# Health 2.0
## It's up to you

The Hague, February 2010

# Contents

## The essence of this advisory

**Health 2.0: patients and healthcare providers work actively together, thus increasing the effectiveness and quality of health services.**

*What problem does this advisory address?*
All parties involved in the provision of healthcare services in the Netherlands agree that the patient (or 'healthcare consumer') should be the focus of the entire process. In practice, however, this is not always the case. This advisory considers the concept of Health 2.0, which is intended to ensure that healthcare provision does indeed become fully 'patient-centric'.

*How will Health 2.0 affect the consumer?*
The consumer will enjoy greater opportunities to become an active partner in his or her health care. He will be able to compare experiences with others in the same situation and will have far greater scope for self management.

*How will Health 2.0 affect the healthcare provider?*
Healthcare providers will be dealing with better informed patients who, as a result, are more conscientious in looking after their own health and in following medical advice. In other words, there will be greater patient compliance.

*How much will Health 2.0 cost?*
There are no additional costs. In fact, because the patient himself will be doing more ('self management') and because certain tasks and responsibilities will shift from specialists to other healthcare providers in the chain, it will be possible to stem the increase in healthcare expenses and relieve the pressure on staffing levels.

*What is new?*
Health 2.0 is a new social development whereby the individual forms part of 'communities' which assist and support him in maintaining good health, recovering from an illness or injury, or learning to cope with any lasting effects of a health problem.

This advisory is the result of a long series of discussions with patients, doctors, healthcare insurers, researchers and others involved in healthcare provision. The debate is not yet closed. We invite readers to join the ongoing discussions about Health 2.0 by visiting the website forum at http://rvz-health20.ning.com

# Health 2.0
## It's up to you

## Summary

*Internet advances*

From information consumer to information provider

The emergence of the internet has narrowed the 'information gap' between the professional and the man in the street. In the early years, only a relatively small group of providers offered information to the general public. Web 1.0 entailed a one-way traffic of that information from provider to passive user. Today, anyone is able to publish information on the web, whether in the form of text, the spoken word, music, photos or videos. Internet users can – and do – publish blogs and wikis, and they set up online discussion platforms. Hyves, Facebook, Twitter and YouTube are probably the best known examples of the new 'social media'. User-friendly software and simple, inexpensive devices such as webcams and mobile phones with built-in (video) cameras enable everyone to respond to what is going on around them, anywhere and at any time. This new form of internet usage is widely known as Web 2.0.

*Health, healthcare and the internet*

The early internet was primarily a source of information ........

The internet has penetrated society to a very significant degree. Some ninety per cent of Dutch households are now 'online'. Over the past ten years, people have taken to using the internet to find all sorts of information, including that relating to health and healthcare. For anyone with a health problem, the first step will often be to 'ask Dr Google'. Almost one third of internet users report that they 'always or generally' use the internet to find relevant information before they contact their own general practitioner, while a quarter do so on their return from the doctor's surgery.

...... but is increasingly becoming a discussion platform

No fewer than one in four internet users take part in at least one forum or discussion group relating to health and healthcare. At first, most did so through the websites of the various patient associations. Today, it is increasingly common to take part in the online communities on general social networking sites such as Hyves and Facebook. Patients suffering from a chronic condition are the most likely to seek contact with others 'in the same boat'. Almost half of those who are in contact with their peers exchange experiences about their dealings with the medical profession. Conversely, they discuss the information they find online with their healthcare providers. They also use the internet to compare the quality of doctors and hospitals.

| | |
|---|---|
| From family circle to the entire world | Consumers now attach far greater weight to the opinions of their peers than to the content of advertisements, for example. The social media have served to 'upscale' the traditional mouth-to-mouth advertising of the school playground, the community centre or one's immediate circle of friends and family. The effects of this up-scaling can be either negative – as in the disquiet which accompanied the introduction of a new vaccine for cervical cancer – or positive, as in the case of the online IVF clinic run by Radboud University Medical Centre in Nijmegen. |

*Health 2.0*

| | |
|---|---|
| Health 2.0 = participation | The social trend whereby individuals are brought together by the social media to discuss health and healthcare can be encapsulated by the term Health 2.0 (parallel to Web 2.0). The defining characteristic of Health 2.0 is active participation, with direct communication between patients, between professionals, and between patients and professionals. New developments such as 'wikis' and online communities can support both personal and professional decision-making in all aspects of health and health care. This exchange of information, cooperation and community building can enhance the performance of the individual healthcare provider and that of the healthcare system as a whole. |

