn't mind: how could she have known? 'I see that your heart was racing in the night,' the nurse observes. 'Did you have an exciting dream?' Now it is Mr Algra's turn to look embarrassed. 'Nothing to worry about. See you next week.'

If only the Home Care Service had as much expertise as the clinic, thinks Mrs Algra sometimes. Then her husband wouldn't have to go to the hospital so often. He is always glad to get home again. The one trip to the hospital dominates the couple's whole week. The Algras are very fond of the woman from the Home Care Service – partly because of the help she gives them, of course, but also because they enjoy the daily chat. She lives nearby, so they have a lot in common. Whenever the Home Care woman speaks to Mr Algra or Mrs Algra individually, they express concerns about each other. 'My wife still does a little shopping on her own, but she doesn't see very well. I'm worried that she will have a fall,' Mr Algra will say. 'My husband sometimes forgets to take the pills for his heart. If I wasn't around to keep an eye on him, goodness knows what might happen,' Mrs Algra will confide.

The weekly hospital visit becomes almost routine. Until the day that Mrs Algra suddenly takes a turn for the worse. Having been preoccupied with Mr Algra's health, she has been neglecting her own, and finds one day that she isn't able to control her blood sugar level properly. Feeling worse, she asks her husband to call the doctor. By now they have a cordless phone (a present from their son after the last crisis). But a cordless phone brings its own drawbacks: Mr Algra can't find it. Discovering it missing from the base station, he races round the house, his heart in his mouth and a mounting sense of pressure on his chest. Eventually Mr Algra finds the phone and calls the GP, who is there a quarter of an hour later, at exactly one o'clock. He advises moving Mrs Algra to hospital, until her condition stabilizes.

Mr Algra stays at home alone. Without his wife, he is very aware of how isolated he has become, and he has occasional panic attacks. 'What if my heart starts playing up? The Home Care woman can't be here all the time.' Mr Algra's son drops by during his daily lunch break, even though they haven't always got along. 'It's a shame that it's taken such unfortunate circumstances to bring us together, eh, dad?' 'I'm just glad that you're here, son.' Together they visit Mrs Algra, and on Tuesdays they go to the outpatient clinic. The cardiologist notes that, at quarter to one, Mr Algra's pulse rose sharply. 'Were you overdoing it a bit, Mr Algra? I see that there have been a few

occasions when your heart rate has been abnormal. You are taking your pills regularly, aren't you?' It isn't clear how long Mrs Algra will have to stay in hospital. The house is very quiet when Mr Algra comes home.

One evening, Mrs Algra cannot sleep. She lies in bed, tossing and turning. Previously, she and her husband had always been a strong team, but she isn't confident about their ability to cope now. Whichever way she looks at it, she comes back to the same conundrum. It just isn't responsible for the two of them to continue living on their own, but she isn't prepared to impose on others either.

By contrast, the Algras' son feels guilty. If he and his girlfriend had kept a better eye on his parents, maybe his mother wouldn't be in hospital now. 'You've got your own life to lead, son,' says Mrs Algra. 'When I come out, we will simply have to move to a care home or something.' She doesn't want to be a burden on her son, however much he wants to help.

(This case is based on the Wireless Health care Project.[31])

It will be apparent that Mr and Mrs Algra are very dependent on one another. Up to an advanced age, they form a strong couple. When he has a heart attack, it is she who calls an ambulance and gives him mouth-to-mouth resuscitation and heart massage. When she is subsequently taken ill, it is he who summons help. As time goes by, the Algras' son plays a bigger and bigger role. First he takes his father to the outpatient clinic once a week. Later he starts taking his lunch with his father and accompanying the older man on his daily trip to visit Mrs Algra in hospital.

Social considerations

Even self-care has a social dimension. Support is needed – from the Home Care Service, for example – in order to continue living independently. Mrs Algra reminds her husband to take his heart medication while the nurse and cardiologist give him advice on the basis of data from his heart monitor. Mrs Algra has had diabetes for thirty years and has been able to manage her condition largely unaided until she becomes so preoccupied with Mr Algra's health that she neglects her own. This forms another example of the social dimension of self-care. After allowing her health to deteriorate, Mrs Algra is admitted to hospital and it is unclear whether she will be able to return to her old home. As a result, Mr Algra's self-care is jeopardized because, among other things, the danger of him forgetting his medication increases.

Technology

Technology plays an important role in relation to social support and in other ways. One of the main technological aids used in this case is the telephone. Mrs Algra calls an ambulance when her husband has a heart attack. The Algras' son buys a cordless phone, because he doesn't want his mother to go through another experience like watching through a window as Mr Algra lies motionless on the ground. However, when Mr Algra subsequently wants to call the GP for assistance, he has trouble finding the new cordless phone. To enjoy the mobility afforded by the cordless phone without the risk of losing valuable time in an emergency, a degree of self-discipline is required: the phone has to be put back on its base station every time after it has been used, so it can be found easily when needed.

Interpretation of data

The heart monitor serves several purposes. Recording data on Mr Algra's heart rate makes it easier to match his activities to his present capabilities. The recorded data can also highlight issues surrounding the effectiveness of his medication or Mr Algra's diligence in taking it. The case history shows how important it is to know the context in which certain values are measured. What does an abnormal heart rate suggest? That Mr Algra has not taken his medication? Or that the medication doesn't work? Or that he has been trying to do too much? A combination of these factors or something completely different?

The monitor faithfully recorded the sudden increase in Mr Algra's pulse when his wife asked him to call the doctor. When he couldn't find the phone, Mr Algra's heart rate hit a second peak and he experienced chest pains. Clearly, Mr Algra was putting himself under a lot of pressure at these times. But whether he was overdoing it, as the cardiologist asks, is another matter. He was putting himself under pressure because his wife, whom he cares about dearly, was in danger. During the crisis, it was up to him to ensure that she got the help she needed. So, while he may have been pushing himself harder than was good for him, he wasn't pushing himself harder than was good for her. Self-care is a social matter.

In the Algras' case, the primary context awareness issue is the extent to which the couple's social setting is aware of their circumstances. Mr Algra has to report his chest pains himself, for example. Mrs Algra then calls an ambulance, gives their address and says that the paramedics should come to the back of the house, because her husband is in the garden. If she had not been at home when Mr Algra had his heart attack, he probably would have died.

Later, the nurse proves unaware that Mr Algra had his heart attack while engaged in precisely the activity that she recommends for exercise. Similarly, when the cardiologist sees the volatile data from the heart monitor the week after Mrs Algra is taken ill, he is unaware that Mr Algra had to act quickly to help his wife. Finally, although Mr Algra's heart monitor records his pulse, it does not maintain a parallel record of his movements or activities. When the nurse asks Mr Algra whether he had an exciting dream, she takes it for granted that he was fast asleep in bed at 1 a.m., and he is embarrassed by her question. Does he have to explain every increase in his heart rate?

More self-care

It is nowadays possible to undertake procedures at a cardiology outpatient clinic that would previously have required hospitalization. Mr Algra can now monitor his heart rate at home, visit the clinic once a week and go home the same day. As long as his wife is at home, he is happy to do things this way. Everything changes, however, when Mrs Algra has to go into hospital. According to the Ministry of Health, Welfare and Sport (VWS), the new approach raises two issues:

> *'The anamnesis remains very important. Regardless of the approach used, the patient's identity and circumstances are critical. Patients are discharged much sooner than used to be the case, even after major surgery. However, this means that the people responsible for their treatment have less insight into how they are recovering'. (Ministry of VWS, 2006)*

This highlights two points that are significant in relation to the assessment of technology intended to enable patients to remain at home as long as possible, or return home as soon as possible following hospitalization: who is the patient and what are the patient's circumstances? Hence, it is important to consider things that are important for recovery, but also what patients can't take with them, such as support, help using technology or domestic stability. Conversely, it is necessary to consider not only the burden (cost) associated with hospitalization, but also what hospitalization may do to alleviate the burden. Hospitalization may relieve a patient or partner of all kinds of domestic chores and responsibilities.

Decentralization versus centralization

What does decentralization require and what does centralization have to offer? In the Algras' case, the decentralization comes out of the comparison less favourably. If Mr Algra had been hospitalized for longer following his heart attack, or had received better support at home, Mrs Algra may have been less likely to neglect her own health. As it happened, she herself ended up in hospital and the couple's fragile domestic set-up is threatened. Indeed, it is not certain that Mrs Algra will ever be able

to return to the couple's existing home – partly because of her own health, and partly because of the demands that her husband's condition places on her.

When the Algras' son offers to provide the additional support that they need, Mrs Algra tells him that he has his own life to lead. Although the younger man is very willing to help, Mrs Algra knows from her own experience how demanding lay care is and what an impact it has on the carer's life. However natural her son thinks it is that he should care for his parents, Mrs Algra doesn't want him to. She would feel like too much of a burden on her son, and prefers to move to a care home.

4.2 What needs are not being properly met?

Context awareness is crucial in a care establishment that is increasingly focused on patient flows, such as an outpatient clinic. If a point of care is constantly moving within a health care practitioner network, there must be adequate provision to meet the demand for health care at various locations. However, from the interviews we conducted, it appears that provision is lacking in a number of respects.[32]

Complex organization

The organization of extramural health care is complex. Such health care often involves several parties: GP, pharmacist, hospital, Home Care Service, lay carer and so on. The quotations below show how the decentralization of health care raises questions about, amongst other things, the allocation of tasks and responsibilities:

> *'The hospital is a sort of distribution centre for aids and resources, even in the modern era of decentralized health care. In the hospital, strict standards and a medical regime apply. Of course, mistakes are sometimes made, but who monitors standards when people are cared for at home?' (Ministry of VWS, 2006)*

> *'Intramural health care is disintegrating. Hospitals could play a much bigger role in the coordination of extramural health care.' (Roessingh Research & Development, 2006)*

> *People often recover at home. The Home Care Service organizes day-to-day care and supervises patients, with the GP playing a central role. The patient refers to the GP for primary medical assistance, and to the hospital for specialist expertise. Medication use could be better supervised by pharmacists. Although pharmacists cannot monitor day-to-day use, they could keep an eye on consumption by checking prescription data.' (Utrecht University Medical Centre, 2006)*

The networking is clearly not optimal at present. Actors in the health care sector currently work quite independently. The Ministry of VWS asks who monitors standards when people are cared for at home, while the researcher comments that

hospitals could play a bigger role in the coordination of extramural health care. For their part, the hospitals see themselves as there to provide specialist expertise. The GP is the first link in the medical chain, the Home Care Service provides general supervision and the pharmacist has the job of monitoring medication use.

The decentralized organization of health care necessitates new ways of thinking and acting, in fields such as logistics, knowledge sharing, the integration of health care services and the creation of positive surroundings.

Logistics

One of the changes necessitated by decentralization is the adoption of a new approach to logistics. Internal hospital logistics are mathematically and administratively extremely complex. Not surprisingly, therefore, hospital logistics systems are rarely linked to external logistics systems. However, the provision of adequate patient support in a decentralized regime depends on the availability of appropriate skills and resources at the point of care, and on the ability to consult and plan on an *ad hoc* basis.[33]

Knowledge sharing

Patients cannot be given proper care unless there is appropriate information about medication use and complications at the point of care. A stroke victim, for example, can suffer irreversible injury if care is delayed or inappropriate. Information sharing is currently compromised by various parties' continued use of paper records, and by terminological differences and competence inequalities. Cardiologists and internists use different systems of notation, for example, while a specialist in one discipline will often have only a layman's knowledge of another. For his or her part, a GP will find it almost impossible to obtain an overview of complex medical issues.

Integration of health care services

The position at the point of care is an isolated snapshot of the care chain situation encountered by a patient. For the patient and the health care practitioner, the bottom line is the integrated availability of information access, storage and consultation services. Just as the pharmaceutical ideal is a 'pill for all ills', so the ICT ideal in the health care sector is a single 'box of tricks' that can handle the entire process of information gathering, filtering, combination, interpretation, highlighting and communication.

Positive surroundings

Self-care is not a spontaneous process. It depends on surroundings that encourage and enable the patient to care for him/herself. As things stand, ensuring that patients adhere to their medication or therapy regimes is a major challenge. Many hospital admissions are the result of people failing to take their medication, or to do so as directed.

4.3 The potential benefits of Ambient Intelligence

In this section, we consider the scope for using Ambient Intelligence to support the decentralization of health care and to promote self-care.[34] As the case presented above illustrates, it is difficult for health care practitioners to establish exactly what patients need. Both Mr and Mrs Algra have particular clinical conditions: Mr Algra has a heart problem, while his wife has diabetes. A health care practitioner is likely to see either individual's condition from the outside only. It is hard for a practitioner to determine who actually needs help, because – as we have seen – each spouse's problems can be attributed in part to a problem that the other has.

Ambient Intelligence can be useful in such situations, by providing information about a patient's domestic circumstances. Intelligent surroundings could record and process data on parameters such as heart function, exercise and medication use. The technology could then be used in the exchange of data between links in the care chain (provided a system of electronic medical records were introduced).

> *'Without a basic electronic medical records system, neither patients nor health care practitioners have any assurance that all the relevant data will be available at the point of care. Monitoring data need to be saved, managed and secured in a coherent manner, together with information on the patient's medication, use of aids and so forth, and then made accessible on an appropriate basis.' (Netherlands Organization for Applied Scientific Research (TNO), 2006)*

Intelligent surroundings could reliably handle the whole process, from the measurement and filtering to the combination and communication of sensitive medical data. Such data would be specific to the individual patient's case history and could be made available at any given location. In this chapter's future scenario, we see just what such a system could mean for Jeanne and Hans who can go on a walking holiday despite the latter's heart problems.

4.4 Future scenario: Despite his heart condition, Hans takes a holiday

The year is 2021. Hans and his wife Jeanne live in a quiet neighbourhood on the outskirts of Rotterdam. He is seventy-five, and always likes to feel in control of his life; he dislikes uncertainty. She is sixty-eight: a quiet woman who takes life as it comes.

Hans retired five years ago. Retirement at seventy or older is now the norm (society having accepted 'the Bovenberg principle', that for every year that average life expectancy increases, the retirement age should go up by six months). 'Good job we're not immortal,' quips Jeanne, 'otherwise we'd still be on the treadmill now.' Hans actually stopped work two years sooner than originally planned, after suffering a heart attack. Since his retirement, the couple have done a lot of travelling. Last year they visited their daughter in Australia. The year before – right after Hans'retirement – they made a tour of the Mediterranean after being enchanted by Paul Theroux's famous travel book The Pillars of Hercules.

Before they set off, Hans bought a digital travel companion from the ANWB (a Dutch road users' organization). He saw the product advertised in a brochure entitled MyAdventure: the complete pocket-sized digital solution for travellers. The brochure highlighted the many useful services included in the package: 'With MyAdventure, travel has never been easier. Galileo, the new European navigation system, will take you anywhere you want to go. Descriptions and explanations of every place of interest are provided in all forty-three European languages. You can also use MyAdventure to book a last minute hotel, or reserve a table at your favourite restaurant. MyAdventure will change the way you holiday forever.'

This year, Hans and Jeanne want to go walking in the mountains. However, the cardiologist feels that it is no longer responsible for them to go away without support. Hans already has a pacemaker; now the cardiology outpatient clinic provides him with an external aid: the Heart Manager. Sensors on his body continuously monitor his heart rate and brain activity (by means of EEG, electroencephalography). The GP felt that the brain monitor wasn't really necessary, but the insurer wanted everything done by the book. Hans has an elevated stroke risk, so early detection is in his interest. It also helps to keep rehabilitation costs down. Hans is very positive about it all. Mountain walking is his passion. 'I always wear a hat anyway, because of the cold, and the EEG gadget fits neatly into my hat. So it's no discomfort or inconvenience.' Hans and Jeanne count themselves lucky to get all the equipment paid for through their health insurance scheme. They have some friends – people whom they met at

the outpatient clinic – who are not so well insured and consequently can't make trips like this.

If Hans' heart starts to behave irregularly, the sensors send a wireless signal to the Heart Manager on his mobile phone. The sensors are smaller and more flexible than a postage stamp. If there is no signal, they send an SOS message to a local mobile phone network. Depending on the nature of the irregularity, either the nearest doctor is alerted or an ambulance is called. The measured data are automatically sent to Hans's Heart Manager Log: a sort of cardiac weblog. Hans can view the data himself, as can his daughter in Australia. However, any emergency service that is called in to help can also access the data and pass it on to the duty cardiologist. Thus, the medics responding to an emergency know exactly where to go, who they will find there and what they need to be ready for.

Fortunately, Hans has no problems while he is away. Occasionally he feels a little light-headed, but who doesn't at altitude? On the penultimate outing, however, Jeanne twists her ankle on a steep slope and doesn't feel up to the walk planned for the last day. 'Why don't you go on your own?' she urges 'You might as well make the most of it while we're here.' Hans won't be persuaded, though: 'I've had a great holiday, and we're due to go home the day after tomorrow anyway. Let's just cut the holiday short and come back later in the year.'

The day after getting back, Hans' medical supervisor calls round. 'What's this: the outpatient clinic visiting me?' Hans says with a laugh. The supervisor brings disagreeable news, however. The changes in altitude have not been helping Hans' heart: 'I'm not sure that your insurer will be prepared to pay for medical support abroad if you go walking in the mountains again.' Hans is taken aback, and wonders whether it really is a good thing to know so much about one's health. He had been feeling fine in the mountains; in fact, he felt better for making the trip. 'So what are you saying? I'm not allowed to go walking anymore? Whose life are we talking about: yours or mine?' The supervisor doesn't know quite what to say. He wonders whether he will be held to account if the client puts his health at risk. Hans is not pleased with the way things have turned out. He hadn't considered this possibility when he allowed the insurer and the health care practitioners access to his data. 'And by the way, how could you even know we were back home…?'

(This scenario is based on conversations with Huib Broekman of Teleprotect and Ger Dijkman of BestMedical.)

4.5 Analysis

The very thing that Hans really enjoyed, and which gave him a sense of freedom, turned out to be bad for his health. He had always supposed that the light-headedness he experienced was something everyone felt when walking in the thin mountain air. Applying the assessment tool introduced in chapter 2, we can make the general observation that situationally aware technology makes associations between a patient's location, his/her behaviour and his/her health (functions). This introduces the possibility of making certain choices regarding the funding of equipment and medical interventions (normative issues). And the choices made may become a cause of dispute if the measured data are forwarded automatically and support is triggered automatically (automation). These points are considered in more detail below.

What functional improvements can Ambient Intelligence provide?

Situationally aware technology is in the first place facilitative. Whereas Mr Algra's health was automatically monitored at home, Hans' health can be monitored while he is out and about, even in another country. As a result, appropriate support can be provided more quickly in the event of a problem. In neither case, however, was technology used for direct functional support. Unlike the technology given to Mr Algra, that used by Hans knows where he is. By the time in which the scenario is set, the problems associated with lack of data sharing have been resolved. So Mrs Algra's future counterpart would not have to tell the emergency services to come round to the back of the house, and a future Mr Algra would not have to fear leaving the house unaccompanied.

Normative issues raised by the scenario

It is debateable whether the scenario depicts a situation which is better than that described in the case history. The use of situationally aware technology raises issues concerning the funding of medical equipment and interventions, freedom of choice concerning the use of equipment, and personal responsibility for one's own health.

Funding

The very things that technology makes possible are actually put in doubt by the use of technology. The aids provided to Hans and Jeanne are paid for by their insurer, but their use may lead to the couple losing their entitlement to medical support abroad. The advertiser's claim that '*MyAdventure* will change the way you holiday for ever' proves to be correct in an unexpected way. Hans finds himself in a situation where he

must personally meet any costs incurred as a result of activities that – because of his technological aids – he knows to be bad for him. Hans and Jeanne's friends are not even provided with equipment like Hans', because they do not have such comprehensive insurance.

Is technology use really optional?

Once it becomes possible to establish links between behaviour and health, failure to use situationally aware technology is liable to be seen in a different light. Health care practitioners and insurers may increasingly view ignorance of the risks associated with a form of behaviour as a personal choice. As it is, some gynaecologists argue that smokers should not be eligible for funded IVF treatment (*in vitro* fertilization), since it is widely known that smoking has an adverse effect on fertility.[35] Just as access to funded IVF treatment could become conditional upon stopping smoking, so access to other treatments might be given on the condition that one make use of Ambient Intelligence.[36]

Where potentially omnipresent technology is concerned, the importance of an exit option becomes very relevant. The Medical Treatment Contracts Act (WGBO) gives a patient the right to 'not know'. Within certain limits, a patient may decline to be given information about his or her medical status. What does this imply for Ambient Intelligence? Do people (patients) have the right to live in unintelligent surroundings if they choose? If so, is it fair to attach consequences to their decision?

In the context of a person's ability to act according to his or her own interests, a distinction is made between having a voice and having an exit option.[37] If the individual has a voice, his or her complaints or wishes are used to improve or modify a service or product.[38] An exit option is an opportunity to vote with one's feet, by moving to another health care practitioner or insurer. An exit option can also serve as a means of refusing input. Mergers between hospitals and insurers are reducing the number of exit options, and it is pertinent to ask what the implications of this trend are for individuals' ability to act according to their own interests.

Freedom of choice with regard to the use of the intelligent technology ultimately depends on how the quality of health care is monitored. Will quality monitoring be the task of a regulatory or coordinatory body, such as the Health Care Insurance Board (CVZ) or the Health Care Inspectorate (IGZ)? Or will it be a function of the increasing level of direct interaction between patients, service providers, insurers and technology suppliers? Because people are not equally able or inclined to look after themselves, the latter situation could lead to major differences in the quality of health care.

Tasks and responsibilities

It is very important where situationally aware technology is concerned that the various actors' tasks and responsibilities are clearly defined. Information access and usage rights also need to be specified. Privacy is an important issue in relation to the exchange and use of sensitive medical information. Thus, protection against hackers and computer viruses is clearly vital.

Mr Algra and Hans both come to realize that more is known about them than they had anticipated and perhaps more than they would like. When asked with a wink whether he had an exciting dream, Mr Algra finds himself wondering whether from now on he is going to have to explain every rise in his pulse rate. Hans has even less privacy. His health care practitioners know very well what he has been doing; he had to allow them access to the relevant data before the insurance company would agree to pay for the equipment. The medical supervisor knows, for example, that Hans and Jeanne are back from their holidays, without the couple informing him. They only realize how much privacy they have surrendered when the supervisor explains that changes in altitude are bad for Hans' heart. They are not happy about the supervisor using the medical information to make an unannounced visit the day after their return.

In our future scenario, the supervisor is inclined to use the information he has in another way. When the supervisor says that the insurer may be unwilling to fund future medical support abroad, Hans asks whose life they are talking about. Although Hans gave his consent for the supervisor to access his data, he did not appreciate the full implications of doing so. The supervisor is himself uncomfortable in an unfamiliar situation, as evidenced by his inability to respond adequately to Hans' question. Users are liable to become suspicious and feel spied upon if they do not know exactly what data will be collected or what will be done with those data.

Automation

Nothing needs to be done with most of the measured data that intelligent surroundings collect. Only if a predetermined critical value (heart rate, glucose level, etc.) is exceeded is it desirable to make active use of the data. The task of setting the critical values must be left to humans.[39] Hans' intelligent surroundings know not only how he is, but also *where* he is. Thus, if the intervention of a health care practitioner is needed, Hans can be found quickly and the practitioner knows what to expect when he is found, without Hans or Jeanne having to do anything. If anything goes wrong, human assistance is automatically summoned.

However, automation is not a panacea for the entire process of data measurement, filtering, combination, interpretation, highlighting and communication. Situationally

aware technology can only measure, filter and combine data. The input of an expert and concerned person is still needed to determine what the significance of the measured data is and whether (and, if so, which) treatment is in order.[40]

Having technology that functions well is no guarantee that the right information is available in the right place and used in the right way, as our future scenario illustrates. Ideally, therefore, debate on the use of Ambient Intelligence should be preceded by debates on the division of tasks and responsibilities in the health care sector and on automated data sharing on the basis of electronic medical records.

5 Paediatric physiotherapy: personalization

The paediatric physiotherapist is an important link in the care chain that supports young children with locomotor problems, motor retardation and/or paresis. Treatment sometimes may begin when the child is only a few weeks or months old, depending on the seriousness of the symptoms and how quickly they are picked up. There can be considerable variation in the latter factors. If a problem goes untreated (or inadequately treated) during a child's early development, the child is liable to suffer lasting problems. These may take the form of joint deformities or spinal abnormalities, which in the worst cases can necessitate surgical intervention.

Referral to a paediatric physiotherapist is nearly always through a paediatric clinic, paediatrician or GP. If a child exhibits serious symptoms, such as abnormal and unusually rapid (or slow) involuntary movements, a neurologist may also be involved in the diagnosis and treatment. Treatment often takes a form that falls intermittently between cure and care. If the underlying problem is brain damage, it is often impossible to do more than merely mitigate the consequences. An effective treatment programme depends on a high degree of commitment from the parents, particularly where the child is liable to be at risk of developing other conditions and diseases as a consequence of not eating normally and/or getting enough exercise.[41]

In this chapter we concentrate on personalization: the (manual) tailoring of health care functions and services to the needs, interests and/or characteristics of individual patients. Paediatric physiotherapy is a setting in which personalization is very important. A paediatric physiotherapist is confronted by all manner and degrees of locomotor disorder, which are difficult to predict, but liable to have a major impact on the child and his/her parents. In contrast to the situation in the other forms of health care featured in this report, in paediatric physiotherapy it is typically not the patient who decides on a treatment method.

Structure of this chapter

This chapter begins with a case history that is illustrative of established practice in paediatric physiotherapy (section 5.1). We then briefly review the current situation and identify the needs of the child, the parents and the therapists that are not being adequately met (section 5.2). That is followed by an exploration of the potential of

Ambient Intelligence to enhance personalization (section 5.3), which is illustrated by means of a future scenario (section 5.4). Finally, in section 5.5, we consider what functional improvements the future scenario envisages, relative to the situation described in the case history, and we identify the associated normative issues.

5.1 Case history: Michael only likes to lie on his right side

It is Monday: the day that the paediatric physiotherapist makes his weekly home visits. Michael is only eighteen months old, but the physiotherapist has known him since he was just twelve weeks. A doctor at the paediatric clinic had become concerned that three-month-old Michael had not yet rolled over onto his stomach and barely used the left-hand side of his body. He suspected hemiplegia. Because this locomotive disorder is caused by brain damage, he referred the infant to a physiotherapist and a neurologist.

'Is it serious, doctor?' Michael's parents had asked.

'Your son has a form of cerebral palsy, a form of partial paralysis caused by brain damage,' the neurologist had replied.

Michael's parents were naturally terrified. 'What does that mean? Is he mentally impaired?'

'That's hard to say. Some children with his condition develop epilepsy or other coordination problems and some suffer partial blindness; others have behavioural problems or simply have difficulties with verbal expression or lexical problems. Fortunately, his brain damage will not get worse. And, if we begin treatment right away, we may be able to minimize his problems.' After that, the care team devised an intensive programme in consultation with Michael's parents.

For the first few weeks, the parents found it difficult to come to terms with the situation. The father was unsure of himself and pessimistic, while the mother felt an overwhelming sense of guilt. While she had been pregnant she had had skin cancer. 'Was my cancer the cause of this? I barely felt pregnant.' The physiotherapist tried to reassure her: 'Disease or other problems during the pregnancy can cause cerebral palsy, but we have no way of knowing whether that happened in Michael's case. Besides, it wasn't your fault that you had skin cancer. What we can improve are Michael's stamina and fitness.' To the father, the physiotherapist says, 'You coach a youth football team, don't you? That's a real plus. It means you know a thing or two

about working with children. True, this little star is going to need a different approach from the kids you are used to, but we'll develop that approach together.'

The treatment programme began with a demonstration for the parents. The physiotherapist laid Michael alternately on his right side and his left side. Every time he was put on his left, he screwed up his eyes and screamed. He would thrash about until he rolled onto his back or belly, positions that he found just as uncomfortable. He only wanted to lie on his right side. The parents found it very distressing to watch the physiotherapist deliberately causing their child discomfort; it was even worse when they had to do it themselves. They just wanted to let him lie the way he found comfortable.

The physiotherapist gets the parents to make videos of Michael as they do exercises with him. They are then able to review the little boy's development and the way they interact with him. Sometimes the interaction can become confrontational. 'If you get angry with Michael,' the physiotherapist counsels, 'you are giving him an extra reason to avoid the positions he finds uncomfortable.' There are things to laugh about as well, though, such as when little accidents occur during nappy changing. The physiotherapist records everything in his notebook. Michael's mother asks, 'We've been ill recently and haven't been doing nearly as much with Michael; will his development suffer as a result?' The physiotherapist can't really answer her question. He can only see when things are going better or worse; he can't be sure of the reasons.

Over the last year, Michael and his parents have made a lot of progress, although there was considerable debate on that score. Earlier in the year, the neurologist had said, 'I can't see any progress on the Bayley Scale[42], so things don't look very hopeful.' (The Bayley Scale of Infant Development is a tool for monitoring the motor development of children up to the age of forty-two months.) The physiotherapist is amazed: 'No progress? Not very hopeful? The parents are already coping much better with Michael. They find it easier to put him on his left side and they don't get cross anymore if he cries!'

After a while, it is moving to see Michael happily and easily doing what he initially found so difficult and disagreeable. 'Look,' says the physiotherapist, 'he can lift his head up now! That's because of all your hard work.' Happily, the boy's motor retardation relative to his peers is decreasing. Michael looks at things with clear interest and seems to listen to what is being said. His parents are becoming less nervous about the exercise programme. The physiotherapist notices these things. He believes in taking things gradually. Nevertheless, the mother's unanswered questions

prey on his mind. Could Michael's disability have been prevented during the pregnancy, and could the boy's development have suffered during the period that the parents were not able to do so much with him?

(Source: interviews with a paediatric physiotherapist and information from BOSK, the Association for People with Motor Disabilities and Their Parents[])[43]

Less than three months after Michael's birth, his parents find themselves involved with the medical system. The pregnancy was hard enough, because of the mother's skin cancer. They probably expected things to be very different. Neurological tests show that Michael has brain damage; there is no question about that. But the implications are hard to predict. It is major progress for the family just to get to the point where Michael can lie on his left side without too much discomfort, but their success in reaching this milestone says little about the boy's prospects. Uncertainty also surrounds the cause of Michael's brain damage. The mother feels guilty because the doctor cannot exclude the possibility that the illness she had when pregnant could have been a factor. The whole situation is rather uncertain.

It is Michael who has the neurological problem, but in practical terms his parents have a problem too. They have to be gently comforted, encouraged and energized by the therapist. He has to care for the parents, so that they can care for their child. The case history shows how he is sensitive to the parents' feelings and works on them in an effort to secure the best possible outcome. First, he reassures the mother that she has no reason to feel guilty. How could she help developing skin cancer? It is the future that matters and what the parents can influence: they can make a difference to the development of Michael's physical functions. This is where the father – whose outlook has been pessimistic – comes in. The paediatric physiotherapist knows that he is a youth football coach. So he praises the man's expertise, thus showing confidence in him and encouraging him to bring his skills to bear. Together they will develop a training method that is right for their little star.

Ambivalence

The paediatric physiotherapist has an ambivalent attitude towards measured data. This is illustrated by the differing views taken by the neurologist and the physiotherapist in our case history. The neurologist focuses on Michael's clinical status, as measured on the Bayley Scale, and can see no evidence of improvement. The physiotherapist is sceptical about these findings, believing that the measured data do not fully reflect all the relevant progress made. His assessment takes account of his observations of the child in his social setting. The physiotherapist is in a position to observe any motor progress made by Michael without using the Bayley

Scale. In his view, the measurement and registration of physical functions are of limited value under such circumstances.

Nevertheless, the mother's two unanswered questions prey on his mind. Both of the questions involve personalization issues. The first question – what impact (if any) did the mother's illness when pregnant have on Michael's condition – highlights the possibility that if more emphasis had been placed on prevention, Michael might not have suffered brain damage. The second question – how significant was it that, for a while, the parents did less with Michael because they were ill – highlights the fact that not enough is known about the relationship between Michael's motor development and the effort put in by the physiotherapist, Michael and his parents with a view to stimulating such development. Neither question can be answered without the measurement and registration of data.

Needs versus interests

Personalization is a social matter. It entails catering for needs, but also taking account of interests. Needs and interests are not necessarily in step with one another. Michael's parents would prefer to lay him on his right side, because he is most peaceful that way. But the first thing the paediatric physiotherapist does is put the boy on his left side. Michael has no immediate *need* to be on his left side, but laying him on his left side is in his long-term interest. The physiotherapist convinces the parents that, in this case, it is sometimes best to upset the child.

5.2 What needs are not being properly met?

At present, paediatric physiotherapists make relatively little use of digital aids for the treatment of children or for interaction with parents. That is not surprising, because physiotherapy is a very tactile and visual form of care. Nevertheless, ICT is starting to enter use in the primary physiotherapy process. A lot of experimental use is being made of video, but it does not yet form an integrated component of treatment. The feedback from our interviews suggests that a number of practical needs are not being met as well as they might. The needs in question relate to reporting, communication with parents, communication among professionals, the availability of relevant information at the start of the treatment, and the possibility of follow-up once the formal course of treatment has ended. The paediatric physiotherapist is keen to identify ways of improving his own performance:

> *'A lot of tests are available. We use a limited set. The ones we do use are questionnaire-based tests designed to establish whether children can process sensory information effectively – sensory integration, as it is known. Most tests contribute little to the treatment. Nevertheless, it would be good to be able to*

produce an objective report on a child's development, in order to demonstrate to the parents the functional benefits of treatment.'[44]

The need for better reporting is readily understandable in the context of the desire that treatment be tailored to the particular case (i.e. to the individual patient, his/her particular motor problems and so on) as far as possible. As our case history shows, the tools used by neurologists (e.g. the Bayley Scale) do not entirely meet the needs of the paediatric physiotherapist. From his viewpoint, it is vital to also take into account more narrative information on matters such as how the parents and child interact and how their relationship is developing. However, such things are just as difficult to objectivize as a child's muscle control, or the extent to which a child is able to perceive the position and movement of its limbs and body.[45]

The combination of information

Personalization necessitates the combination of dissimilar empirical and test data with other treatment data. As this chapter's case history illustrates, even the physiotherapist needs measured data. Using measured data, he and the neurologist could carefully evaluate the effectiveness of various treatment options, or determine the precise effect of variations in the frequency with which exercises are performed (as associated, for example, with periods when parental illness impairs their ability to do as much with the patient). Weekly contact is sufficient for the physiotherapist to monitor the situation reasonably well. If consultations were less frequent, however, it would be difficult to know how closely the exercise programme was being adhered to.

Digitalization

Personalization also increases the need for the digitization of data, because handwritten notes cannot easily be exchanged. Even the Bayley Scale is still completed in pencil. Administrative records are often held on computer, but correspondence goes by post. Progress is being made in both fields but without a standardized system of digital medical records, the administrative implications are considerable. As a result, there is little consultation or data exchange between GPs, paediatric clinics, neurologists and physiotherapists. Since little is typically known about a patient's problems at the time of first contact (the consultation that leads to referral), it is normal for very little information to be available at the start of a treatment programme.

Follow-up

Finally, there is a need for better arrangements regarding the conclusion of the formal treatment period. Follow-up can be important as a context for assessing the long-term effectiveness of treatment, making adjustments as necessary and providing additional

support or advice. Follow-up could take the form of home visits or the periodic assessment of images submitted by parents. Naturally, the latter option implies access to appropriate resources, such as a (digital) camera, as well as Internet access if the images are to be submitted by e-mail. Many parents, particularly those in difficult socio-economic circumstances, do not have access to such resources. It is important to bear such practical problems in mind when considering the use of health care technology at home.

5.3 The potential benefits of Ambient Intelligence

The needs identified in the previous section all directly or indirectly involve the tailoring of health care functions and services to particular situations (individual patients, specific ailments and needs, etc). How might Ambient Intelligence be used to cater for these needs? In chapter 4, we saw how intelligent surroundings with context awareness could make general associations between a person, a location and the person's physical condition. In order to support personalization, intelligence needs a much more detailed profile of the client or patient:

> *'Intelligence should be interpreted primarily as social intelligence: it should offer forms of interaction that people find appropriate. People respond to machines and computers as they would respond to other people, on a person-to-person level. It is particularly important that people get what they expect.' (Philips, 2006)*

In principle, Ambient Intelligence could make a big difference to paediatric physiotherapy. It can support the compilation of detailed personal profiles, the digitization of reporting, the integration of various information flows and the exchange of information. Thus, it can contribute to the provision of therapies that are better suited to the particular circumstances of young patients and their parents.

Detailed profiles

Ambient Intelligence has the potential to support the compilation of patient profiles containing all the information relevant to the provision of personalized health care. Personalization implies taking account of the characteristics that make a person who he or she is. Relevant data might include a child's age, gender and public service or other identification number, as well as details of his or her particular problems, motor development and insurance status. A profile might also contain information about the person's particular sensitivities, allergies and so on, with a view to aiding the prescription of medication, for example. Patients have been known to be given the wrong medication, sometimes with fatal consequences. Intelligent surroundings could warn of potentially serious side effects before medication is given. Finally, in view of

the central role of parents in the treatment of paediatric physiotherapy patients, profiles could include information about the patient's family circumstances.

Digital reporting

Digital reporting could be very useful in paediatric physiotherapy. It would provide a basis for objective reporting of patients' health status and progress, and for recording treatment arrangements and points requiring particular attention. Digitization could also greatly improve formal record-keeping for communication and accounting.

The sharing and combination of information

Once data are available in digital form, it becomes easier to combine and share different bodies of information. A digital treatment diary, for example, could be used to record images or videos, which the physiotherapist and the parents could then refer to as necessary. A treatment diary that both the physiotherapist and the parents can access and contribute to, could also serve to encourage parents, who would be able to look back and see how much progress had been made and how they had contributed to that progress. It would encourage self-analysis and thus support the adjustment of approaches and methods at appropriate moments.

Treatment could also be improved by making data accessible to other stakeholders, such as a neurologist, and by allowing such actors to input information of their own. If more relevant data concerning the client were available at the outset, it would be possible to get treatment off to a better start. Furthermore, being able to see the 'bigger picture' (including details of the client and his/her physical functions) would enable individual actors to refine their separate contributions. This could result in improved outcomes in terms of the physical functions of children such as Michael. Digital correspondence such as that envisaged here would have to make use of a unique identifier, such as the public service number, so that information from all the relevant sources could be correctly associated.

Coordination

Greater scope for the digital recording of self-care will allow therapists and parents to coordinate their activities better. At present, parents and children are instructed and guided by means of person-to-person consultations. The use of digital diaries would enable parents to exercise more direct control. It is they who must ultimately put the therapies into practice. Technology could thus allow the paediatric physiotherapist to act more as a remote coach than a hands-on therapist. This is another example of intelligence being used to facilitate decentralization.

The greater the number of parties who have access to detailed information about a person's health and behaviour, the greater the importance of coordination. The point being that anyone who has access to information is likely to wish to make use of it, especially if access to patient data is role-dependent. The parents, physiotherapist, clinic doctor and neurologist may each have slightly different access rights, however, or may all access the same body of information, but in a form appropriate to their role. Against this background, it is important to consider who would be responsible for ensuring that each party is able to access the right information and that such information is put to appropriate use.

5.4 Future scenario: Let's hope Dirk doesn't turn into a hypochondriac

In this section, we sketch a future scenario illustrating how Ambient Intelligence might be used to support the personalization of paediatric physiotherapy. The scenario is set in the year 2013.

Dirk is sixteen years old and slightly spastic. He has problems with uncontrolled movements, but – provided he gets a little understanding and support – he can manage fairly well. His parents didn't realize for a long time that anything was wrong with Dirk. It came as a real shock when the doctors discovered that Dirk also had a minor heart defect. Dirk gets tired easily and has palpitations if he overdoes it. At school he gets teased, because he isn't very good at sport: 'Run, Fatty, and try not to trip!' As a result, he is often lonely and unhappy, and when he feels low he tends to overeat. He gets through a lot of crisps and cola while playing online games with his virtual friends.

Last year, Dirk spent two weeks at a special camp for spastic children with weight problems. He was the only child with a third health problem, but everyone was nice to him. At the camp, Dirk learnt that his spasms are aggravated by stress and caffeine. When he is feeling stressed, he was told, he shouldn't reach for food, but do some light exercise instead. Dirk's spasms and palpitations have since got a little better. The camp helped him to make friends and improve his health. Within a few months, though, Dirk slipped back into his old ways. He found it harder and harder to discipline himself. When he flopped down at the computer with a bag of crisps, his mother would bring him a glass of fruit juice. 'At least it's healthy,' she thought.

On Wednesday, Dirk has the day off school to visit Magda, his paediatric physiotherapist. Magda specializes in helping children with motor problems. Dirk is one of the oldest children on her books. 'You are up to 75 kilos now. That's ten kilos

more than when you finished the camp. Are you eating sensibly? Are you getting enough exercise? It's important that you watch your weight, Dirk, because being overweight is dangerous for you with your heart defect and bad for your joints. People with cerebral palsy, like you, often don't have very strong joints.' A while back, Magda gave Dirk a set of daily exercises to do, with a view to gradually improving his fitness and strengthening his heart muscle. When she heard that he was having problems sticking to the exercise routine, Magda suggested giving him technical support as well.

A movement specialist whom Magda knows told her about something called the Little Acrobat. This is a device that you attach to your belt, which is programmed to monitor your activities and encourage you to change the way you behave in your own surroundings. Dirk wears a number of sensors attached to his skin or hidden in his clothing. These measure his body fat, muscle tension and muscle activity, record his palpitations and perform regular EEGs. The device also tells Dirk what sort of food he should eat. At the insistence of the European Commission, all products of this kind have to have a unique radio-frequency ID chip. All Dirk has to do is scan the label of anything he is thinking of eating or drinking. The fruit juice his mother has been giving him is rejected right away, because it turns out to be full of caffeine.

The Little Acrobat records the data that it measures in Dirk's log and periodically forwards them to Magda as well. Magda uses the Physio Day Manager System, whose features include the collection and categorization of patient data. The Little Acrobat also alerts patients when the measured data stray outside certain prescribed values; if they want they can automatically make an appointment with Magda. The company Magda works for has integrated the Physio Day Manager with its client record system. The latter system contains an accurate record of the guidance given to patients and how long they have been under supervision. Another feature of the Little Acrobat is that it allows Dirk's parents to see how he is getting on, because of course they like to know what the situation is.

Dirk is increasingly independent these days. He often declines food offered to him by his mother; she knows a fair amount about what Dirk should and shouldn't eat, but she doesn't know how suitable absolutely everything is. 'I reckon I should take that thing with me to the supermarket,' she says. Since finding out what was in the fruit juice, Dirk has tended to trust the Little Acrobat rather than his parents. His mother doesn't mind, though: 'As long as all this gadgetry helps Dirk to eat better, that's all I care about.' However, when Dirk's grumbles aren't backed up by the measured data, she sometimes thinks, 'I hope this isn't turning him into a hypochondriac.' Her concerns increase when Dirk asks one day, 'What about all the physical functions

that are not measured? How do I know that there's not something else wrong with me? I get headaches sometimes; does that mean anything?' Dirk starts to get stressed about it all. Then the Little Acrobat sends him a message: 'Please make an appointment with your physiotherapist.' In her office, Magda asks Dirk's parents, 'You are making sure that Dirk looks after himself, aren't you? The company is worried about the spiralling cost of his treatment.'

(This scenario is based on feedback from interviews with two paediatric physiotherapists and with personnel from Roessingh Research and Development.)

5.5 Analysis

Dirk and Michael were both born with a form of cerebral palsy. Michael's hemiplegia was picked up early and treatment started straight away. He has since made great progress and now his parents are coping well. Dirk's cerebral palsy is less severe than Michael's, and consequently wasn't diagnosed or treated until he was an adolescent. At that stage, it was discovered that Dirk had several interrelated medical conditions. Because of his palsy and his weight, he has been teased at school. He needs to exercise more, but if he does too much, his heart problems flare up. The teasing makes him eat for comfort, so he ends up eating too much and often eating unhealthy things. His eating habits influence his weight, and his weight affects both his heart and his state of mind. Stress and low spirits then aggravate his spasticity. And thus the vicious circle is completed.

Consequently, treatment is a considerable challenge. In the following paragraphs, we identify the functional improvements provided by Ambient Intelligence (relative to the case history) and we describe the associated normative issues. In this chapter, we are concerned specifically with the manual adaptation of health care functions and health care services to suit patients' particular circumstances.

What functional improvements can Ambient Intelligence provide?

In Michael's case, it was only the neurologist who used measurement tools (such as the Bayley Scale). The paediatric physiotherapist was ambivalent towards such tools. He did not believe he needed a lot of equipment to observe improvements in Michael's motor functions or in the interaction between Michael and his parents. However, the mother's unanswered questions highlight the value of measured data. Without such data, the paediatric physiotherapist was unable to say whether Michael's condition was the result of the illness his mother had suffered during

pregnancy, or whether the boy's development was held back by a period when his parents were ill and unable to do exercises with him.

By the time in which the Dirk scenario is set, much more is possible: information is combined, digitalized (automation) and exchanged as necessary. When Magda hears that Dirk is unable to discipline himself to take gentle exercise at times of stress and to control his food intake, she provides him with the Little Acrobat. This device provides him with measured data at home and encourages him to adjust his habits accordingly. It also shows exactly what effect various changes have and gives access to the treatment data for all the relevant actors: Dirk, his parents, the physiotherapist and the company.

Normative issues raised by the scenario

The use of Ambient Intelligence to support the personalization of health care functions and services raises at least four normative issues. The concentration on measured data can lead to undue emphasis on the person in isolation, as opposed to in the context of his/her social setting. Hence, while allowing individuals to function more independently, personalization can create new forms of dependency. Greater scope for the provision of customized health care also means greater scope for providing access to health care facilities on a selective basis. Finally, what people expect from intelligent surroundings can differ to such an extent that it is not clear what the goals of personalization should be.

The patient's social setting

If in the pursuit of personalization undue emphasis is placed on measured data, the social integration of intelligent health care technology can be compromised. Michael's case – with the disagreement between the physiotherapist and the neurologist – illustrates how measured data might provide insight into only one form of improvement that therapy may yield: improvement in the individual patient's physical functions. A patient profile that concentrates exclusively on individual risks neglects important factors such as developments in the parent-child relationship. In Michael's case, the parents bore the main responsibility for implementing the treatment. Their progress in coming to terms with the situation was very important in the paediatric physiotherapist's eyes. Improvements in a person's ability to cope with a condition do matter, even if they are not accompanied by improvement in the condition itself.

Independence and new forms of dependency

In this chapter's future scenario, measured data play a greater role. Dirk is able to perform various measurements using his Little Acrobat. The feedback provided by the

gadget makes him more independent, perhaps too independent. After discovering that the fruit juice given to him by his mother is high in caffeine, he starts to trust the Little Acrobat more than his parents. The Little Acrobat facilitates the involvement of various parties in Dirk's treatment, but his parents tend to be excluded by the young man's focus on the intelligent health care technology.

Intelligent health care technology can create new forms of dependency. At first, Dirk needs the Little Acrobat to help him adjust to the discipline of a healthier lifestyle. However, the realization that he can't always depend on what his body is telling him he should eat or do, makes him worry about the physical functions that are *not* measured. Such concerns could establish a purchasing spiral, with people constantly buying newer and better models of their favourite health gadgets to obtain personalized support. The patient as a materialist health care consumer is a vision that may be regarded as an undesirable consequence of using Ambient Intelligence, or as the manifestation of a universal economical principle.

However, we should not lose sight of the fact that catering for people's needs does not guarantee that they will be able to look after their own interests. It is important to consider whether people have the competence to weigh needs and interests against one another and the opportunity to do so independently. That leads us to the question of access and exclusion.

Access and exclusion

To make health care functions and health care services more personalized, it is necessary to have more detailed information about the client/patient: information about physical functions, behaviour, whereabouts at different times of the day, and so on. The availability of such information to all parties involved in the provision of treatment, potentially facilitates the imposition of conditions concerning access to particular forms of health care. This in turn raises the possibility of exclusion. In Michael's case, no one could say how significant it was that for a period his parents did not give him much exercise. By the time in which the scenario is set, it is possible to ascertain such things very precisely. Dirk's parents are reminded not only that unhealthy behaviour influences the cost of treatment, but also that they have a responsibility for their son's behaviour (Dirk being a minor).

A number of important questions therefore need to be addressed in relation to personalization: who may use the information necessary for personalization, and for what purpose? The interests of patients, health care practitioners, insurers, regulatory and executive bodies, government and industry are not always complementary. Indeed, they may be in mutual opposition. Detailed information about a patient can be

very useful for promoting the interests of various actors. Against this background, legislation, clear agreements, and codes of conduct, are all the more important.

Expectations

The considerations set out above cast a new light on the quotation presented in section 5.3: 'It is particularly important that people get what they expect.' This is especially so where the interaction between man and machine is concerned. Unfortunately, however, it is often unclear just what citizens and patients *do* expect or need:

> *'In the years ahead, technology will become smaller, faster, cheaper and less dependent on hard wiring. However, the introduction of Ambient Intelligence to specific clinical applications will proceed incrementally. We do not anticipate any sudden breakthroughs. There is a lot to be done, but we must not hurry things. Each clinical condition and each application needs to be investigated with care.' (Roessingh R&D, 2006)*

It has been shown that in the field of intelligent health care technology, little research has yet been conducted with a view to ascertaining the precise wishes, needs and expectations of potential users.[46] Much of the research that has been carried out has been small scale, fragmented, designed according to quantitative principles, and concerned more with the effects that the intelligent health care technology has on users than on their needs and preferences. It often seems to be assumed that if the technology is good enough, acceptance will inevitably follow. Researchers also seem to take it for granted that there is actually a need for the technical support under investigation.

There are two other reasons why it is not yet possible to say whether Ambient Intelligence could indeed serve as a basis for extensive personalization. First, the assertion that people should get what they expect ignores the issue of access to health care; it assumes a situation where people already have access to the intelligent health care environment or can obtain it. Second, while the potential demand for health care may be practically infinite, the supply is certainly not. The availability of financial and material resources will always constrain the scope for the personalization of health care functions and health care services, even in a personalized health care system.

Automation

At the third level of intelligence, characterized by personalization, health care services will still be manually adapted to the particular circumstances of the patient. The

degree to which adaptation can be automated and the issues associated with automated adaptation are considered in the following chapter.


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6 Follow-up care for cancer patients: adaptation

Every year, around 80,000 people in the Netherlands are diagnosed with cancer.[47] There are more than a hundred different forms of cancer. Uncontrolled cell division may be benign or malignant. Cancer may begin in one organ, such as a lung or the bowels, or may develop in the blood, bone marrow or lymph glands, leading to the rampant growth of cells in various parts of the body.[48] Roughly 40,000 Dutch people a year die of cancer. It is now the main cause of death in males, having overtaken cardiovascular disease.[49]

Nevertheless, in many cases cancer can be cured or kept under control for a prolonged period. That is partly due to the fact that cancer medicine (oncology) is relatively well organized. The Netherlands has a National Cancer Institute and nine Comprehensive Cancer Centres, which coordinate the consultation between experts from the regional hospitals and super specialists from University Medical Centres. In addition, there are various high-level expertise centres, such as the University Medical Centres. In 2005, the National Cancer Control Programme (NPK) was started, with the aim of tackling cancer in various ways, including prevention (the discouragement of smoking, etc.), therapy, and follow-up care.

Follow-up care is very important to patients. Cancer often places enormous strain on a person's physical and mental health. Once a person has been diagnosed with cancer, he or she has to deal with a huge change in his/her circumstances. The treatment is often extremely onerous, and even when it has been completed, there can be a long period of great uncertainty about future prospects. In this chapter, we focus particularly on the scope for personalizing follow-up care for cancer patients. The far-reaching implications of cancer often necessitate considerable adaptation of the support given to patients. We accordingly consider the extent to which Ambient Intelligence can enable the automatic adaptation of such support.

Structure of this chapter

This chapter's case history tells the story of Anna Bosma (section 6.1). She was treated for a malignant breast tumour more than ten years ago, but has recently been diagnosed with metastases in her hip and spinal cord. People with cancer currently need a lot of support as they see the many specialists involved in their care. Such

support is important during treatment and during the follow-up phase (section 6.2). We consider the role that Ambient Intelligence can play in this context (section 6.3). Because patterns can be detected in the course of the disease, it is, in principle, possible to automatically adapt health care functions on the basis of such patterns. Our future scenario therefore looks ahead to a time when primary school teacher Karen is the beneficiary of such adaptive assistance (section 6.4). In the analysis, we identify the improvements that Ambient Intelligence can bring and the associated issues (section 6.5).

6.1 Case history: Within a week, one of Anna's breasts had been removed

It is April 2006. Anna Bosma is fifty-four. Ten years earlier, in October 1996, she consulted her GP, because she had felt a lump in her breast. Anna immediately feared that something was wrong. The GP referred her to the hospital, where her fears were confirmed the same day: she had a malignant breast tumour. Her lymph glands were also affected. Swift intervention was not felt to be a medical necessity, but was regarded as desirable. Within a week, one of Anna's breasts had been removed. She was then given chemotherapy for the metastases. Since her treatment, Anna has visited an internist-oncologist every six months for a check-up. Once a year she has a mammogram. The check-ups are always very tense occasions.

Ten years after her breast cancer, Anna develops a pain in her leg and is immediately concerned. She makes numerous visits to a physiotherapist, but the pain just gets worse. She has the leg X-rayed, but the X-ray reveals nothing. As it happens, the husband of a close friend is head of the nuclear medicine department at the local hospital, and he arranges for her to have a bone scan. Tumours have higher metabolism levels, which show up on this kind of scan. Within a week, she has the results: metastasis in her hip and spinal cord. The treatment is not so bad this time: metastases of a breast tumour can be treated using the same hormone as that used to inhibit the growth of breast tumours.

Looking back, Anna says that it has been a psychologically difficult time: 'I feel that I was left to fend for myself. Ten years ago, the message was: if the pain gets worse come and see us. But I received no support from the official health care practitioners. And I wasn't referred to anyone else. Through talking to people I heard about the Recovery and Balance Foundation. The people there gave me psychosocial and active support: counselling, meetings with people in a similar position, and supervised sport.'

Since the final treatment, the cancer has taken its toll. In the last year the treatment has become more intensive. Anna is now in contact with a surgeon, an internist-oncologist, a radiotherapist and indirectly, with her GP. Each of these carers helps in his/her own way, but no one is responsible for maintaining an overview. Anna wishes she could talk to an expert. Only her physiotherapist takes the time to discuss the situation and helps her think things through. Following a second metastasis, Anna seeks a second opinion from the Antoni van Leeuwenhoek Hospital in Amsterdam. The relevant protocol is very good; there is plenty of opportunity for discussion and explanation.

Anna's concerns are aggravated by what she sees as the 'stupidity' of the doctor. Every two to three months, a sample of her blood is taken for testing. Recently, the doctor forgot to indicate on the lab form what tests were supposed to be performed on the sample. He then sought to play down his oversight by suggesting that the tests weren't all that important. However, when the next sample was taken, it turned out that the tumour activity had increased. Anna's confidence is low and she is nervous. She used to be a nurse and isn't afraid to speak her mind, but she no longer knows whether she should press the doctors for answers. She perceives an irony in the situation she has encountered: 'If it's clear what the matter with you is, you get support right away, no matter how grim the situation is. Bu, if the picture is confused, as in my case, you are just left to get on with it, even though, if anything, you are more in need of attention!'

It is nine months before Anna's hip is operated on, during which time she is often in great pain. Through her friend's husband, Anna had arranged for another X-ray. This revealed that the bone had become so porous that the orthopaedist recommended immediate surgery. However, following a team meeting, the internist-oncologist decided on a course of radiotherapy, which was expected to reduce the pain. In fact, the pain only got worse. 'In the end, I just couldn't bear it any longer,' Anna recalls. 'I just exploded and had a real go at them. That finally got things moving: I was admitted to Heerlen hospital on a Friday as an emergency case. Even then, it was Saturday evening before I was given proper support, and the following Tuesday before the specialist nurse came back off holiday. He took the trouble to find out the details of my case and advised appropriate action. From then on, the pain was managed much better. But why did I have to spend three days in hospital before receiving the care I needed? Surely it shouldn't have taken that long.'

Since Anna finally had her hip operation, her problems have become more bearable. 'Each evening, I take a small dose of methadone. Walking isn't easy and I get very tired; I just don't seem to have much energy. But I don't mope; I'm not made that way.

I make the most of each day.' She still worries about her family, however. 'How do you deal with the possibility of death? It's not something I find easy to talk about. The talks I've had with a psychologist at the hospital have been very important for me. The impact of my medical history is clear now. My partner wasn't always around, because of his work, and the boys had to look after themselves a lot of the time. I feel that they didn't get the attention they deserved. Now I'm living in a home for older people, the situation is easier to take in and more manageable. And I get plenty of visits, not only from my family, but also from my old neighbours. All the same, it's hard to come to terms with the way things have worked out. I should have had a case manager all those years: someone with the right knowledge and skills, who could maintain an overview of my case and sit in on consultations with the specialists.'

(Sources: Anna Bosma[50] and a member of staff at the West Netherlands Comprehensive Cancer Centre, 2006)

Anna's case illustrates the progress made by medical science: the prospects of recovering from or surviving with cancer are much greater than a hundred years ago. Increasing understanding of the disease is leading to ever better treatment: not only is treatment becoming less onerous, enabling patients to go home sooner, but doctors can more confidently say whether a patient has a realistic prospect of survival. This progress owes much to the high degree of specialization and the way cancer treatment is organized.

However, the advances made have had unwanted side effects. Patients are confronted with a complex situation, in which the consequences of their decisions can be difficult to take in. The chance of recovery, for example, is normally expressed as a percentage, reflecting the rate of recovery in previously treated cases. The value of such a statistic to an individual patient is questionable; it offers no certainty. This situation is not helped by a doctor playing down the significance of tests after failing to complete the lab form properly.

Anna's case also emphasizes how dependent a cancer sufferer can be. After she learns that she has cancer, everything changes for Anna. The very next day, she is told that the tumour is malignant and within a week she has had a mastectomy. Ten years later, she has metastases in her hip and spinal cord. Throughout the intervening decade, regular cancer testing and all that goes with it are a fact of Anna's life. Yet she is not given the support she needs to make the right decisions. No one is appointed the task of taking an overview of her situation.

6.2 What needs are not being properly met?

One of the people interviewed for this study was a staff member at the West Netherlands Comprehensive Cancer Centre (WNCCC). The WNCCC coordinates between health care providers, support providers and patients. Its personnel therefore have a good insight into the problems and challenges associated with the treatment of cancer and the provision of follow-up care. Alongside curative care, psychosocial support is very important. The WNCCC has an information centre, which seeks to help patients and former patients by providing information and advice. The centre also supports the 'buddy' system.

Feedback from our interviews with professionals involved in cancer treatment and follow-up suggests that there are gaps in the support provided to patients. Patients would benefit from case management and psychosocial support. Psychosocial support during the follow-up phase can help patients to look after their own (psychological) health. Finding the type of support one needs in the follow-up phase is not always easy, as Anna discovered. One of the topics addressed in this section is the 'buddy' system, which is currently used mainly as a vehicle for psychosocial support, but which also has an important case-management dimension.

Case management

Anna made the point that she would have benefitted from having a sort of case manager. Many years may pass between a cancer diagnosis and the patient's recovery or death. During this time, patients are literally in fear of their lives as they go from specialist to specialist. Anna used to be a nurse and isn't afraid to speak her mind. Yet she is unsure what to do when she has reservations about her treatment; she is dependent on the relationship of trust that she has with her doctor. The lack of support thus affects her twice over: she doesn't know where to turn for support, and without support she is unsure how to view the decisions being made regarding her health.

Anna's uncertainty about the treatment decisions is closely related to the uncertainty about her position in the decision-making process. These problems are amplified by the high degree of specialization in oncology. Specialization may aid effective treatment, but in cases where a patient isn't clearly the concern of any one specialist discipline, there is a lack of coordination. In Anna's case, the various specialists each continued to address her problems from their own perspective, leaving her with the feeling of falling between stools: she receives medical attention, but not the attention she needs. In an effort to get around this, Anna turns to her friend's husband for help on several occasions, hoping that he will be able to shed new light on her situation.

This does not strengthen Anna's faith in the quality of her care, which is already shaken by her carers' mistakes. While anyone can make a slip, her doctor's response to his oversight does not serve to reassure.

What is needed to ensure appropriate treatment is case management. Because the cause of Anna's pain is not immediately apparent, no one feels responsible for deciding what to do next. The situation is made worse by the decision-making surrounding her hip operation. The treatment strategy could have worked out better if the support services and specialist health care had been properly integrated. A case manager, backed up by a patient-centred electronic medical file, could then have supported Anna in her contacts with the various specialists. The information given during consultations with specialists is often difficult for patients to take in. To be effective, a case manager would of course need to have the ability to provide expert assistance to the patient in dealing with physicians, lawyers and other professionals.

Psychosocial support

The problems outlined above derive not only from a lack of oversight, but also from a lack of psychosocial support. Following her treatment, the care given to Anna consists only of pain management. There is nothing else that the professional health care system can do to help her – to help her *physically*, that is. However, Anna believes that the professionals could do more for her in psychosocial terms. She doesn't complain, though, for fear of jeopardizing the help that she *is* getting.

Psychosocial support is also important during the follow-up phase. Feedback from our WNCCC interviewee suggests that there are gaps in the support provided to help people live with their illness:

> *'In follow-up care for cancer patients, it is important to distinguish between two groups of patients. First, there are those whose prognosis is good, whose cancer has been treated effectively. Then there are those whose condition is incurable. People in the second group can sometimes live for quite a long time with the disease. About half of those with untreatable cancer receive palliative care, which includes pain management. But what is often overlooked is that when a person has cancer or has had cancer, they often feel extremely tired and listless. The care they receive should be geared to helping them with these problems as well.' (WNCCC, 2006)*

The quotation above illustrates how important it is to tailor support to the needs of the individual patient. Although Anna wasn't affected by fatigue and listlessness, many people in her position are. Such people need day-to-day support as they recuperate and recover. A supervisor could, for example, monitor a patient's activities and provide feedback on their rhythm and intensity.

Anna's case shows how important feedback and support are with regard to pain management decisions, for example. Where pain management is concerned, the precise indication of dosages is very important. Using additional morphine patches might reduce pain but has side effects, such as impaired concentration. In this field, consideration has to be given to quality of life. It is already possible to discuss such matters with a nurse, but support from a trusted adviser could be of significant added value. Furthermore, someone with an overview (a case manager) would be able to reduce the threshold that must be reached before contacting the doctor. The value of such an arrangement is again illustrated by Anna's hip operation. When Anna was in acute pain but the normal specialist was away, teleconsultation with an available specialist could have saved her a great deal of suffering.
Case management is also conducive to good psychosocial support:

> *'It is not unusual these days for a woman to undergo a mastectomy and be back at home the same day. There are various approaches that can be taken to help a person deal with that kind of fundamental change. It is known, for example, that getting plenty of exercise is healthy and can counter depression and apathy. But it is difficult for patients and care practitioners to establish what the best approach is and difficult for patients to adhere to that approach.' (WNCCC, 2006)*

Clearly the knowledge needed to provide appropriate support is already available, but hospital treatment is not coordinated with follow-up support, which isn't provided by the hospital. In other words, there is an unhelpful separation of cure and care. This is apparent in our case history: it is only by chance that Anna hears about a foundation that provides follow-up care. And it is only with hindsight that Anna realizes how far-reaching the original decision to have a mastectomy was: the surgery changed her whole life. The fact that everything happened so quickly amplified the impact.

As the scope for treating cancer increases, so does the importance of support in the follow-up phase. The development of evidence-based medicine, for example, is leading to ever more effective cancer therapies, but treatment decisions remain extremely problematic:

> *'Evidence-based medicine is great, but does lead to certain problems. We know that people sometimes attach a lot of hope to one last procedure, even though – given their prognosis – the treatment is pointless. If we send these people home without that final treatment, we are effectively giving up on their psychological care as well, because we are taking away the hope that feeds the power to fight. We need to do something about this.' (WNCCC, 2006)*

Patients' uncertainty can often be reduced by follow-up checks, but these are being used less and less frequently, because there is little medical need:

> *'Follow-up checks are becoming less common, and this trend will continue; the reason being that they don't tend to make medical sense. However, in the interests of psychosocial support, for example, it* does *make sense to have such checks done by a GP.' (WNCCC, 2006)*

Anna's case shows the importance of not simply leaving patients to cope on their own. The absence of follow-up checks often means that patients fret about their health and are in considerable need of socio-emotional support from medical professionals. The absence of feedback on the patient's condition can lead to depression, particularly in cases where the prognosis is poor. The Comprehensive Cancer Centres do, to some degree, meet the need for information, but it depends largely on the patient whether good use is made of this channel.

Buddy support

Buddy support is part of the professional health care system, which provides valuable support for many patients. A buddy is in a position to adapt effectively to the patient's situation, even if it is only the speed that he or she walks when strolling with the patient. In our case history, the physiotherapist acted as a sort of buddy for Anna. The buddy is also involved in the process of health care provision. Like an AIDS buddy, a cancer buddy can help the patient make decisions. At the moment, buddy support focuses mainly on the patient's emotional needs, but buddying could be combined with case management to good effect. As previously indicated, this implies having the ability to act as a physician, lawyer or other professional. The difficulty is that, in practice, buddies easily become overloaded.

6.3 The potential benefits of Ambient Intelligence

As Anna's case shows, the duration and unpredictability of cancer make coping with the disease particularly difficult for the patient. As a consequence of her condition, Anna has to change the way she lives: she moves to a home for the elderly. To do so, she needs practical support from her social setting – assistance moving all her things, for example. But Anna's relatives, friends and acquaintances are most important, because they can empathize and adapt to the new situation. Anna's former neighbours visit after she has moved, for example. Anna derives vital support from such visits. It does not follow, though, that Anna's social contacts can take responsibility for her case management. They lack the necessary medical experience. Furthermore, not everyone can count on support from their social setting.

How could Ambient Intelligence enhance the support given to patients? In this paragraph we consider the ability of Ambient Intelligence to adapt to a person's needs, particularly when personal circumstances change. The Ambient Intelligence vision does not merely foresee intelligent equipment, but a situation where we are surrounded by intelligence. For the patient, this implies adaptations both to the health care provision network and to the support network.

Supporting case management with data on personal circumstances

A sound basis for case management already exists in oncology. Oncology was one of the first medical disciplines to introduce teleconsultation as a vehicle for discussion, both among geographically distributed medical professionals and between patients and specialists. Teleconsultation can be realized by means of broadband video conferencing, for instance. Specialists consult one another frequently, facilitating a high degree of terminological standardization and standardization for the purpose of medical data interchange. Such standardization enables the integration of specialists' digital systems.

Ambient Intelligence can help to provide insight into a patient's medical condition and thus facilitate adaptation of his or her professional and social setting. In follow-up cancer care, Ambient Intelligence can be incorporated into devices that help patients to monitor their behaviour and lifestyle:

> *'ICT can play a role in highlighting fatigue, because many people take insufficient exercise. Similarly, technology can pick up on the fact that a person isn't getting enough fluids or is otherwise not doing the right things physically .' (WNCCC, 2006)*

Automatic adaptation

The WNCCC interviewee quoted above mainly had in mind devices that highlight problems. But problem identification is not adaptation. What is needed is advice relating to the matter that has been highlighted: maybe suggesting a walk in the woods, a drink of water or something to eat. The Ambient Intelligence vision also foresees automatic adaptation – in the field of pain management, for example. The precise nature of the adaptation may be based on a pattern, perhaps a physiological manifestation of pain such as reduced skin resistance. Pain medication could then be automatically adapted on the basis of the monitored parameter(s). Caution is needed here, however, since increasing morphine dosages can impair concentration, for example. It must therefore always be possible for the patient or a doctor to overrule the automatic adaptation.

E-buddy

The case history described how Anna had to change her way of life. Such changes can be accompanied – quite literally – by a lot of pain. The course of Anna's illness is erratic and unpredictable, increasing the need for support from a buddy or case manager: someone to keep her and the health care practitioners on their toes and to bring cohesion to her contacts with the various specialists:

> *'The buddy system is really taking off. Buddies are expected to provide company, offer social and emotional support and accompany the patient when visiting health care practitioners. A buddy is made available to the patient for half a day a week. A system of e-buddies could be a useful supplement. Young people can already visit the Internet Safe Haven, for example, where they can make online contact with people in similar circumstances. Making online friends can help prevent loneliness.' (WNCCC, 2006)*

The existing buddy arrangements could be supplemented by creating an electronic buddy network to provide case management services. In Anna's case, various complications suddenly sprang up. Under such circumstances, a cancer patient can benefit from having someone who is aware of changes in the patient's way of life. Anna's physiotherapist played that role for her.

6.4 Future scenario: Karen finds it hard to leave everything to technology

The scenario below is set in the period 2015 to 2017.

Karen has been working at a primary school in Enschede for fifteen years. She is good at her job: she is very patient and has a special talent for dealing with small children. A few months ago, she noticed a small lump in her right breast, but told herself it was nothing. She felt fine; how could anything be wrong with her? She began to worry, though, when she realized the lump was getting bigger. Karen went to the hospital for an examination. A week later, she was back for surgery. A malignant tumour was removed, along with her right breast and lymph nodes. Karen was allowed home the same day, but her life has been turned upside down. She is in a lot of pain. After a few weeks, once she has recovered from surgery, Karen goes to the hospital to start a course of a new type of chemotherapy.

Back at home, Karen gets a lot of moral support. Her pupils send her cards and presents. But she finds it hard to talk about her health. The only person she feels comfortable discussing the subject with is Margot, a friend who developed breast cancer two years ago. Chatting with Margot is good; at least with her Karen can joke

about choosing wigs and such like. Margot tells Karen that she is a member of the Breast Cancer Association, for whom she organizes a lot of activities for fellow breast cancer sufferers. Not long ago, for example, Margot took a group to Marianske Lazne, a health resort in the Czech Republic.

Margot wears a device with sensors. The device, part of the My Life Manager service, monitors her fulfilment of her exercise plan and how relaxed her breathing is during training. The My Life Manager monitors nutrition, stress, fatigue and her activity pattern. It provides personalized advice on what the user should do, given her present capabilities. After chemotherapy, a patient needs to get plenty of exercise, because the drugs damage muscles. The device continued to function when she was abroad at the health resort. At first, Margot wasn't keen on the My Life Manager; she didn't like the idea of it dictating the pattern of her day. However, the compulsory tone of the warnings given by the device persuaded her that she should persist with it. 'I do sometimes feel a bit of a slave to the thing,' she says. 'And it doesn't miss a trick! I think it would be easier to accept if I always understood why it was telling me to do or not do something. As it is, what the Manager says is gospel, and I just have to accept it. – even though my weight is good and I'm pleased with the way things are going.'

To Karen, the device Margot wears sounds like a bother. Margot has sensors implanted beneath her skin to measure skin resistance (an indicator of how much pain she is in). 'But surely you know how bad the pain is, without that thing telling you?' asks Karen. 'Of course I do,' Margot responds, 'but the Manager gives the doctor feedback, so he can see the effect of changes in my medication dosage. All I have to do is answer the questions that the device asks. Another good thing is that I only have to see one doctor, who checks that everything's OK. I'm not saying that everything's great: I'm often in a lot of pain. But I do have a case manager, who I can discuss everything with. He doesn't come with me when I go to see the doctors any more, but he makes sure that I can get all the information that I need for the doctor from the device, in a way I can get my head round.'

A few weeks later, Karen goes for chemotherapy at the outpatient clinic. She has prepared herself well, and Margot has offered to go with her. Karen has been offered a new type of chemotherapy, which should be less unpleasant. Her health insurer has also agreed to cover the cost of a My Life Manager. Margot's support is very important to Karen, and she is willing to give the My Life Manager a try on the basis of Margot's experiences. Margot says that Karen should treat it in the same way as the GPS in her car: you don't worry about the road, you just follow each instruction and you end up in the right place. Karen finds that the Manager does give her a better idea of what is happening to her body. The questions that the device asks help her to

be more analytical about how she feels and why. The Manager also gives her a better overview of her exercise pattern.

Nevertheless, Karen isn't sure whether she has made the right decision. Using the device is quite complicated, and these days she often feels too tired to take in and remember the instructions. The device may give good advice, but it has no idea how much pain and trouble it costs her to stick to the recommended regimes. She has to take extra medication and more painkillers. As a result, she sometimes feels so fuzzy-headed that it's almost as if her body doesn't belong to her. Sometimes Karen just feels like giving up, because she hasn't got the energy left to fight. But My Life Manager won't let her give in: it constantly checks the effectiveness of the pain management, and it monitors her exercise pattern. And if she adjusts the settings to give herself more slack, then she has to decide for herself what dosages she needs. Although Karen knows that surgery is very unpleasant, she wishes that she could have an operation instead. Unfortunately, the My Life Manager doesn't ask questions about things like that.

THans goodness for buddy support! Karen finds that talking about her problems helps: it makes it easier to accept being dependent on the My Life Manager. Indeed, Karen feels it is a pity that buddy support doesn't continue automatically; she doesn't know how she will cope when all she has is the My Life Manager. Margot doesn't find reliance on the device so hard. 'You just have to trust it,' she says.

(Source: WNCCC and the Comprehensive Cancer Centres, 2006)

6.5 Analysis

The case history presented at the start of this chapter described how Anna felt she had been left to cope on her own. She wanted support, but did not know how to obtain it. By the time in which our future scenario is set, Karen and Margot have a quite different experience. Margot has a case manager and Karen a buddy, while both have the My Life Manager to help them adapt to the new circumstances in which they find themselves. However, although Karen and Margot can learn a lot from each other, they are quite different in their attitude to the support provided by the My Life Manager. In the following paragraphs, we analyse the difference between the two women's attitudes and we consider what adaptation by the My Life Manager does and does not make possible.

What functional improvements can Ambient Intelligence provide?

The My Life Manager can be seen as an electronic buddy. The device supports both case management and psychosocial support processes. The Manager makes it easier to set out all the available data in an accessible manner for use in consultation with a doctor. Furthermore, the women need to keep in touch with only one doctor for case supervision purposes. While simplifying things, this does mean that the contact that Karen and Margot have with their one doctor is critical, being the only context in which they can ask other questions.

The My Life Manager also helps to make sure that Karen and Margot get enough exercise and enough to eat. Karen likes the fact that she has a better idea of what is happening to her body. She can't hold a conversation with the Manager, though. When confronted by a problem that's hard to interpret, such as persistent pain, that is a drawback. Karen therefore needs a flesh-and-blood buddy, but with her buddy she mainly discusses the pain itself, not her frustrations with the Manager.

Normative issues raised by the scenario

It is clear that the My Life Manager provides support. However, the appropriateness of that support is a judgement that turns on the views of the health care practitioner and the patient. That is what one would expect, but it means that the use of the Manager is associated with a number of normative issues, because there is an inevitable assumption that the support provided by the device is by definition the right support. Karen's buddy, for example, is expected to take on the case management, and then to gradually hand that responsibility over to Karen and the Manager. In that situation, the advice given by the device is decisive. Unfortunately, in her present condition, Karen lacks the will to make it clear that she would prefer things organized another way. Furthermore, she expects the device to take care of her pain management; that is why she has it. The case manager, buddy or doctor could observe this problem, but each of them is dependent on the expectations that Karen and Margot have of the Manager. Whether those expectations are justified depends on the competences of the patient and the doctor's interpretation of the data.

Patient competences

The first criterion for the success of the My Life Manager is that the patient should possess appropriate competences. Cancer patients typically lose the ability to do many things; sometimes the process is fast, sometimes it is slow. They may become less mobile, for example, as their action radius (the distance they feel able to travel) diminishes, or they may lose their sense of taste and with it the capacity to enjoy food

and drink. Crucially, their ability to adapt is compromised. Yet their need for adapted and adaptive surroundings increases. Dependency is liable to result if the support is not sensitively aligned with the needs of the patient.

It is apparent that Anna, Karen and Margot have different competences. In the case history, Anna describes herself as not afraid to speak her mind, yet she consistently finds it difficult to communicate her doubts. In our future scenario, Karen has similar problems. Karen also has trouble communicating her doubts, but the My Life Manager does not help her to discuss them. The device gives Karen insight into her life pattern and generates reports, but that does not help her to be more self-assertive with the doctor. In other words, the Manager does not change Karen's competences. Margot, too, feels that the Manager has certain shortcomings, but she is able to take them in her stride. For his part, the doctor interprets the adaptations made by the Manager only in terms of pain management. That is not necessarily a problem, but who is responsible for assessment?

Data interpretation

The second criterion for successful use of the My Life Manager is that the available data be correctly interpreted by the doctor. Cancer is often progressive. Although its development is difficult to predict, the disease does follow patterns. Automatic adaptation requires three normative judgements to be made: what patterns are being followed, have any critical values been exceeded and what action should be taken in response? It is nevertheless difficult to decide what adaptations the identification of a disease pattern should trigger: more pain management, further surgery or another course of radiation? As Anna's case shows, it is not always clear what is best. It proved difficult to establish how active her tumour was and the significance of the test data was unclear.

In relation to adaptation, therefore, it is necessary to consider what observations are necessary and who should make them. Sometimes things are very straightforward: to establish whether a person needs to urinate, for example, it is simply necessary to measure bladder distension. Where pain is concerned, the situation is much more complex. Karen and Margot therefore have check-ups with a doctor. He has to interpret what Karen and Margot tell him, with help from the measured data. But the My Life Manager can provide information only about physiological parameters and relate this information to the answers that Karen gives to the Manager's questions. It then adjusts her medication accordingly. But Karen has little feel for what is happening: all the painkillers are making her feel awful. Furthermore, because Karen does not tell the doctor these things, he cannot make a judgement that also takes account of Karen's quality of life.

To what extent can intelligent surroundings automatically adapt to the patient?

In this chapter, we have explored the scope afforded by Ambient Intelligence for enabling adaptation in the automation of health care services. Where follow-up care for cancer patients is concerned, the potential lies mainly in case management and psychosocial support. Our future scenario illustrates how technology might enhance oversight in the case management process: in the follow-up to their cancer treatment, Karen and Margot see only one doctor. The scenario also illustrates various methods of adaptation: the My Life Manager bases its life-pattern advice on the patient's weight and activity level. However, the decision to make an adaptation – i.e. to act upon the Manager's advice – lies with the patient.

On the other hand, the technology envisaged in our scenario could also enable a degree of automatic adaptation in the field of pain management. The My Life Manager has the capacity to learn: it asks questions about pain perception, continuously records the patient's feedback and refines its decision-making about appropriate dosages accordingly. Not everything is left to the device, however. Karen and Margot independently decide to take extra painkillers and are able to adjust the Manager's settings.

Adaptation on the basis of personalization

The considerations presented above suggest that it would be a mistake to expect too much of automatic adaptation in pain management. Adaptation of the kind foreseen in the Ambient Intelligence vision (see chapter 2) is based upon personalization and therefore exhibits the drawbacks of personalization. In technical terms, personalization is realized by combining various personal characteristics in a profile; adaptations can then be made on the basis of this profile. In other words, the adaptations that are made reflect changes in the personal characteristics. Where a cancer patient is concerned, the changing characteristics will often be a consequence of increasing disability brought about by progression of the disease. In this chapter, we have seen how adaptation might work in the field of pain management. The My Life Manager optimizes pain management on the basis of the pain experienced by the patient, but cannot optimize any other treatments that the patient may require. The Manager does not have the intelligence to make the necessary adaptations: the relevant information is not in the patient's profile. It may well be the case that surgery would be too onerous for Karen. However, because she lacks the competences needed to communicate her concerns, the pros and cons of surgery are never properly weighed up by the doctor, the buddy or Karen. This brings into question the

extent to which the adaptations made by the Manager are actually appropriate to Karen’s personal needs or interests.

7 Sport: anticipation

If there is one activity that has a clear correlation with health and welfare, it is sport. The importance of regular exercise is emphasized at every turn. Good health later in life is, to a significant extent, the product of leading a healthy lifestyle in one's youth. So it is never too soon to take up sport.[51] Sport is good as a means of avoiding depression and obesity, for example, and helps to prevent or delay the progression of conditions such as osteoporosis and Alzheimer's disease. Where many physical functions are concerned, the message is clear: use it or lose it.

All kinds of people exercise. At one end of the spectrum is the dedicated athlete, at the other, the 'couch potato'. Some people will happily walk the dog for hours, while another will be satisfied if the pedometer registers ten thousand steps a day.[52] Dutch biologist and science writer Midas Dekkers observes that human beings have a curious attitude to exercise: on the one hand they automate everything so as to minimize physical exertion involved in everyday life (how many people use the stairs if there's a lift?), while on the other they keep coming up with new forms of recreational exercise.[53]

In this chapter we consider the final level of Ambient Intelligence: anticipation. This is the level of Ambient Intelligence that promises the most: intelligent surroundings that sense the direction in which our needs are developing and automatically make appropriate adaptations.[54] We explore this level of intelligence through the medium of elite sport. Anticipatory technology may represent a new high point or low point in terms of taking a responsible approach to health, welfare and comfort. Which it proves to be depends on exactly what the technology is required to anticipate – whether it is geared to maintaining the health of the sportsperson or helping the sportsperson optimize his or her performance. Opting for one may be at the expense of the other, as the nature of sport becomes less recreational and more elite.

Structure of this chapter

Our case history describes how Jack, a 100-metres sprinter, is preparing for the Beijing Olympics (section 7.1). Try as he might, he cannot draw on that last ounce of strength potentially at his disposal. The utilization of that strength is a need that is not currently met (section 7.2). We consider how Ambient Intelligence could address this and other needs by means of so-called field labs (section 7.3). In the chapter's future scenario, we meet Iris, another sprinter who *is* able to access all her reserves with the

aid of technology. Doing so enables her to run faster, but also jeopardizes her health (section 7.4). Finally, we compare the situation described in the case history with that described in the scenario We consider which functions and relationships have been improved by Ambient Intelligence, and what normative issues are raised by use of the technology. To what extent can intelligent surroundings automatically anticipate the needs of individuals (section 7.5)?

7.1 Case history: 'You've got a record in you, Jack, but how are we going to get it out?'

Jack is a nineteen-year-old athlete. His discipline is the 100- metres. He has been selected to represent the Netherlands at the Beijing Olympics in 2008 – a dream come true. Jack is ambitious. He is aiming for gold and wants the world record as well. Before the Games, however, he has a demanding training programme to complete and a number of national meetings to compete in. Although he doesn't really have much serious competition in the Netherlands, he definitely plans to run in the events. 'A world record is still some way off, Jack,' says Arnold, his coach. 'We need to take you to another level yet'. His father has his reservations about it all. 'And what if you win in Beijing? I don't suppose you'll be going back to school. In ten years you'll be finished as a sprinter. But you'll still be forty years off retirement age, with no education.' Jack is determined, though, and – after a heated discussion with his parents – he puts his education on hold.

Jack has faith in Arnold. Which is just as well, because there's a lot at stake: a gold medal, of course, but also, if he's not careful, his health. Jack's faith is justified: Arnold knows just how far he can push his athletes. He knows them well. Jack, for example, thrives on pressure. He performs best when the pressure is greatest, but between training sessions, stress is to be avoided as much as possible.

When Arnold goes away for a while, Jack is left to the assistant coach and the sports doctor. It is only then that Jack realizes how important Arnold is to him. Not long ago, for example, Jack had some health problems. The sports doctor reckoned he should keep training, but Jack's GP disagreed. The physiotherapist and the assistant coach kept out of the argument. So Jack called Arnold, who was away on holiday in Dubai. 'You know yourself better than any of these people,' said Arnold. 'If you think you can do it, then do it.' Jack did it.

Arnold has invested a lot in Jack's technical guidance. Together with the sports doctor, the physiotherapist, the assistant coaches and the dietician, they are able to monitor and guide Jack's performance during training. In this way, they are able to

ensure that he peaks at the right time. Jack's heart rate, body fat percentage, heart rate variance, breathing rate and muscular oxygen uptake: everything is recorded. Arnold is also experimenting with the measurement of Jack's brain activity using an EEG (electroencephalogram). An expert system collates the measured data. Sometimes Arnold gives Jack feedback during training and gives him directions. Jack hates that, especially when he is doing a sprint. The biofeedback interferes with his concentration. 'Can't you save your comments until afterwards? I can do without all this stuff going on around me! It just makes me slower!' The clock backs him up: he's 0.381 seconds slower, to be precise. So they give the in-session feedback a miss for a while. Arnold adapts his methods on the basis of Jack's response, coupled with his own experience.

Four months before Beijing, Jack is still 0.07 seconds off the world record: he can now do the 100 metres in 9.84 seconds. In a bid to discover where in the event those last few hundredths of a second might be shaved off, Arnold takes Jack to the Olympic Stadium in Amsterdam. A basic field lab – a trackside laboratory for collecting data under near-competition conditions – has been set up for their visit. Fortunately the assistants can get everything ready, because it is a time-consuming business. Jack wears a vest with an array of built-in equipment. It is very light, but Jack still feels it is weighing him down. He perceives the equipment more as an obstacle to the achievement of his goal than as a form of assistance.

Arnold and Jack disagree about the best approach. Should Jack try to jump harder out of the blocks, or kick in the closing metres, or measure his effort more evenly over the distance? To help them decide, they measure the power Jack is generating in his starting effort. But, no matter what they try, 9.84 is the fastest Jack can manage. 'The figures indicate that you are not using all your potential strength,' says Arnold. 'You've got a world record in you, Jack, but how are we going to get it out?'

(Source: literature study and interviews with coach Henk Kraaijenhof and NOC*NSF)

Jack is a young, ambitious athlete whose goal is to win the Olympic 100 metres. He would also like to set a world record for the distance. As yet, however, he is 0.07 seconds too slow. It sounds very little, but it means everything. Jack puts his studies on hold so that, as his coach says, he can take his sprinting to a new level. As for life after elite sports, well … he'll cross that bridge when he comes to it.

Jack's case illustrates how intensively technology is used to enhance elite performance. If you want to compete with the best, there is no other way.[55] Jack will never break the world record running barefoot on sand.

Although various health care professionals are involved in his quest for gold, Jack remains responsible for his own health. When he is feeling under the weather, Jack is unsure whether to begin his hard training programme. After getting conflicting advice from his physiotherapist and his GP, Jack calls his coach.

Arnold's advice to Jack – that he knows best whether he's up to training – is in sharp contrast to Arnold's scientific approach to the training itself. Arnold acts as an expert consultant, saying what the data from the instruments all mean for Jack. In order to find out exactly what he needs to do to break the world record, Jack is evidently dependent on the knowledge and insight of his coach, sports doctor, assistant coaches, dietician and physiotherapist.

Whatever strategy the team adopts, Jack isn't able to go faster than 9.84 seconds. Having biofeedback while sprinting has an adverse effect, and the test equipment itself is too much in evidence for Jack's liking. Besides, the data tell him only that when running his fastest he isn't using all his potential strength; they don't tell him how to utilize that untapped strength.

7.2 What needs are not being properly met?

When milliseconds and millimetres make the difference between winning and losing, it is vital for an athlete to be able to call on every ounce of strength he or she can muster. However, the utilization of 'hidden' reserves is not the only need that is not currently met by elite sports practice.[56] Other unsatisfied needs have to do with the balance between health and improved performance. These include:

– Better protection of athletes' health
– Consensus as to what constitute acceptable means of improving performance
– Improved coordination within athletes' support teams, including trainers, sports doctors and dieticians
– The exchange of information between grassroots and elite sport[57]

These five needs are briefly considered in turn below.

Improved performance

In elite sport, there is currently a great need for insight into the interrelationships between measured data, behaviour and performance. Such insight would make it possible to individualize the training and supervision of sportspeople with a view to optimizing performance.

Health protection

The greater the physical and mental strain a sportsperson is under, the more likely it is that his or her health will suffer. To avoid irreversible damage, in elite sport there is a real need for knowledge about the health implications of constantly striving for improved performance.

Consensus

The third need identified above is closely related: the need for consensus as to what is and is not acceptable as a means of enhancing sports performance.[58] One of the guiding principles here is that there should be a 'level playing field' for all.[59] Although consensus already exists on many points, continuous review is necessary. Medication, for example, may be used in sport only as therapy in the event of illness or injury; medication may not be used for performance improvement. However, if a sportsperson uses medication to recover more quickly and resume training sooner, is that not a form of performance enhancement? Furthermore, as with doping, it is open to question how healthy the practice is.[60]

Coordination

The fourth point identified as an unfulfilled need, is the lack of coordination among the various parties associated with a sportsperson. It is only by sharing knowledge and experiences that the professional support team around the sportsperson can optimize decision-making. This is important if they take different views of the sportsperson's condition, for example. Our case history highlights a possible conflict deriving from such a difference of opinion: when Jack is feeling under par, the sports doctor advises the runner to stick to his demanding training schedule, but his GP disagrees.

Experience from grassroots sport

The final need listed above is the need for information to be exchanged between grassroots and elite sport. Elite sportspeople and their supervisors require considerable competence to predict the effects of interventions such as special diets, specific training schedules and new materials. How will such factors influence the performance or health of the athlete? The numbers participating in grassroots sport are far greater than those involved at the elite level, yet the standard of performance and the degree of reliance on technology is often nearly as high. Information about the benefits and drawbacks of using technology in grassroots sport can therefore be very useful in elite sport.

7.3 The potential benefits of Ambient Intelligence

The needs identified above all relate to the balance between the sportsperson's health and performance. In the following paragraphs, we consider how intelligent surroundings might support the maintenance of that balance. What scope is there for using Ambient Intelligence to facilitate coordination and information sharing among professionals associated with the athlete? Or to promote the exchange of data between grassroots sport and elite sport? Finally, can Ambient Intelligence contribute to the development of consensus with regard to what is and is not acceptable in sport?

These questions bring us to the issue of field labs, a basic example of which featured in the case history. A more complex facility equipped with various instruments would be a form of intelligent setting. Field labs are being used in more and more sports. The Netherlands Organization for Applied Scientific Research (TNO) and premier league club PSV Eindhoven have developed a field lab for use in football, for example. The lab allows numerous variables, including players's position, speed, acceleration and heart activity, to be measured and visualized. Training can even be monitored remotely from the perspective of each individual player. Furthermore, coaches get immediate feedback about tactics, performance and players' cardiac loads. With input from the Dutch sports umbrella organization NOC*NSF, these systems are now being adapted for use in speed skating and athletics.[61]

The health-performance balance

Ambient Intelligence promises to bring an end to the imbalances that are frequently created between a sportsperson's health and performance.

In other words, the biggest challenge for field labs is to make the transition from data collection to intervention. Luc van Agt, fitness coach and exertion physiologist at PSV, is convinced that the use of field labs can result in the optimum balance being found for every footballer:

> *'Because we can now monitor players' heart rates in real time, we can develop individual training programmes that stretch each player to the optimum without risking breakdown.'*[62]

Other field labs established in the Netherlands include that used by the Eindhoven National Swimming Institute (Dutch initials: NZE) and the Flik-Flak gymnastics complex in 's-Hertogenbosch. At the NZE, twelve underwater and overwater cameras are built into the wall of the training pool. Via a computer, coaches can then observe

a swimmer's stroke very closely and analyse it using the Vision Training System (VTS).

At the Flik-Flak, runways, landing mats, equipment and gymnasts are fitted with instruments. In order to establish the ideal line for an individual to follow when addressing the horse, pressure sensors in the runway measure the gymnast's push-off and speed. A heat-sensitive camera enables hand placement on the horse to be studied. Finally, sensors record the speed and angle of the gymnast's landing.[63]

Optimum coordination

Coordination and information sharing among the people associated with an elite sportsperson can be supported by applications such as the Sportlog.[64] The Sportlog is a digital log that gives a sportsperson access to statistical and visual information on his/her performance, as well as a historical summary of training schedules and results. In addition, coaches, specialists and other professionals who have appropriate authorization, can view data and give advice. The Sportlog promotes standardization in the registration of injuries suffered by elite sportspeople. Coaches have access to the technical data, but not to the athlete's medical details.

Experience in grassroots sport

Resources such as the field lab and the Sportlog can be used in competitive grassroots sport, as well as elite sport. Because the measured data are stored digitally, they can be made available in anonymous form for use in elite sport. Experiments are also being conducted incorporating intelligent surroundings into recreational sport. One example is FitGames: a combination of games and sport. Participants perform rhythmic exercises to music on a special mat. The speed of the exercises depends on the speed of the music and participants are given instructions using a projection screen. Sensors in the mat 'note' whether the participants make the right movements, and automatic feedback is given on their progress and sense of rhythm.[65]

There is a growing consumer market for heart rate meters, calorie meters, pedometers and such like. Earlier, we referred to running shoes that can communicate with the wearer's iPod. Other examples of this trend include the Nintendo Wii games console and so-called 'exoskeletons'. The Wii's controller is fitted with sensors and is either held in the hand or worn on the wrist. The user makes real-world movements which are mimicked by his/her virtual *alter ego* in on-screen the game. So the user hits a virtual golf ball by making a real swing in front of the console. Exoskeletons are 'external skeletons' developed to aid the mobility of people with locomotor problems (such as paraplegics). If such a person still has some

muscle strength, this can be reinforced sufficiently by an exoskeleton to afford the person a degree of mobility. The games industry has turned this principle on its head: players wear exoskeletons that increase the force needed to make certain movements, thus simulating the feel of, say, climbing a mountain.[66]

7.4 Future scenario: Iris finds it hard to choose between better performance and good health

Below we present a future scenario which envisages the use of intelligent surroundings to help maintain a balance between the health of sprinter Iris and her athletic performance. The professionals around her coordinate their activities and share information, with each other and with Iris.

It is 2018. Iris is a twenty-four-year-old aspiring sprinter. A few days ago, she moved back from South Africa to Amsterdam to prepare for the 2020 Olympics. She is sometimes referred to as the new Nelli Cooman: explosive and self-willed. In 1984, Nelli set a world record for the 60-metre dash, covering the distance in just seven seconds: a mark that stood for nine years, until Irina Privalova shaved just 0.08 seconds off the time. 'Those two women are my role models,' says Iris. 'It is extraordinary that they ran so fast without the benefits of modern technology!'

In training, Iris wears a SmartTracksuit, into which a range of ultra-light instruments are incorporated, constantly feeding data back to a mobile field lab. The instrumentation and lab together form a wireless Body Area Network (BAN). The tracksuit fits Iris like a second skin. Iris thinks back to how, as a thirteen-year-old, she had watched one of the Dutch squad's last training sessions before Beijing. Jack was her hero; she had a schoolgirl crush on him. She still clearly remembers the way he threw his vest on the track in anger because of all the annoying instruments. She, by contrast, barely notices the equipment in her clothing. 'This is the way to get data on performance under competition conditions!' These days, the 100 metres is the love of her life.

Arnold recalls the scene with the vest as vividly as his current protégé, Iris. Iris's personal best for the 100 metres is 10.62 seconds. The women's world record has remained in American hands since 1983 and currently stands at 10.29. However, the Dutch econometrists Einmahl and Magnus have calculated that it should be possible to clip 0.18 seconds off that time. In 2005, they calculated ultimate records for fourteen athletic disciplines, using the so-called extreme values theory (which had

previously been used only to work out the risks of extreme damage arising from air crashes, earthquakes, dyke failures or oil tanker groundings).

Arnold was fascinated by the calculations. 'I want to see if we can bring your stress reaction under control,' he says to Iris. 'Stronger muscles and better nutrition won't count for much if you keep cracking under pressure. We've got two years to get your time down by at least 0.33 seconds.' Iris's sponsor has provided her with a SmartSportmonitor, complete with a home vest to measure the build-up and reduction of stress. 'Great,' says Iris, 'I don't have to do a thing. It's very comfortable, and I want that record!' The data collected while Iris is at home resting indicate that she needs more time to recover from hard sessions, so her training schedule is adjusted accordingly. After a while, the ConditionManager – another device that Arnold likes to work with – says she is in better shape than ever. Indeed, it is clear to everyone from Iris's Sportlog that that is the case.

Two weeks before the national championships, everyone gathers for a final training session. The print mat is ready, the power platform has been tested and the high-speed cameras are put on their fastest setting. According to the ConditionManager, a new PB is on the cards. Iris is very confident. She has been tapering for the event, taking longer gaps between sessions. As a result, she is feeling very relaxed. 'You can really go for it today,' says Arnold. 'We'll give the sponsors their money's worth.' At the gun, Iris explodes out of the blocks with extraordinary power. She surges down the straight like a train on a track and smashes her Personal Best by five hundredths of a second. She is overjoyed.

A week later, however, Iris can tell that she has pushed herself too hard. She decides that she needs to be more careful with her health. All the same, the first race of the season is only a week off. The sports doctor prescribes her medication to accelerate her recovery. At the meeting, Iris doesn't feel 100 per cent, but still manages a very respectable 10.58 seconds. It is apparent, though, that the more her pre-race recovery is accelerated, the longer it takes before she feels right afterwards. So, when she still feels off colour two weeks after the race, she agonizes about what to do for the best. 'Should I take even more pills? It's two months before the next race, but I'm not going to be in shape for it if I don't resume training soon.' When her father calls and asks whether she'd like to come over for a meal, Iris declines. 'I can't keep the form up if I don't get all the rest I can,' she tells herself.

The same day, Iris gets an e-mail from the Anti-Doping Authority: 'Dear athlete, we feel sure that, like us, you are committed to keeping drugs out of athletics. However,

in the pressurized lead-up to a major event, it is easy to forget to tell us where you will be. So we have introduced a new system. If you authorize us to use the location data from your SmartSportmonitor, you can go anywhere, whenever you like, without worrying about keeping us in the picture.

'(Source: literature study and interviews with coach Henk Kraaijenhof and NOC*NSF)

7.5 Analysis

In this section, we compare the situation portrayed in our case history with that in the scenario. We identify the functional improvements that Ambient Intelligence can provide and the normative issues associated with the scenario. Finally, we consider the extent to which intelligent surroundings can automatically anticipate users' needs.

What functional improvements can Ambient Intelligence provide?

Anticipation, the last of the five levels of Ambient Intelligence, is characterized by its integration of observation and intervention to a degree that exceeds that seen at the other levels. The intelligent surroundings recognize issues that have yet to arise (in contrast to mere adaptation) and they do so automatically (in contrast to the personalization level).[67] In this chapter, we have focused on anticipation in two fields: elite performance and health damage. The former needs to be promoted, while the latter has to be prevented.
Ambient Intelligence promises to unify these objectives, and we see this promise partially made good in the future scenario. By using the SmartSportmonitor and the ConditionManager, Iris finds that she needs more rest between training sessions to recover from her efforts. Her training programme is adjusted accordingly. Iris's form improves considerably, with the result that, in the last session before the national championships, she sets a new PB. Via her Sportlog, all parties with relevant authorization have access to Iris's results.

Iris doesn't find the instruments a nuisance while training, because they are embedded in her SmartTracksuit. Things have moved on quite a bit since Jack's day. He had a training vest with instruments fitted to it, linked to a basic field lab, and didn't like wearing the vest at all. All the feedback from the equipment did not help him improve his performance. Under near-competition conditions, he was apparently not using all his potential strength, but the instruments couldn't tell him how to access his untapped reserves. By Iris's day, this problem has been solved, but the solution raises a number of normative issues.

Normative issues raised by the future scenario

In the quest for sporting success, science is becoming established alongside technology. The Sports and Technology Foundation, for example, is bringing the world of sport close to the world of science and technology and the business community.[68] At the Foundation's annual congress in 2005, sportspeople and coaches were given the opportunity to mix with technicians and scientists, so that together they could speculate about the added value that science and technology could bring to elite sport. One coach made the following point:

> *'Suppose that a mother of two comes home from doing the shopping. She has a weak chest and, having lugged her bags up four flights of stairs to her flat, collapses onto the sofa. She is completely done in, and doesn't even have the energy to put the kettle on. Then, through the window, she hears one of her children screaming in the street below. She is back down those stairs in the blink of an eye. The strength that that mother finds in a crisis is what I want to tap into.'*

The quotation highlights how, in elite sport, the temptation is always to try and channel all a person's strength into performance, regardless of the impact on health. Drawing on one's deepest reserves can place a serious strain on someone who is unwell and exhausted. The coach did subsequently say that, in fact, he did not want to draw on the mother's primal reserves: 'As soon as you have released that energy, it is lost.' That is the law of the disadvantage of a head start.

Technology that provides insight into a sportsperson's absolute potential capacity can make it even harder to strike an appropriate balance between health and performance, particularly when the sport's greatest prizes are within reach and the commercial stakes are high. Coaches need not only knowledge and skill, but also a strong sense of responsibility for the health of their charges. The ultimate performances calculated by Einmahl and Magnus could otherwise be the cause of personal disaster for an athlete.[69] The balance between measurement and intuition seen in the case history can easily be disturbed if teams blindly follow the technical data.

It is important to consider the extent to which sportspeople can be expected to take personal responsibility for maintaining the balance between their health and their performance. Iris tries to use the insight provided by the SmartSportmonitor and the ConditionManager to make sure she doesn't undermine her health. But after overdoing it in her efforts to set a new record, she finds herself in danger of getting trapped in a vicious circle of over-exertion and use of recovery-promoting medication. The training programme can still be adjusted to accommodate her need for more rest, but the competition dates are outside her control.

Ambient Intelligence offers the prospect of exhaustive monitoring for the use of proscribed substances in sport. But is that desirable? By asking Iris to give them access to the location data from her SmartSportmonitor, the people at the Anti-Doping Authority are cleverly taking advantage of the fact that she is already being continuously monitored with a view to controlling her stress reaction. The relationship between the demands made of sportspeople and the scope they have for using medication in order to meet those demands, needs to be considered. The greater the mismatch between the two, the more likely it is that sportspeople will resort to proscribed substances. This imbalance can be addressed by using Ambient Intelligence to tighten control, or, alternatively, by easing the constant pressure on sportspeople to perform better .[70]

The increase in the pressure to maintain or improve upon one's physical capabilities is not confined to elite sport. The use of intelligent surroundings in (competitive) grassroots sport and in recreation introduces the possibility that there, too, new demands could be made on people's physical exercise and self-care activities.

Ambient Intelligence promises to give the individual more independence. Whether that promise is realized depends primarily on the way that other parties utilize the health information provided by intelligent surroundings. What are the implications, for example, of introducing Ambient Intelligence to a situation in which government policy places increasing emphasis on prevention and personal responsibility? Or to one in which primary health care practitioners are expected to limit the demands on the secondary health care sector? Or where insurers have increasing influence and a considerable interest in keeping costs down? Will the individual's freedom to indulge in unhealthy behaviour be eroded?

Before intelligent surroundings that automatically anticipate needs that people don't even know they have enter use, we believe a number of key questions must be answered. Just what involvement do citizens and patients have in the progression that Ambient Intelligence can facilitate: from observation and interpretation to automatic intervention? The matching of goals and interventions is more critical in the context of anticipation than in any of the other five levels of intelligence. Who decides exactly how an automated action will be performed? Can it be stopped? If so, by whom? And under what circumstances?

To what extent can intelligent surroundings automatically anticipate individual needs?

The intelligence possessed by anticipatory technology comes closest to the intelligence that we attribute to people. At each successive level of Ambient Intelligence – integration, context awareness, personalization, adaptation and anticipation – more can be expected of the technology. Indeed the point may come where we even believe that the equipment can make decisions for us.

Would that be a reasonable belief, however? After all, the parameters within which technology can make interventions always have to be defined by people. Ambient Intelligence will make use of very detailed user profiles. Nevertheless, if our needs move beyond the predicted eventualities, the equipment will need to be reprogrammed. Hence, the ability of technology to assess whether a given intervention is appropriate ultimately depends on the ability of people to specify well in advance all the circumstances under which that intervention is indicated.

Furthermore, the users of anticipatory technology need to have particular kinds of knowledge and competence. In this chapter's case history and future scenario, the coach remains vital not only for the interpretation of measured data, and thus the formulation of appropriate interventions, but also for defining the objective to which anticipation should be geared: protection of the athlete's health or improvement of his/her performance. What if the equipment suggests a different course of action from that preferred by the health care professional? What exactly is the status of the technology's advice? If a device can genuinely participate in the decision-making process, there is a case to be made that it has a degree of responsibility. Can a machine ever be deemed responsible and, if so, what are the implications? Where exactly does the buck stop when something goes wrong?

Adaptation on the basis of patterns

Adaptation on the basis of a profile means that the intelligence of the health care equipment is restricted to the performance of calculations based on patterns. It is only possible to adapt something if you know to what, when and how it must be adapted. Whether adaptations are made manually, automatically or semi-automatically, automatic adaptation assumes that patterns exist in the 'what, when and how'. No matter how complex the automation is, the technology is always adapting to changing parameter values in a profile. The profile itself does not change. It is only at the next level of intelligence – anticipation, dealt with in chapter 7 – that technology is able to anticipate the changes that might occur in characteristics, even though no pattern has yet been established.

Because of the limited degree of automatic adaptation that is possible, use of the My Life Manager creates a certain amount of dependency. Karen becomes dependent on her buddy, who helps her to use the device. She has to make the effort to learn how to interact with the Manager, when she could do with focusing all her energy on getting better. The fact that the Manager introduces new problems does not imply that the device has no added value to people affected by cancer. The benefits of the My Life Manager lie in the functional improvements that the device offers: it provides a clear and coherent picture of a number of health-related parameters. However, this chapter has shown that knowledgeable, skilled people remain necessary to put the information from the My Life Manager into its proper context.

Part III Analysis and debate

In the final part of this report, we describe the wider context of the debate concerning the use of ICT in the health care sector. We also highlight a number of issues that need to be addressed in the debate on the use of intelligent health care technology to monitor and manage individuals' health.

As indicated earlier, the Ambient Intelligence vision foresees a citizen-centred or patient-centred world. However, the future scenarios we have presented suggest that the reality may be more complex. Health care practices do not lend themselves easily to automation. There are various reasons for this. For one thing, patients do not always have the skills needed to use intelligent health care technology. For another, needs and interests other than those of individual citizens and patients are often at stake in the world of health, health care, welfare and comfort.

Chapters 8, 9 and 10 examine three of the other influences at work. Chapter 8 identifies the leading actors involved in various forms of care and considers how the availability of information about the health of individual citizens and patients generated by Ambient Intelligence might affect relationships between these actors. In chapter 9, we look at the potential of Ambient Intelligence in relation to three significant trends in health care. In chapter 10, we return to the wider socio-economic and cultural-historical developments described in chapter 1, since such developments form the background to debate regarding the use of ICT in health care as well as the use of intelligent health care technology.

Finally, in chapter 11, we list the main points that we believe must be addressed by public debate before Ambient Intelligence can be accepted as part of the discussion around issues of health, welfare and comfort.

8 Actors in the health care sector vie for control of health information

Intelligent health care technology makes it possible to accurately align health care services with the needs and interests of individual citizens and patients. Thus, Ambient Intelligence builds on other proposed technologies that are intended to promote the personalization of health care services, such as electronic medical records.[71]

However, the citizens and patients who will make use of intelligent health care technology in the future do not exist in isolation. Rather, they operate in a setting characterized by interaction between various parties, such as industry, government, health insurers, regulatory and executive bodies and health care practitioners.

It is therefore pertinent to ask to what extent health care practices will in fact become centred on the Ambient Intelligence user. The reality will depend partly on the scope that other actors are given to pursue their own interests, using the privacy-sensitive information about individuals' health that is generated by the technology.

Structure of this chapter

This chapter begins with a brief description of the interrelationships between actors in the health care sector (section 8.1) and the way those relationships are changing. The most important change is the increasing scope for pragmatic action that has resulted from the introduction of market mechanisms (section 8.2). We consider how the use of Ambient Intelligence in this setting may influence both the position of the individual citizen or patient and the government's ability to protect the collective interests of citizens and patients (section 8.3). The conclusion of this chapter is that the government has an increasingly important role to play in placing the citizen or patient at the centre of health care practice (section 8.4).

8.1 Divergent interests

In the following paragraphs, we describe the positions of the actors in the health care sector in terms of their approach to the protection of citizens' and patients' privacy.

Industry

For industry, caring for health and welfare is a growth market. In theory, the need for health care is infinite, as demand for higher levels of service, and for a wider variety of products and services, continues to grow. Furthermore, many interventions are triggered by increasingly minor functional impairments. Take cataracts, for example. In the mid-twentieth century, cataracts were not treated until a person had lost 70 per cent of his or her vision; today, a 10 per cent loss of vision is considered enough for intervention.[72]

Ambient Intelligence offers industry considerable opportunities, since an entirely new spectrum of products and services will be needed, all tailored to the individual user. The market created will increasingly be a consumer market. The opportunities for industry could be further increased by collaboration with health insurers. Health insurers are likely to wish to buy health products in bulk and to use the associated savings to put together loyalty packages, through which the savings are passed on to insured individuals.

There are also risks. The acceptance of Ambient Intelligence by citizens and patients may be negatively influenced if their health information is misused. As long as citizens are willing to surrender a degree of privacy in exchange for the personalization of health care services, they do not seem to regard the use of their data as misuse. In the words of Bert Gyselinckx, Programme Director at the Holst Centre/IMEC-NL:

> *'The question is whether users are prepared to pay a price for increased convenience—to give up some of their privacy in order to receive a variety of electronic aids, for example. It should be recognized that the popularity of personalized health care services will suffer if there is any misuse. Industry and users have a shared interest in protecting privacy.' (Holst Centre/IMEC-NL, 2006)*

The government

For the Ministry of Health, Welfare and Sport (VWS), the question is whether shared interests provide sufficient assurance of socially acceptable solutions in the health care sector. Jos de Waardt, Head of the Ethics Unit at VWS, made the following observation concerning Ambient Intelligence:

> *'The rise of this third generation of computers, which surround people invisibly, is slightly insidious. Ambient Intelligence is not like genetic engineering; it does not directly affect the body itself. So it seems quite innocuous at first sight. However, the potential impact is in fact considerable. Take personalized health care services. Who will manage all the data? Is it OK for a health insurer to offer a*

discount in exchange for personal information? We are concerned that standards in this field will be affected. However, controls can be imposed only if people understand how those controls are in their interest.' (Ministry of VWS, 2006)

While favouring control, VWS is not clear what should and should not be permitted. The ministry's main task is to create appropriate conditions for the provision of health care. By doing so, and by supervising the sector, the government seeks to safeguard a variety of interests.[73] This is associated with some difficult questions: to what extent, for example, should citizens decide for themselves about the use of medical technology? Jos de Waardt continues to say:

'People who are willing to let their health insurers have data about their daily activities may get quality for a reduced premium. Or those who are not prepared to go down that path may have to pay more. These are consequences that we can predict. We in government may not like such developments, but will the public see things the same way? And, if the government takes a radical line on supervision and control, what then? These are tricky issues.' (Ministry of VWS, 2006)

Health insurers

Health insurers offer three types of health care service. First, there is a basic level of cover, which provides for essential health care. Insurers have a statutory duty to cover these forms of health care, so that everyone with a relevant condition has access to appropriate health care. A system of risk equalization is used, which means that everyone in the Netherlands pays the same amount for their basic cover. Health insurers are compensated for the associated cost. The insurers are largely free to determine what supplementary cover they wish to offer their customers, and what to charge whom for such cover. Finally, there are other health care services, which fall outside the scope of the statutory insurance system.[74]

For the health insurer, the principal questions are as follows: How do we assemble our complete health care package? Should we focus on 'luxury cover' or gear our offering to the mass market? How do we secure the services of health care practitioners on favourable terms? Harry Nienhuis and Anton Stekelenburg of health insurer Menzis summed up their considerations:

'What products and services should we offer? Should we select products and services that appeal to people? Or products and services that are good for people, have preventive benefit and support client retention?' (Menzis, 2006)

According to Menzis, these considerations are reflected in the way that health insurers respond to health care trends, such as primary prevention, i.e. keeping healthy people from getting ill. Some health insurers want people to have regular

check-ups. The position of the health insurer is changing, according to Menzis. The sphere of activity is greater and the nature of the service offering is different:

> *'The distinction between health and illness is becoming less clear. In the past, it was the individual's personal responsibility to avoid ill health. The health care insurer was concerned only with secondary prevention, i.e. preventing ill people getting worse. As the distinction disappears, we are seeing the emergence of a mix of marketing and health care.' (Menzis, 2006)*

At the start of 2006, the provision of health insurance was fully privatized in the Netherlands. The Health Care Insurance Act replaced the Health Insurance Act and the distinction between the national and private insurance schemes disappeared.[75]

Supervision and implementation

Although the responsibility for running the health insurance system has been transferred to the private sector, this does not mean that health insurers are free to offer clients whatever they choose. The Dutch Health Care Authority (NZa) supervises the insurers' market activities.[76]

The Health Care Insurance Board (CVZ) advises on the interventions and forms of health care to be included in the basic package. For an intervention or form of health care to qualify for inclusion, the following criteria must be met:

– The associated disease or health care requirement should preserve solidarity, taking the cultural context into account (need).
– The intervention or health care form should be an effective means to the intended end (effectiveness).
– The cost should be in acceptable proportion to the benefit (cost-effectiveness).
– Inclusion in the basic package should be sustainable in the short and longer term (practicality).

It is not clear whether applications of Ambient Intelligence would be explicitly covered by the system described above. The need for and the normality[77] of such applications is uncertain, according to Floor Rikken, Head of the Innovation Department at CVZ. With Ambient Intelligence, it is often a matter of health care service peripherals, such as telephone or video links.

According to CVZ, the personalization of health care services through the use of Ambient Intelligence (utilizing electronic medical records) would raise a variety of complex issues surrounding access to health care data and privacy. The government is concerned about the situation, but the public is apparently indifferent. The critical

question is: what will happen to health care data that enter the digital care chain? Floor Rikken made the following point:

> *'The personalization of health care services creates a curious paradox. The more personalized health care services become, the greater the level of institutional intervention required. This is because we will need to have strict agreements on access to health care data within the care chain, which implies institutional supervision.' (CVZ, 2006)*

According to CVZ, the public is not particularly interested in the issues surrounding Ambient Intelligence, but is that wise?

> *'The public is lukewarm about personalized health care services. Ten years ago, privacy was a major issue. Nowadays, people seem less bothered. In the past, you made more of a conscious choice as to whether you disclosed your personal details. But now, you can't use the Internet for long without sharing your profile data, even though you don't really know quite what happens to the data you provide. Similarly, we don't really know what happens to our health care data within the digital care chain.' (CVZ, 2006)*

Health care practitioners

Health care practitioners have a very complex position on privacy. They have to assess patients' care requests on the basis of considerations such as need, urgency and prudence. However, they decide exactly what care to provide, in consultation with their patients. To do so, health care practitioners need to draw on their clinical experience and ability to build trust with patients and share knowledge and ideas with them. However, it is not unusual for someone with a rare or chronic condition to know more about it than his or her GP.

One issue that complicates the process of deciding whether treatment should be given is the balance between the scope for treatment and the patient's ability to adapt. Maarten IJzerman of Roessingh R&D says:

> *'People tend to be very adaptive. Someone who suffers a spinal cord injury learns to live with disability. To an able-bodied person, it is hard to imagine life without the use of one's limbs. However, people who are put in that position learn to cope, and as they do so their need for, say, neural implants to restore a degree of hand movement becomes less. It is an ethical and philosophical dilemma. Immediately after an accident, a victim will want to be put on a rehabilitation programme, but later he or she will see less value in such a programme. The patient's perceived quality of life increases as he or she gets used to his or her circumstances. A health care practitioner has an important role to play in making this sort of assessment with the patient.' (Roessingh R&D, 2006)*

The greater the scope for utilizing Ambient Intelligence in health care, the more complex the role of the health care practitioner is likely to become. For example, being part of a network to which other health care professionals belong is likely to complicate matters. In order to do their job properly, health care practitioners will need to share medical information about patients with others in the care chain. How privacy may be protected in such a set-up is an important consideration. Is relevant medical data reaching the right people? Are some professionals being given more information than strictly necessary? Such questions are also pertinent in relation to the introduction of electronic medical records.

The citizen or patient

The extent to which health care practice is centred on the individual citizen or patient depends partly on the individual's personal circumstances. Citizens and patients have an interest in the availability of affordable, accessible high-quality health care. In practice, access to health care and the quality of health care depend partly on the skill, assertiveness and demands of the citizen or patient.[78] The affordability of a form of health care is to some extent income-dependent. The individual decides what he or she can and is prepared to pay. A person who wants to minimize his/her risk exposure will be willing to pay more, while someone whose means are limited is likely to accept a higher level of personal risk or to allow other actors access to personal data in order to secure a discount.[79]

8.2 Greater scope for pragmatism

The introduction of market mechanisms has given actors in the health care sector more scope to pursue pragmatic policies.[80] The activities are increasingly shaped by local circumstances – in other words, by the interests and desires of the direct stakeholders in the given situation.[81] As the government has withdrawn from the field, so industry and health insurers have taken on a more active role.

Industry is, of course, bound by statutory constraints, but wherever possible is guided primarily by the expectations of the client. If those expectations change, industry adapts accordingly. Thus, the citizen or patient is gradually becoming a health care consumer.

Health insurers now have more policy latitude as well. They have increasing scope to differentiate themselves by the nature of the supplementary packages they offer. Through mergers and other developments, insurers have also enhanced their ability to negotiate favourable prices with health care providers. They give health care

providers the incentive to withhold more expensive treatments than strictly necessary.[82]

Health care practitioners are bound by statutes and codes of conduct, and they base decisions as to what health care should be provided partly on their clinical experience. Increasingly, however, they must negotiate with insurers to secure funding for treatments that they consider necessary.

The government has moved to the background.. The assertive citizen has primary responsibility for his or her health and is increasingly expected to decide for him/herself what is best.

8.3 Individual needs versus collective interests

The increased scope for pragmatism raises two important questions regarding the introduction of Ambient Intelligence. Will the individual citizen or patient become the central figure in health care practice? And is the government able to adequately protect the collective interests of citizens and patients? The more the personalization of health care is accompanied by individualization, the more likely it becomes that the answer to both these questions will be ‘No’. We explore the reasons for this below.

Ambient Intelligence promises to make extensive personalization – the tailoring of health care to the needs of the individual citizen or patient – technically possible. However, the more scope actors in the health care sector have to pursue pragmatic policies, the more decisive the interests of actors other than the citizen/patient are liable to be when it comes to determining what health care an individual should receive. The various actors may vie for control of sensitive information about the health of citizens and patients, and it is by no means certain that the latter group will win out.

At the same time, the individualization of health care is liable to compromise the protection of citizens’ and patients’ collective interests. The government is the principal protector of such interests as the accessibility, quality and affordability of health care services. However, the increasing ability of actors in the health care sector to pursue pragmatic policies allows the extensive individualization of health care provision. The more the individual’s needs and interests become the primary points of reference and determinants of health care, the less consideration and protection there will be for collective interests.

These developments bring both opportunities and perils. New manifestations of solidarity may emerge, such as organizations for people with a shared interest or medical condition. On the other hand, new forms of behaviour-shaping and exclusion may also appear. Our future scenarios illustrated various possibilities, such as insurers making the funding of health care services conditional upon the client making 'healthy' lifestyle choices.

The government is placing increasing emphasis on the assertiveness and independence of the citizen or patient, who is expected to take primary responsibility for his/her own health. However, decision-making in the field of health care is not straightforward. Healthy citizens differ greatly in their ability to decide what is good for them. If a person is ill or infirm, this can further compromise their ability to weigh up the pros and cons of treatment options. At the same time, the increasing number and diversity of available health care services (with and without medical supervision) will inevitably complicate many decision-making processes.[83]

Another extreme manifestation of self-assertiveness on the part of individual citizens and patients is the phenomenon of a person going to see his/her GP and saying, on the basis of an hour's Internet research, 'I have such-and-such condition and want you to prescribe me such-and-such medication.' Often, the patient's demands are based on a one-dimensional assessment of his/her situation: he or she may, for example, simply want to be free of pain and may see a particular painkiller as the answer. In the health care sector, however, situations often have several dimensions and require complex assessment. The reduction in pain, for example, might be attainable only at the risk of an unwanted side effect, such as serious dizziness.

It is important that a health care practitioner go over with the patient all the considerations influencing a decision. With this in mind, account needs to be taken of the potential for the individualization of health care to affect the relationship between doctor and patient. Maarten IJzerman of Roessingh Research and Development fears that individualization will further complicate that relationship:

> *'I am worried that people will get out of the habit of making decisions in consultation with an experienced health care practitioner. Individualism could ultimately make it very difficult for a medical professional to arrive at a decision with a patient in any situation where several criteria need to be weighed up against one another. This is a seriously underestimated aspect of diagnosis and decision-making in relation to treatments and rehabilitation programmes.' (Roessingh R&D, 2006)*

8.4 The increasing role of government

As indicated above, the modern trend in government is to leave more and more aspects of health care to the citizen and the market. However, the arrival of Ambient Intelligence will increase the need for governmental input. It will be vital that the government protect the interests of citizens and patients both individually and collectively. The reason is that intelligent health care technology has the potential to support the personalization of health care, while market mechanisms have the potential to further individualize health care. If health care is both personalized and individualized, there is a danger that individuals' health information will be utilized to further the interests of other actors in the sector. As a result, the objective of placing the citizen or patient at the centre of the health care process is liable to become more difficult to attain. People who indulge in unhealthy behaviour might, for example, find themselves not the beneficiaries of personalized health care, but the victims of selective exclusion from certain health care services.

9 Ambient Intelligence and trends in health care

In this chapter, we discuss the interaction between the use of Ambient Intelligence and three important trends in health care: decentralization combined with the growth of self-care; the prevention of disease in combination with the pursuit of greater comfort; and the shift in emphasis from therapy improvement to human enhancement.[84]

The chapter leads to two significant observations. First, the degree to which the development of Ambient Intelligence corresponds to the three trends does not necessarily indicate whether intelligent health care technology actually meets the needs of citizens and patients. Second, there is a critical limit to Ambient Intelligence's ability to add momentum to the trends, without jeopardizing the fundamental objective of promoting the health, comfort and welfare of citizens and patients.

Structure of this chapter

Sections 9.1 to 9.3 deal with the three trends in turn. In each case, we consider the extent to which the development and use of Ambient Intelligence is influenced by the trend, and conversely the extent to which Ambient Intelligence may influence the trend. We explain how the trends are in part an expression of the desires of other actors in the health care sector, and we identify the conditions under which citizens and patients can nevertheless occupy centre stage. On the basis of these deliberations, we illuminate the two observations briefly outlined above (section 9.4).

9.1 Decentralization and self-care

The trend towards decentralized health care has been going on for some years. In chapter 4, we highlighted the rise of the outpatient clinic as a manifestation of this trend. Hospital stays are getting shorter, so that patients are spending more time recovering and recuperating at home. Decentralization implies not only a shift in the point of care, but also a shift in the responsibility balance: people are increasingly expected to watch their own health and to take action when necessary. We therefore refer here to the trend of decentralization *and* self-care. Large groups of people, such as older people and cardiac patients, are increasingly reliant on self-care.

Mutual influence

Ambient Intelligence can help to satisfy the demand for decentralized health care services, but by doing so may also add momentum to the decentralization trend. The sooner patients are sent home following treatment, the more technical support they are liable to need at home. Conversely, the more technical support it is possible to provide in the home, the sooner patients can be discharged from hospital. Thus, a situation can be created where demand stimulates supply (in pursuit of decentralization, more Ambient Intelligence is needed), but supply generates additional demand (the availability of Ambient Intelligence leads to more decentralization).

Trend drivers

The trend towards decentralization and self-care may indicate that citizens and patients wish to take responsibility for their own health and welfare wherever possible. However, certain other actors may simply see the promotion of decentralization and self-care as a way to save money. In the Ambient Intelligence vision, health care functions and services migrate from institutions to patients, wherever they happen to be. However, the point of care is not necessarily the locus of control.[85] Decentralized support enables not only self-care, but also remote influence and management. One therefore needs to ask: what changes are taking place in the provision of health care, and in whose interest?

Conditions

Self-care is not possible without support, as previously illustrated at various points. If, partly as a result of the availability of Ambient Intelligence, health care is to be further decentralized and patients are to become more reliant on self-care, at least two conditions must be met. First, the patients in question must be able to care for themselves and to make the relevant decisions – including the decision to summon the support of others if they cannot manage alone. Second, the people concerned must have proper access to a professional health care network, through which appropriate professional support can be obtained when needed. A reduction in hospitals' in-patient capacity is justified only if the standard of support available to people in their own homes is adequate. Power outages, severe winter weather or summer heat waves can have serious implications for people recovering at home. Alternatively, consider the situation faced by a woman who has undergone a mastectomy on an outpatient basis, as often happens now; Wendy Duchenne of the WNCCC makes the following points in that context:

'A woman goes to the hospital, where she is given a general anaesthetic and undergoes major surgery before returning home the same day. This patient is unlikely to receive the attention and reassurance associated with a stay in hospital. Her home effectively becomes a hospital, but without the facilities and services that a proper hospital would afford her.' (WNCCC, 2006)

People who need health care are often increasingly dependent on others. Social support may be needed in order to make proper use of intelligent health care technology – for example, to interpret measured data on physical parameters, or to use such data as the basis for decision-making.[86] The case histories and scenarios show that sensible decision-making and proper supportive care are tasks for people, not technology, and will remain so for the foreseeable future.

9.2 Prevention and comfort

The second of our three keynote trends in health care is the increasing emphasis on prevention. Health care practitioners seek to identify and address health problems as soon as possible (early diagnosis and treatment). Prevention may have the aim of ensuring either that healthy people do not become ill, or that ill people do not get worse. These are referred to as primary and secondary prevention. As illustrated by the growing interest in diet and exercise as means of preventing cardiovascular disease, overweight, and other such problems, primary prevention is becoming more important, just as all other forms of prevention will.[87]

The longer people continue to live independently at home, or the earlier people return home to recover following treatment elsewhere, the more important comfort at home becomes as a health care issue. We therefore refer to the prevention and comfort trend. Interest in comfort is increasing in general; comfort is a significant issue not only in institutions such as hospitals[88] but in leisure activities as well.[89]

Mutual influence

The use of Ambient Intelligence is not only consistent with the prevention and comfort trend, but can also add momentum to it. Threats to our health and welfare can be picked up earlier by monitoring our physical functions. Personalization can then help to make preventive intervention as comfortable as possible. With a heart monitor, a cardiac patient can go on a holiday that would otherwise be deemed too great a risk.

The earlier we spot changes in our physical functions, the sooner we can identify a situation as potentially hazardous to our health and welfare, and the sooner we can intervene if we consider it necessary. The shift from secondary to primary prevention is an example of this process at work. In this context, there is an interesting link

bween prevention and anticipation, the fifth level of Ambient Intelligence. Intelligent surroundings that anticipate the development of health problems could also support (automation of) the primary prevention of those problems.

Trend drivers

Demand for the prevention of health problems is not generated only by citizens and patients. The government and the health insurers are enthusiastic proponents of better primary and secondary prevention, on the assumption that the prevention of ill health can reduce the demand for expensive curative care. With a view to cutting costs even further, actors in the health care sector may be inclined to let people take more responsibility for their own health.

When considering the extent to which citizens and patients can be held responsible for their own health, socio-economic factors need to be taken into account. In some economic or social circumstances, healthy lifestyle choices can be harder to make. . Junk food is still cheaper than a healthy meal, and many children grow up in settings where exercise is not encouraged. Is it therefore reasonable to hold everyone equally responsible for their diet and their exercise habits?

There is no simple correlation between the level of preventive action and the level of expenditure needed to meet the demand for health care. The treatment of cancer confined to one part of the body will often be cheaper than the treatment of the same form of cancer following metastasis. The prevention of metastasis can therefore help to keep costs down. However, prevention can actually increase health care expenditure. This has been the case with the over-diagnosis and -treatment of breast cancer on the basis of screening.[90] There is ultimately no value in screening everybody for illness as a matter of course, as is sometimes suggested. It would cost a lot of money, without actually making the population healthier.[91]

Conditions

If comfort levels are to remain in step with the prevention of disease and infirmity, it is important that the characteristics of the likely users of Ambient Intelligence are taken into account. People can be suspicious of and feel spied on by computers that constantly record everything they do. In addition, they may worry about any physical functions that are not monitored. After all, the message from the early-diagnosis school is that, although you may *feel* fine, that doesn't necessarily mean you *are* fine.

Furthermore, the more intelligent the surroundings become, the more decisions the user has to make, and the sooner he or she has to make them. Thus anticipatory

technology places more decision-making pressure on the user than adaptive or adaptable technology, and automatically adaptive technology more than manually adaptable technology. Ambient Intelligence is referred to as a 'calm technology', because it does its work quietly in the background. In order for it to operate that way, however, a certain amount of 'busy' preparatory work always has to be done. The more intelligent the surroundings need to be, the more such work is required, because of the need to draw up and maintain detailed personal profiles. It is uncertain how users will respond. How far ahead will they be willing and able to make the relevant decisions?

9.3 From therapy improvement to human enhancement

Anyone who is ill or infirm will come into contact with therapies that address their condition, successfully or otherwise. Medical science is constantly trying to develop more effective therapies that have fewer adverse effects and are tailored to a particular variant of a condition or to the characteristics of the patient.

Technology that serves to make ill people better can often also be used to improve the physical and mental capabilities of healthy people. Usage of the former kind is called 'therapy', while usage of the latter kind is termed 'human enhancement'. The drug Ritalin, for example, is used to treat people with attention deficit hyperactivity disorder (ADHD). However, people without ADHD can use the drug to improve their concentration. The use of drugs by healthy people to influence their physical functions generally encounters moral censure, transgresses codes of conduct and/or is against the law.[92]

It is possible, however, that the arrival of new treatment options will shift the boundary between therapy and human enhancement. Physical and mental conditions that were not previously thought of as illnesses may come to be defined as such, and it may therefore be deemed reasonable to treat them.[93] ADHD is a good example:[94] what we now regard as the therapeutic use of Ritalin to treat hyperactive people who find it difficult to concentrate could have been termed human enhancement prior to the definition of ADHD as a medical condition.

Mutual influence

The Ambient Intelligence vision ties in with the demand for better therapies. Intelligent health care technology can contribute to therapy development and refinement by generating detailed information on individuals' physical functions.

Thus, for example, medical science is increasingly able to combat – and may in due course be able to prevent – cancer-related pain by the more targeted administration of pain medication (see chapter 6). Intelligent health care applications are now coming onto the market for diabetes, heart disease and COPD as well.[95]

Ambient Intelligence can amplify the trend away from therapy and towards human enhancement. First, it can contribute to the definition of new conditions by yielding insight into the functioning of the human body. Furthermore, intelligent health care technology can indicate not only how healthy a person is, but also what he or she is capable of doing. Growing interest in health may be accompanied by growing interest in performance (see chapter 7). This may in turn lead to functional impairment and infirmity being viewed more negatively. Finally, Ambient Intelligence increases the technological scope for influencing physical functions. A memory chip designed to help people with Alzheimer's disease might also improve the cognitive performance of healthy individuals.[96]

As applications of Ambient Intelligence become available on the consumer market (i.e. without medical supervision), this interaction is liable to increase.[97]

Trend drivers

Citizens and patients have an interest in the availability of improved therapies for a wide variety of conditions. However, Ambient Intelligence users could lose a degree of control over their own actions. We have described how this might happen in the setting of elite sport, but this dynamic may not be confined to the sporting arena. Employers might seek to use intelligent workplaces to ramp up the performance of their personnel, for example. In the future scenario in chapter 4, the pensionable age was substantially higher than it is today. Under such circumstances, it would be not only average healthy life expectancy that counted, but also each individual's situation.

Conditions

If the citizen or patient is to be the central figure in the therapy improvement/human enhancement trend, the use of Ambient Intelligence needs to meet a number of conditions. What we perceive to be the three key conditions are identified below. They relate to the social aspects of health care provision, to the question of what constitutes acceptable behaviour-shaping and to the issue of retention of personal identity.

In the use of intelligent health care technology, it is important to consider the social aspects of health care provision. If, through the application of evidence-based

medical principles, we develop improved criteria for deciding what treatments are appropriate under what circumstances, we will also build up a clearer picture of the situations in which treatment no longer makes sense. Health care practitioners need to decide together with patients when therapy should stop and acceptance of the inevitability of their medical condition should begin. In this context, the personalization of health care should not focus too much on *individual* patients; otherwise the treatment is liable to overlook important issues involving developments in social relationships, such as between parents and child (see chapter 5).

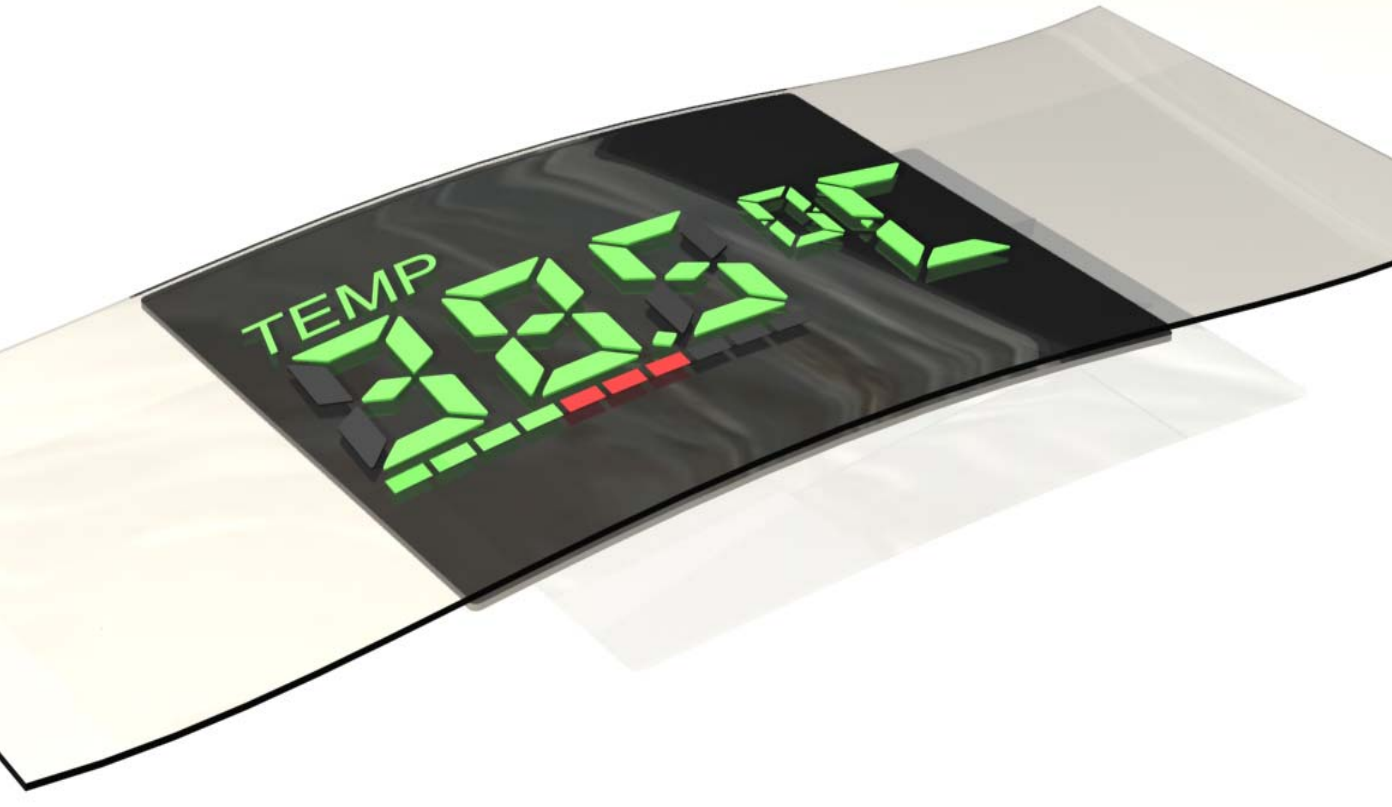
Ambient Intelligence may be expected to increase the scope for influencing the way citizens and patients behave. It is therefore essential to have clear agreements as to what forms of influence are and are not acceptable. The measurement of physical functions can shed light on physical or mental reserves that were not previously apparent. It is a short step to assuming that such reserves may be accessed, and then to doing so. This may compromise protection of the individual's health.

Human enhancement – through the development of implantable memory chips, for example – raises questions concerning the retention of personal identity. Questions of particular relevance in relation to the introduction of Ambient Intelligence include: What may or can one change, without losing one's identity? At what point do you become someone else, to your relatives, your friends or yourself?

9.4 Conclusion

In this chapter, two significant observations are made, which together call into question the extent to which the individual citizen or patient occupies centre stage in the interaction between the trends that characterize the health care sector and the development of Ambient Intelligence. First, the trends should not be interpreted as driven solely by the needs of individual citizens and patients. Other actors in the health care sector have economic interests in the promotion of decentralization, self-care and prevention.

Second, there is a critical limit to Ambient Intelligence's ability to add momentum to the trends before it begins to jeopardize the fundamental objective of promoting the health, comfort and welfare of citizens and patients. There are limits to the amount of self-care citizens and patients can perform. The automation of health care functions (such as primary prevention) can also adversely affect the comfort of using Ambient Intelligence. Finally, the use of intelligent health care technology could lead to increasingly high performance being demanded of individuals. —demands that can put their health and welfare at risk.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10 Ambient Intelligence and the future of health care

Debates regarding health care often have a negative point of departure: waiting lists are too long, the health care available to older people or people with disabilities is inadequate, or there is too much bureaucracy. Such problems are not, of course, necessarily indicative of the quality of the health care that is provided, yet they often serve as drivers for improving health care standards.

The trends identified in chapter 9 all relate to such problems, but also take place against a background of more general socio-economic and cultural-historical developments. We face certain communal challenges in terms of the way we deal with health, welfare and comfort. The first challenge is to keep the circumstances of the average person in the Netherlands from deteriorating as a result of demographic developments. The second is to bring about a degree of individualization in the health care sector.

In this chapter, we consider the extent to which intelligent health care technology can help in meeting these challenges. Ambient Intelligence brings together certain important developments in health care and ICT. Intelligent health care technology enables the automation of health care services in such a way that they can be ‘personalized’, i.e. tailored to the individual citizen or patient. The introduction of electronic medical records is an important precondition for further innovation in this field. Such records can provide a basis for a close-knit, efficient health care network.

Structure of this chapter

In section 10.1, we ask just how much health care provision technology may realistically be expected to take over from people. Drawing on our conclusions in that regard, section 10.2 illustrates how networking is both a precondition for and a potential obstacle to personalized health care. In section 10.3, the point is made that the more the individual needs of citizens and patients are emphasized, the more their collective interests, such as the accessibility, quality and affordability of health care, are liable to be compromised. Indeed, it is open to question whether, against the background of such developments, the circumstances of the average person in the Netherlands can be adequately protected. In section 10.4, we argue that the identified

collective challenges are relevant to all actors in the health care sector, in particular the government.

10.1 How much health care can technology take over?

In chapters 3 to 7, we considered the extent to which health care services could be automated by using intelligent health care technology. It is our conclusion that, to a considerable degree, health care provision is and must remain the work of people. This conclusion is briefly explained below.

At each successive level in the Ambient Intelligence vision, technology takes over more of the tasks previously performed by people (see chapter 2). Integration and context awareness, the first two levels of intelligence, ensure that individual needs are appropriately recognized. Personalization, the third level, involves the automatic translation of individual needs into a personal profile, on the basis of which health care services are manually adapted to the needs of the individual. Finally, at the adaptation and anticipation levels, intelligent surroundings decide what health care a person needs and will receive.

From our analysis, it does not appear reasonable to expect intelligent health care surroundings to possess the intelligence needed to make good the promises described above. The personalization of health care services calls for the personal input of an individual. In consultation with a health care practitioner, for example, a patient must decide which physical functions should be monitored and when intervention is desirable. Given that Ambient Intelligence is intended to place the citizen or patient at the centre of the process, it would seem appropriate that the citizen or patient should decide whether the tailored health care is ‘a good fit’.

The foregoing considerations are even more valid in relation to adaptation and anticipation realized by means of intelligent health care technology. The more intelligent the surroundings are, the more relevant human standards and their possible transgression become. To progress from the measurement of physical functions to intervention, it is necessary to interpret the measured data. Decisions need to be sound, rational and taken at the right time. But who decides whether a decision satisfies these criteria? Who programmes the equipment accordingly? In the health care sector, it is often necessary to weigh up several potentially conflicting needs and interests, such as the costs and benefits of a treatment. Are the possible side effects of a drug justified by its pain-relieving qualities? Deciding matters such as

these cannot be left to our intelligent surroundings, certainly not before we have had a chance to make up our own minds.

Even if it were possible to automate such decision-making processes, there are liable to be good reasons for not doing so. One being the statutory requirement that patients must give informed consent to medical treatment. In mainstream health care, the patient's entitlement to be involved in medical and clinical decision-making has never been greater. Health care practitioners are obliged to take account of their clients' wishes.[98]

10.2 Networking as a requirement for and obstacle to personalized health care

In chapter 1, the point was made that health care practitioners increasingly work less in isolation and more in the context of a health care network.[99] Within the sector, professional networking is a topical issue.[100] A system of electronic medical records is central to the ability to exchange patient data among lines of care and specialisms, at any time and any location. We also see a growing need to personalize health care provision, i.e. tailor health care to patients' individual wishes and characteristics, rather than match it with their generalized clinical status.

Ambient Intelligence unifies these two developments. An intelligent health care setting makes both personalization and networking possible. This can lead to transition from specialized supply-driven health care to more patient-centred and demand-driven health care: personalized health care.

Networking is a precondition for the extensive personalization of health care, but it can also be an obstacle to that process. This is because the network of professionals needed for personalization must operate in the context of competing interests described in chapter 8. The information that Ambient Intelligence yields regarding the health of citizens and patients could in principle be used to further the interests of other actors in the health care sector,[101] particularly since these actors now have more scope to pursue pragmatic policies as a result of the introduction of market mechanisms, as explained in chapter 8. Such policies are not necessarily in the interest of the citizen or the patient. The health care sector is not a perfect market.

The use of Ambient Intelligence requires the investment of considerable human effort – by patients, by their relatives and by health care practitioners. Consider the management of user profiles, and the time and patience needed to gradually familiarize oneself with the technology. The more intelligent the equipment becomes,

the more tempting it is to regard support and explanation as superfluous. The truth is, however, that careful explanation is all the more important if rejection by the client is to be avoided. Precisely because it is so clever, an intelligent health care function is liable to be misunderstood and therefore mistrusted.[102] This serves to amplify the importance of having a social network around citizens and patients who are in need of health care. If they do not receive adequate support, they are liable to become more dependent and more isolated.

10.3 Communal challenges

Personalization and networking depend on close collaboration among the various actors in the health care sector. The relevant needs cannot be met by any one actor alone. In this section, we consider the collective challenges facing the actors in the health care sector in the advancement of health, welfare and comfort.

Socio-economic developments necessitate the adoption of a new approach to old age, disease and welfare. The Netherlands faces the challenge of ensuring that the circumstances of the average citizen do not deteriorate as a consequence of demographic and other developments.[103] The population is aging: older people now make up a larger proportion of the population, and they are living longer. This has economic and other implications for the whole of society. Partly because of the change in demographics, health care expenditure in the Netherlands has more than doubled in the last twenty years. At the same time, families of non-western origin, single people and one-parent families have all risen in number. People in these three groups tend to live in less favourable circumstances than members of other groups.[104]

The individualization and liberalization of Dutch society constitutes another major trend. People desire and are able to go on seeking personal development to an advanced age. Consequently, actors in the health care sector face the challenge of individualizing health care provision to some degree. The introduction of market mechanisms into the health care sector marks the start of this process. The recent reform of the system is based upon a particular take on the liberalization of social services. It also reflects the established belief[105] that the citizen is able to reach independent decisions about many matters affecting his or her personal health, or the health of his/her children. The Ambient Intelligence vision of the individual functioning more independently in intelligent surroundings is therefore very much in line with the outlook that characterizes the contemporary health care setting.

10.4 A dilemma for government

The collective challenges described in section 10.3 create a dilemma for the government. Distancing itself from the development, introduction and use of Ambient Intelligence could have negative repercussions. There is good reason, therefore, for the government to take a more active role. Yet unduly close involvement is likely to have drawbacks of its own.

One horn of this dilemma has already been highlighted in chapter 8. By introducing market mechanisms, the government has made itself more remote from health care in general and from its practical provision. However, if the personalization of health care by means of intelligent health care technology leads to the needs of the individual being adopted as the primary point of reference in the provision of health care, there is a danger that the government will lose its ability to protect the collective interests of citizens and patients. It is unclear whether the applications of Ambient Intelligence fall within the regulatory responsibilities of the CVZ. Meanwhile, the Ministry of VWS is unsure whether to take a more active role. Under such circumstances, matters such as access to health care and the quality and cost of the new generation of health care services are likely to be guided increasingly by the interrelationships between citizens, industry and health insurers.

The question is, will increasing individualization have implications for people's inclination towards solidarity, their sense of shared responsibility for the chronically ill, for older people, for people who – despite all the available information on healthy living – continue to make unhealthy lifestyle choices? In the late nineteenth century, government bodies were created to oversee the funding and organization of health care. The challenge facing the government of that era was to effect a transition from individual to collective health care provisioning -- a policy that enjoyed the general support of the population. Abram de Swaan posed the following question concerning the rationale behind this support:

> *'How and why did people decide to create collective national compulsory schemes to combat shortages and setbacks that affected them individually and that appeared to demand individual remedies?'*[106]

According to De Swaan, the answer is simple: people were dependent on one another. An epidemic threatened everyone. The key question about individualization and the potential of Ambient Intelligence is therefore whether people still need one another. If we answer this in the affirmative (as the preceding chapters suggest we should), then the question is to what extent the circumstances of the average person can be maintained at their present level in the current social landscape.

These considerations suggest that the government should take a more active role in the development, introduction and use of Ambient Intelligence. However, the dilemma has two horns. Throughout the first half of the twentieth century, there was a similar debate as to whether the government should exercise more control, or let developments take their course. De Swaan warns against concentrating too hard on efficiency:

> *'The worst case, a welfare state, which functions with perfect efficiency, functions thus only as a police state. This, more than anything else, is the future dilemma of social policy.'???*

This warning is as topical and as powerful today as when De Swaan penned it more than 25 years ago. That much is evident from the more than doubling of health care expenditure in the last twenty years and the issues associated with demographic changes such as population aging. It is therefore vital to establish just how closely the government should be involved in the development, introduction and use of Ambient Intelligence, in order to ensure that it does not adopt either extreme position and that both scenarios are avoided as far as possible.

11 A starting point for wider debate

In debates about health care, people often point to the importance of ICT as a means of organizing health care more efficiently. For example, it is suggested that a system of electronic medical records would make it possible to manage large volumes of patient data and interconnect various health care networks. Ambient Intelligence would add two dimensions to the computerization of the health care domain: health care services would be tailored to the individual and made available at any given location. It is no surprise, therefore, that Ambient Intelligence features in major investment programmes for telemedicine, e-health and assistive technology.

The history of electronic medical records emphasizes how fraught the protection of a collective interest can be. After many years of discussion, there is still no national system of electronic medical records. ICT experts say that computerization of medical data is not a major technical challenge.[107] The problem is the organization arrangements within the health care sector. Automation always entails changes in the relevant competences, powers and responsibilities.[108] The introduction of Ambient Intelligence could be even more difficult in this respect.

Ambient Intelligence is liable to radically alter our individual and collective approaches to health, welfare and comfort. It is a scenario for the future in which we deal with health, welfare and comfort on an increasingly automated basis. Using detailed and digital personal profiles, intelligent surroundings will keep track of where you are, how you are and what your health care needs are. In an emergency, a health care practitioner will be summoned automatically. Furthermore, as our surroundings become more intelligent, more and more of the health care will be provided automatically, without you – the citizen or patient – consciously having to do a thing. The cleverest health care setting will even automatically anticipate health problems you are not aware of (see chapter 2). And the whole process of providing health care will be designed around you, the individual user.

The exploratory study reported here indicates that the use of intelligent health care settings raises a variety of important questions. The existence of these questions does not warrant halting or even slowing the pace of development. However, it does imply that actors in the health care sector need to seek agreement on the relevant

issues, in order to ensure that Ambient Intelligence makes a positive contribution to the future of health care.

Structure of this chapter

In section 11.1, we summarize the most important issues to emerge from the case histories and scenarios presented in the body of this report. For the reader's convenience, each summary includes bracketed references to the passages of the report where the relevant issue is covered in more detail. In section 11.2, we conclude by presenting a road map for use in the development, introduction and use of Ambient Intelligence in the health sector.

11.1 Urgent issues

We have identified nine themes that need to be addressed if the health care process is to be centred on the citizen or patient. Each of the theme titles below highlights a field of contention within which decisions regarding the use of intelligent health care technology need to be made. Arriving at such decisions will require concerted input from all actors in the health care sector: industry, health insurers, the government, regulatory and executive bodies, health care practitioners, citizens and patients (see chapter 8).

Personal access - selective exclusion from health care

The existence of intelligent health care technology that enables citizens and patients to be identified wherever and whenever necessary, so that their surroundings know exactly how they are and what their health care needs are, opens the way for the provision of all manner of customized mobile health care services. However, it also makes it possible for citizens and patients to be selectively excluded from health care services.
What criteria determine access to intelligent health care services? Who defines those criteria? Who reviews them? Who programmes the intelligent health care setting? (See section 5.5; section 8.1 and section 10.4.)

The personalization of health care services - in exchange for privacy

Intelligent health care services can be closely tailored to an individual's particular circumstances. The more tailored the services need to be, the more detailed the information necessary to set the services up. It will not always be apparent to a citizen or patient whether it is in his/her interest to relinquish personal information. It cannot be left to the individual alone to define the parameters within which his/her

personal data are collected and used. In the definition of such parameters, considerations pertinent to all actors in the health care sector, such as the cost of health care, play a part.
What measures can be put in place to ensure that no more personal data are collected for the personalization of health care services than is strictly necessary? Who is responsible in this regard? Who will have access to the personal data? For what purposes may the information be used? How can the privacy of citizens and patients be assured? Is it necessary, for example, for the citizen or patient to give consent for each new use of his/her information? (See sections 2.1-2.2; section 4.5 and chapter 8.)

Save costs – let the citizen pay the price

The rising cost of health care would appear to necessitate a new approach to care and cure. Citizens and patients are increasingly deemed responsible for their own health. Because Ambient Intelligence affords insight into the ways that different interventions and forms of behaviour affect health, it makes it possible to hold people accountable for their lifestyle choices. People who are in a position to influence their condition through their behaviour could, for example, be required to accept a higher deductible (the part of an insurance claim that is not covered by the insurer). However, a person's scope for making healthy lifestyle choices depends to a significant extent on his/her socio-economic circumstances. Some people could be trapped in a vicious circle: being less able to lead a healthy life, they incur higher insurance costs and their ability to make healthy choices is further compromised.
Can citizens and patients be held entirely responsible for their health? What are the implications of personal responsibility for health? What implications will this have for a person's economic and social scope for making healthy lifestyle decisions? (See section 4.5; sections 8.2-8.3; section 9.2 and section 10.3.)

Self-care – restriction of self determination

Intelligent health care technology makes personal health care possible at any location where the individual may require it, including self-care at home. This does not necessarily mean, however, that the recipient will have or be able to retain control over his/her care. As more health care services are provided through (remotely controlled) technology, an increasing degree of control over health-related behaviour in the home is liable to pass to other actors in the health care sector. It will become possible, for example, to closely monitor and influence patients' adherence to therapy regimes.
To what extent should professional health care be allowed to enter the individual's private life? What level of behaviour management and influence is reasonable in the

context of such health care? Do people have the right to live in unintelligent surroundings? (See sections 4.1-4.2; section 4.5; section 5.3; section 7.5 and section 9.1.)

Medical supervision – the citizen or patient as health care consumer

Since 2009, the use of medical equipment has required supervision by a doctor or another medical body.[109] However, the Dutch health care system is gradually becoming more demand-led. Market forces have created more manoeuvring room at the interface between the demand for and supply of health care services. Citizens and patients are increasingly looked upon as health care consumers, who are free to choose from a wide range of services. Health care is not, however, a perfect market. Citizens and patients do not always have the skills needed to decide whether they need intelligent health care technology, to use it appropriately and/or to interpret the results. This can have an adverse effect on the quality of health care.
What skills are needed by the users of Ambient Intelligence applications, such as people with physical and/or mental disabilities? Do the potential users have such skills? How can unnecessary use of commercial medical tests and health care technologies be avoided? Are the existing advertising codes adequate in that regard? Who is responsible for quality assurance in a decentralized health care setting? (See section 3.2; section 4.2; section 6.2; section 6.5; section 7.5; section 8.1 and section 9.3.)

Individualization – solidarity on the brink

The personalization of health care services using intelligent health care technology will increase the scope for organizing health care practices around individual health care needs. However, as individual needs become the standard point of reference, solidarity within the health care system may be undermined.[110]
How can health care practices be organized around individual health care needs without undermining or reducing solidarity? What is required to prevent such unwanted side effects and who is responsible for their prevention? How will the combined personalization and individualization of health care affect the relationship between patients and health care practitioners? (See section 10.4.)

The automation of health care services – informed consent

The Ambient Intelligence vision foresees the extensive automation of health care, welfare and comfort-related matters. The citizen's or patient's active involvement in determining his or her health care needs and shaping his or her health care provision will be curtailed as far as possible.

How does the automation of health care using Ambient Intelligence fit in with the statutory provision that medical treatment may be given only with the patient's informed consent? Will the automated health care setting have a 'stop button'? How can the provision of inappropriate treatment be prevented? (See chapter 2; section 3.5; section 4.5; section 5.5; section 6.5; section 7.5 and section 10.1.)

Calm technology – increasing unrest

Ambient Intelligence is referred to as a 'calm technology', because it does its work quietly in the background. If the automated provision of health care using intelligent health care technology is to satisfy the law's informed consent requirement, citizens and patients will need to decide at an increasingly early stage what health care they wish to receive under what circumstances. The more intelligent the surroundings become, the earlier in the process decisions must be made.
How will citizens and patients respond to being asked to decide earlier in the health care process what health care they wish to receive under what circumstances? How far ahead can people be expected to clarify their wishes? On the basis of what information will such decisions be taken? (See section 9.2.)

More prevention – more illness

Intelligent health care technology can make an important contribution to the prevention of health problems and thus to the control of health care expenditure. However, growing insight into the working of the human body can also lead to the definition of new medical conditions. In addition, as people's willingness to accept function loss and impairment declines, people with very minor conditions are increasingly likely to be regarded as unwell and in need of treatment. Ambient Intelligence will increase the technological scope for influencing and improving physical functions. This will lead indirectly to ever higher expectations of human function. Hence, the latent demand for health care is in principle almost infinite.[111] This obviously has implications for health care expenditure.
Is an infinite supply of intelligent health care services the answer to infinite demand? Is it necessary to define boundaries for health care? If so, who should define those boundaries and on what basis? Does the training given to health care practitioners pay sufficient attention to the growing role of ICT in health care and its influence on disease perception? (See section 8.1; sections 9.3-9.4 and section 10.3.)

11.2 Road map

We conclude this report by returning briefly to the subject matter of chapter 1. In section 1.1, the words of Bill Joy were quoted, warning that humanity's last chance to

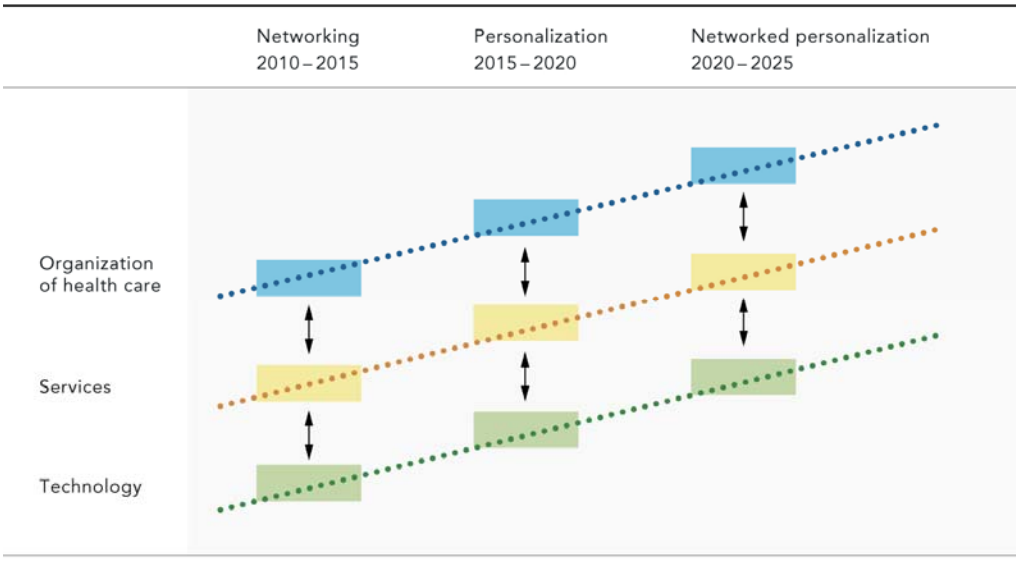
assert control over new technologies capable of transforming our daily lives was fast approaching. In his article, Joy called for the development of a steering plan.

In section 11.1, we saw how the potential impact of Ambient Intelligence can vary considerably, to say the least: hence, it may be seen as viable future of pernicious phantom. Whether Ambient Intelligence proves to be a benign or malevolent influence depends mainly on the way that its technological potential is integrated into the organization of health care, and on whether the health care services that are provided cater properly for the needs and interests of citizens and patients.

As a first step towards the development of the sort of steering plan envisaged by Joy, we present below a road map covering the period up to 2025 (figure 3). The road map is intended as a tool to help the actors in the health care sector to arrive at a common vision of how health care should be organized in the future and what is required to that end. The road map's horizontal axis shows the need for networking as a means of personalizing health care (see also section 10.2). The vertical axis reflects the need for the organization of health care to take account of technological developments, in order to ensure that health care services meet the needs of citizens and patients.

The spaces on the road map have deliberately been left blank, since their content needs to be decided by debate. In section 11.1, we identified the key themes on which we believe the relevant actors need to seek consensus so that, by about 2025, the central promise of Ambient Intelligence – that the citizen or patient will be placed at the centre of the health care process – is within reach.[112]

Figure 3 Road map



The issues identified in this report require collective action. As health care services become more personalized, the need for more collective arrangements increases. As explained in chapters 8 and 10, the government has a central role to play in this regard.

The issues identified in this report require collective action. As health care services become more personalized, the need for more collective arrangements increases. As explained in chapters 8 and 10, the government has a central role to play in this regard.

Appendix 1 Interviewees

Best Medical
– Ger Dijkman (Director)

Health Care Insurance Board (CVZ)
– Dr Floor Rikken (Head of Care Innovation)
– Arnold R. van Halteren
– Niklaas Pruijssers

Physiotherapy
– Pier Spyksma (independent paediatric physiotherapist)
– Sietske Spyksma (paediatric physiotherapist)

Holst Centre/IMEC-NL
– Bert Gyselinckx (Programme Director)

Netherlands Organization for Applied Scientific Research (TNO)
– Gerard Freriks

West Netherlands Comprehensive Cancer Centre
– Wendy Duchenne (Head of Supportive Care)

Koninklijke Philips B.V.
– Boris de Ruyter (Principal Researcher)

Marina de Wolf Centre, Meerkanten Psychiatric Hospital
– Marionne Bartels (Head of Clinical Treatment)

Southern South Holland Disability Support Organization, Technological Information Point
– Gerard van Kerchove (Project Manager)
– Dirk Nicolaas van der Hoek (general staff member)

Menzis Care and Income
– Harry Nienhuis (Head of Innovation Department)
– Anton Stekelenburg (Innovation Department Officer)

Ministry of Health, Welfare and Sport (VWS)
– Dr Jos de Waardt (Head of Medical Ethics)
– Sicco Kuijper (Medical Ethics Policy Officer)

NOC*NSF
– Dr Gery Misat-Steenge (Innovation Programme Manager)

Roessingh Research and Development
– Dr Miriam Vollenbroek-Hutten (Cluster Manager Technology Assisted Pain Rehabilitation)
– Professor Maarten IJzerman (Scientific Director)
– Professor Hermie Hermens (Professor of Neuromuscular Control and Telemedicine)

Utrecht University Medical Centre
– Dr Paul Jansen (Geriatrics Department staff member)

Sport
– Henk Kraaijenhof (coach)

Telematics Institute (now: Novay)
– Henk Eertink (Research Fellow)
– Stanislav Pokraev (Scientific Researcher)
– Henk de Poot (Scientific Researcher)
– Hans Schaffers (Research Fellow)

TeleProtect
– Huib Broekman (Director)

Appendix 2 Technological developments (2020-2025)

Broadband network infrastructure and network services			
Technologies	Short term 0-5 years (2010-2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)
Interoperability across heterogeneous networks 'Smart' ad hoc context-based networks	Automatic suitability for use in various networks Automatic adaptation of equipment to network (limited functions)	Automatic interoperability across heterogeneous networks Automatic adaptation of equipment to network	Seamless network interoperability Smart ad hoc context-based networks (e.g. user profiles, interoperability)
Growing broadband	Cable xDSL < 50Mbit to home	Optical fibre; 100 Mbit/s ethernet to home	Optical access
Universal Internet protocols (IPs)	IP will remain the carrier of all services. Whether IPv6 is rolled out will be a (business) policy decision; the technology is there, but it is not yet supported by producers or network operators.		
Fully distributed environment	Limited web access for and to sensors and actuators Main applications: monitoring and warning	Limited standardization of M2M services	Extensive electronic M2M services Web-based services in sensors and actuators in all equipment, using standard formats and protocols

Transparent access to distributed data (individual sensors, actuator data or derived data) in local networks (home, building)	Transparent access to individual sensors in a building	Secure external access Data combination becomes easier	Standardized methods of adding domain knowledge to sensor data and thus deducing information and knowledge ('smart sensors')

Digital sensors and actuators			
Technologies	Short term 0-5 years (2010-2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)
Intelligent battery management	Increased granularity and more efficient use of energy in sensors	New power sources, e.g. fuel cells	
Sensors and actuators	Individual sensors on the body Domain-specific: • Heart rate • Blood pressure • Diet	Portable incident-monitoring system Warning generator, e.g. for blood levels	Movement interpretation, intelligence, deduction of people's activities by the combination of information; introduction of application-specific knowledge
Location reporting Standardized exchange of location information	GPS, integration with GSM, domain-specific exchange of location information	Integration of all manner of mechanisms (local sensor technology, microphones, video, radio) Generic exchange of location information and intelligent combination of	GALILEO (EU version of GPS) with greater precision

		different sources	
Data logging (gathering, logging, evaluation and interpretation of context information)	Gathering of data in particular applications Simple data clustering and pattern recognition	Gathering of large volumes of data (e.g. from sensors), automatic clustering and evaluation	Evaluation and decision-making by reference to data, using application-specific and domain-specific knowledge

Multimodal interfaces			
Technologies	Short term 0-5 years (2010-2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)
Speech/sound/ movement/gesture (for application control)	Spoken commands (specific and limited multi-setting and context) Direction monitoring on the basis of movement (games) or sensors in clothing.	Improved comprehension of natural language, speaker-independence Interpretation of gestures	Full comprehension of natural language, related to semantic interpretation, understanding of content, some emotions Facial gestures for application control

Intelligent situationally aware adaptive technologies (with sensors and profiles)			
Technologies	Short term 0-5 years (2010-2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)
User profiles	Profiles within enclosed environments	Dynamic and roaming profiles for various environments	Situationally aware man-machine interfaces with sensors, profiles and limited emotions

Intelligent, situationally aware man-machine interfaces with sensors and profiles	Detection of presence of individuals/groups, location functionality	Situationally aware with sensors and profiles (multiple diverse environments)	Learning-enabled user interfaces (with limited understanding of human behaviour)
Learning user interfaces	Learning user interfaces (adaptable menus, single user, simple collaboration)	Learning user interfaces (multiple diverse environments)	Understanding of user behaviour
Security	Basic plus start of multi-environment for privacy and security	Multi-environment for privacy and security aspects extended with trust etc.	Technology for complete security support

Based on ITEA Technology Roadmap and Embedded Systems Roadmap

Steering Committee

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Jan Gerrit Schuurman (1967) is a visiting professor at the University of Lincoln (Community Operational Research Unit and the faculty of Health, Life and Social Sciences), where he holds a chair in health and community development. He also leads a cancer rehabilitation programme in the Netherlands, where his research is funded by the Foundation Alpe d'HuZes and the Dutch Cancer Society. He read experimental cognitive psychology at the University of Groningen before obtaining a doctorate from the University of Twente in 1999, with a dissertation on knowledge transfer in ICT training. He supervises postgraduate students doing work in multimedia interaction, the application of information systems in health care, and the design of anticipatory systems consisting of networks of actors. Since 2000, he has been involved in various health care sector projects commissioned by the Erasmus Medical Centre, the Utrecht University Medical Centre, the Dutch Cancer Society, the Ministry of Health, Welfare and Sport, and others. Between 1991 and 1994, Schuurman worked at the University of Amsterdam with Gordon Pask, one of the pioneers of cybernetics.

Ferial Moelaert El-Hadidy (1959) is a senior scientific researcher at Novay (formerly known as the Telematics Institute). The emphases in her multidisciplinary background are remote collaboration, situationally aware services, ICT solutions and platforms, health care and multimedia. She is currently engaged in health care research and has a particular interest in the boundary between welfare and health. She is involved in the National Freeband Programme and the European CogKnow Project, through which multidisciplinary research is conducted into user-centred solutions designed to support people with dementia in their daily lives. She is also associate editor of the *IEEE Transactions on Information Technology in Biomedicine*.

André Krom (1974) is a researcher at the Ethics Institute of Utrecht University. He worked as a senior project officer Technology Assessment at the Rathenau Institute. He read philosophy at the University of Amsterdam and has worked for the Rathenau Institute in various fields. In the field of biomedical technology, he has contributed to projects on organ donation, the use of (gene) technology in elite sports, human enhancement, and anti-aging. His methodological projects have included decision-making on medical technology and CIPAST, a European project on public participation in science and technology. At the Ethics Institute he is currently working on the PhD project "Infectious Disease Control and the Harm Principle".

Bart Walhout (1978) is a researcher at the Rathenau Institute. He was trained as an electronics designer and graduated from the Faculty of Technology and Society at Eindhoven Technical University, with a dissertation on government policy in relation to the social controversies surrounding biotechnology. At the Rathenau Institute, he has undertaken a number of projects in the field of nanotechnology. He has also been involved in projects concerned with converging technologies, such as nanotechnology, biotechnology, information technology and cognitive sciences. The realization of Ambient Intelligence is to a significant extent based on the opportunities afforded by the combination of these scientific and technological disciplines.

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Notes

[1]The first electronic computer was the Colossus, which began operating at the end of 1943. Of the Colossus, only ten were built.
[2] Weisser (1991).
[3] Joy (2000).
[4] In other words, Ambient Intelligence combines ubiquitous computing (Weisser) with social user interfaces (Reeves & Nass, 1996).
[5] The authors thank Stanislav Pokraev (Telematics Institute) for his input.
[6] The organizations and individuals concerned are listed in appendix 1.
[7] See also Francis & Glanville (2001).
[8] See appendix 2 for a brief summary of the key technological developments foreseen for the period 2010 to 2025.
[9] The term 'personalization' is often used in a more general sense, to refer to any matching of services to individual needs and preferences. This more general form of personalization is evident at all stages of the Ambient Intelligence vision. In Part III of this report, we use the word 'personalization' in this general sense, when considering the extent to which the use of Ambient Intelligence may be expected to make the individual citizen, patient, or care consumer the focal point of the care process.
[10] Only the values assigned to the variables in the user profile are automatically modified, not the definition of the variables to be monitored.
[11] IMEC is Europe's largest independent inter-university research centre for nano- and micro-electronics.
[12] The elements correspond to three different views of intelligence. Within the Ambient Intelligence vision, intelligence is primarily a relational concept (augmentation, see Norman, 1993). In the context of a normative view, the focus is not on functions, but on values. Where inherent intelligence is concerned, the person or thing to whom/which intelligence is ascribed is assumed to be capable of some degree of independent decision-making. This is why robots are nearly always given names, such as Cog. See Dennett (1994). Associated qualifications include prudence and appropriate timing. A good example is artificial intelligence. See, for example, Moravec (1998).
[13] Gyselinckx et al. (2006).
[14] Naturally these scenarios are set in the future and largely based on speculation concerning the course of developments.
[15] Parliamentary Committee on Policy on Older People (2005).
[16] Because residential care zones often have mobility problems and require support, certain facilities, such as bus stops, must be within specified distances. Rural areas often lack the population density necessary to make such zones viable.
[17] De Klerk & Schellingerhout (2006).
[18] Thesaurus of the Dutch Institute for Care and Welfare (NIZW).
[19] Coe & Neufeld (1999), p. 575.
[20] Domotics (from *domus* [home] + telematics) involves communication between electronic applications in a home or residential environment, for the benefit of residents and service providers.
[21] The project was organized jointly by Philips and Zilveren Kruis Achmea and ran from June 2005 to June 2006.

[22] For details, see www.nitel.nl.
[23] Wehrens (2007).
[24] At a Rotterdam disco called the Baja Beach Club, for example, visitors can have a subcutaneous RFID chip fitted, which serves as a 'digital wallet'.
[25] Physical and social integration do not necessarily go hand in hand, as underlined by the fact that John prefers the itchy patch over the more convenient and cheaper option of a subcutaneous chip.
[26] Care chains with a more or less standardized make-up are also referred to as clinical paths.
[27] Francis & Glanville (2001).
[28] The shift towards the provision of care outside traditional care institutions is also referred to as extramuralization.
[29] The inclination to send patients home straight after treatment whenever possible is also based partly on the observation that many people actually *become* ill in hospital, where infections can proliferate.
[30] WHO (2002).
[31] Biemans et al. (2005).
[32] Compare also Francis & Glanville (2001).
[33] Some care cannot be planned, however. This demands a high degree of coordination and alertness within the care network.
[34] In addition, Ambient Intelligence has a number of other potential health care applications. At the Academic Medical Center in Amsterdam, for example, RFID chips are extensively used for logistics purposes and for monitoring the whereabouts of both patients and care practitioners. Eindhoven's Catharina Hospital has the world's first Ambient Experience cardiology unit, which enables doctors to perform heart catheterizations more efficiently and makes the procedure less stressful for patients, who can choose their own visual themes and lighting.
[35] See, for example, Khler (2006).
[36] Information about one person could also have implications for others. A person whose parent or sibling develops type 2 diabetes, for example, might be instructed to maintain a healthy weight, since type 2 diabetes tends to be hereditary.
[37] Horstman (2006).
[38] The individual's voice may be made heard through a patient's association or a thorough medical pilot project.
[39] Debate concerning the normative issues associated with Ambient Intelligence is not advanced by proffering proverbs or truisms such as '*meten is weten*' ('measurement is the basis of knowledge'). One does not know any more than what one has measured.
[40] An automatic external defibrillator (AED) is an exception in this regard. Such a device ascertains whether cardiac arrest has occurred or atrial fibrillation is in progress, and provides a therapeutic shock only in the latter case. In theory, an AED can be used by any passer-by.
[41] Van Seventer (2006).
[42] This is a standard way of assessing the cognitive and motor development for children from 1 month old until they are 3 years 6 months.
http://www.babydevelopmentnews.com/bayleyscaleofinfantdevelopment.html
[43] This case history does not reflect the working methods of the interviewed physiotherapist in all respects. Some elements are based on information from the Association for People With Motor Disabilities and Their Parents (BOSK). See www.bosk.nl.

[44] In the treatment of school-age children, testing is already established as a way of monitoring motor development.
[45] In this respect, reporting is a more complex matter in physiotherapy than in, say, oncology. Compare chapter 6.
[46] Wehrens (2007).
[47] Comprehensive Cancer Centres Knowledge Network. Data for 2000 to 2003. See www.iKCnet.nl.
[48] Queen Wilhelmina Fund Dutch Cancer Society.
[49] Statistics Netherlands 2006 (data for 2005).
[50] Anne Bosma lives in a home for older people in Welten (Heerlen).
[51] Ministry of Health, Welfare and Sport (2005).
[52] Ten thousand steps a day roughly equals the recommended minimum exercise level of half an hour's moderate exercise five times a week.
[53] Dekkers (2006).
[54] Anticipation brings Ambient Intelligence closest to inherent intelligence. Compare note 12.
[55] See Van Hilvoorde & Pasveer (2005). In our case history, the emphasis is on the use of instrumentation to record data as a basis for refining training. However, technology is very important in other areas as well, such as sports clothing, diet and track surfaces.
[56] This conclusion is based on interviews with people from the Dutch sports umbrella organization NOC*NSF and trainer Henk Kraaijenhof.
[57] In this context, 'grassroots sport' means any form of organized athletics, including both recreational and competitive sport.
[58] In this context, we are concerned with what is permitted both in training and in competition.
[59] Results should ideally depend only on relevant inequalities between contestants. However, this may not be realistic. For example, economic differences can have a strong effect on the level of technological support available to an athlete.
[60] See Krom & Pasveer (2006).
[61] See www.fit-for-football.org/fieldlab.
[62] Litjens (2006).
[63] See www.sportsandtechnology.com.
[64] The Sportlog was developed by the Telematics Institute in conjunction with the Royal Dutch Swimming Federation (KNZB) and Dutch sports umbrella organization NOC*NSF.
[65] For more information, see www.fitgames.nl.
[66] Exoskeletons are also used for space travel and by the military. The US Defense Advanced Research Projects Agency (DARPA) has set up a special programme entitled Exoskeletons for Human Performance Augmentation, for example.
[67] Compare, respectively, chapters 6 and 5.
[68] See www.sportsandtechnology.com.
[69] Einmahl & Magnus (2006).
[70] Krom & Pasveer (2006).
[71] In Part III of this report, we use the term 'personalization' to refer to all aspects of the alignment of services with the individual's needs and preferences. See also note 9.
[72] Baumol (1998).
[73] Other tiers of government play a role in care as well. The municipalities, for example, are involved in the provision of care forms such as residential care zones (chapter 3).

[74] The difference between supplementary insurance and other care services is mainly a question of form (the type of contract). In theory, anything that is not covered by statutory insurance may be offered, with the exception of such procedures as open heart surgery. Other services can also be provided for in supplementary contracts with employers.
[75] Before the new act came into effect, 76 per cent of Dutch people were covered by national health insurance schemes run and supported by the state. The remaining 24 per cent had private insurance.
[76] The NZa was created by the merger of the National Health Tariffs Authority (CTG) and the Supervisory Board for Health Care Insurance (CTZ).
[77] In this context, 'normality' relates to the existence of evidence in support of the relevant intervention or care form.
[78] In some cases, status is also a factor. Famous sportspeople, members of the royal family and other high-profile individuals are liable to be less affected by waiting lists than the average person.
[79] Inequalities in what people can afford are not new and not necessarily problematic. Detailed analysis of the meaning of citizen-centred or patient-centred care leads to the conclusion that Ambient Intelligence has little bearing on such matters.
[80] In other words, the way care sector actors go about their business is less directly dictated by the principles or rules of the care system. In political science, a principle-based model is referred to as an enactment model (Williams, 2005). One example is Dworkin's law theory (2000). An approach based on rules is referred to as a structural model (Williams, 2005). An example is Rawls's law theory (1999). Principles and rules together form a system of enforcement and a moral system (Williams, 2002).
[81] Pragmatism differs from opportunism. See Williams (2002) and Shklar (1989).
[82] To this end, price tags have been attached to diagnosis-and-treatment combinations.
[83] See also Mol (2006).
[84] The identified trends by no means fully describe the way care is currently developing. They suffice in the present context, however, insofar as they provide an adequate scenario in which to assess the central promises of the Ambient Intelligence vision.
[85] The place where control resides.
[86] This may be seen as paradoxical, given the nature of Ambient Intelligence. In the final sections of chapters 3 to 7, we used the Assessment tool to gauge the extent to which care functions can or cannot be automated. We return to the potential of Ambient Intelligence in chapter 10.
[87] Van Kammen (2002) refers to the growing emphasis on primary over secondary prevention as a shift from intervention to prevention.
[88] Consider, for example, the Ambient Experience referred to in note 34.
[89] The trend towards improved comfort may therefore also be seen as largely independent of the health sector.
[90] Over-diagnosis means giving women a diagnosis of breast cancer that, without screening, might never have been made. Over-diagnosis is distinct from erroneous diagnosis (the result of false screening results). Over-treatment is the use of a more invasive form of intervention than strictly necessary, motivated perhaps by a safety-first approach, or treatment where no cancer is in fact present. See Health Council (2002), chapter 6.
[91] See Becker & Lucas (2006).
[92] See chapter 7.

[93] Early diagnosis and prevention on the basis of medical parameters may contribute to this process.
[94] See Pieters et al (2002).
[95] See appendix 2. Chronic obstructive pulmonary disease (COPD) is a generic term for a variety of conditions, such as chronic bronchitis and emphysema.
[96] This sets the stage for increased 'disease mongering': regarding people as ill and treating them accordingly at the slightest sign of functional impairment. See Moynihan (2006).
[97] This is particularly likely where big business has an active interest. In this context, Baumol (2002) refers to oligopolistic rivalry.
[98] The informed consent requirement is contained in the Medical Treatment Contracts Act (WGBO).
[99] See figure 1.
[100] In this context, the term 'networked care' is also used.
[101] Because care is increasingly provided by chains of carers, what the one professional does has a significant effect on the scope for action enjoyed by those further along the chain. Each must deal with the outcome of the previous actors' input. Thus, patient information communicated along the chain opens each carer's work to the scrutiny of the others.
[102] Client mistrust can led to anxiety and thus affect the measured data. It is therefore important to know what is being measured.
[103] Roes (2005).
[104] De Kam & Nypels (2000).
[105] See Taylor (1994; 1996).
[106] De Swaan (1996).
[107] The one thing that could prove difficult is the protection of sensitive health information.
[108] See Berg et al. (1998).
[109] Neuro-implants, for example, are subject to strict legal restrictions. See Rodota & Capurro (2005).
[110] Van der Veen (2005).
[111] Baumol (1998).
[112] The point should be made that the ultimate outcome of the collective efforts of the care sector actors is path-dependent. Not all desirable outcomes are possible, and not all undesirable outcomes are avoidable. See, for example, Trappenburg et al. (2005).