*The impact of Health 2.0*

| | |
|---|---|
| Informed, participative patients | The key feature of Health 2.0 is that the patient is no longer a passive observer but an active participant in the healthcare process and is therefore truly the focus of that process. 'Patient-centric' care is no longer an empty promise. The patient enjoys greater opportunities for self-management and receives appropriate support. Participation in social networks serves to highlight the importance of prevention to reduce the risk of developing a health condition in future. The patient is able to take control of his or her own health, and is supported in doing so by a network of fellow patients and professionals. This results in a different relationship between doctor and patient, one from which both derive benefits. The doctor is now dealing with a well informed patient and no longer has to explain simple, basic matters. This makes his work somewhat more attractive. The patient will have acquired this basic information from the internet prior to the consultation. He knows the content of his medical records, he knows what treatments are possible and what they entail, and he will have read about the experiences of patients who are, or have been, in the same position. Armed with this information, the patient can ask about any matters which require further explanation. He and the doctor can then make a joint decision with regard to the most suitable treatment plan. |

It is not only the patient and the healthcare provider who will benefit from Health 2.0. There are also potential advantages for the government. A more involved, participative healthcare consumer is someone who takes greater care of his own health. He adopts preventive measures without coercion, complies with professional advice more readily, and takes greater responsibility for self-management. This is likely to reduce healthcare costs – or at least stem the ongoing rise in costs – since there will be less demand on the time of the professional care providers. At the same time, it is likely to resolve the problem of an impending staff shortage in the healthcare sector. It is therefore in the government's own interests to remove or mitigate any obstacles to the adoption of Health 2.0 and to facilitate its implementation.

*Why produce this advisory?*
Whether Health 2.0 is indeed to be implemented, and how quickly, is primarily a matter for the general public to decide. At first glance, a formal advisory addressed to the Minister of Health seems inappropriate or redundant. Nevertheless, the government can and must play a role. First, Health 2.0 offers certain opportunities to pursue and achieve the stated policy objectives, and these opportunities must not be passed up. The government must therefore take an active part. Second, there are certain obstacles to the adoption of Health 2.0. If these obstacles are allowed to remain in place, it will be impossible to derive the benefits of Health 2.0, while the risks (such as patients taking action based on inaccurate information) will be exacerbated. It falls to the government to smooth the path of Health 2.0.

*Obstacles to Health 2.0*
The current organizational structure of the healthcare system and the manner in which it is funded are not entirely appropriate to the Health 2.0 concept. Moreover, there are various institutionalized organizations which appear unwilling or unable to adapt to new circumstances, and which would actually benefit from the retention of the current Healthcare 1.0 situation. The proposed situation, in which the consumer himself is in charge, will make many representative organizations entirely redundant unless they alter their strategy. It is fair to state that the culture within the healthcare sector is not geared to change. Not all parties in the field seem willing to embrace transparency. These factors are likely to result in a slow and painful development of Health 2.0.

*Threats*
A further problem is that some healthcare consumers are not adequately aware of the opportunities and threats that Health 2.0 will bring. In the new situation, absolutely everyone becomes an information provider. The risk of that information being unreliable, i.e. *misinformation*, therefore becomes even greater than it already is.

Health 2.0 will require people to give up some of their privacy. The added value of sharing information will outweigh individual interests. It is therefore possible that others will misuse personal information.

**The risk of a widening digital divide**

In practice, some healthcare consumers will take a very active part in Healthcare 2.0. They will benefit from the many possibilities offered by the new situation. However, there will remain some people who are unable to take part at all, perhaps because they cannot afford internet access. It is essential to ensure that the 'digital divide' does not become any wider.

The government must steer and guide the adoption process in order to ensure that the opportunities are maximized and the risks are minimized. The various field parties must also accept their respective responsibilities.

*What must be done?*

**Combining 1.0 and 2.0**

First, it is necessary to combine the positive elements of Healthcare 1.0 and Health 2.0. Healthcare providers must be able to impart their specialist medical knowledge, the result of many years' training, in a patient-friendly and understandable way, perhaps by means of the hospital website. There are already many possibilities in this regard, such as videos and podcasts describing certain tests or operations, and blogs describing new technologies the healthcare provider is able to offer. These are all available in the Healthcare 1.0 situation. To them must be added the experiences of patients themselves, one of the prime components of Health 2.0.

**An adequate response is required**

All actors within the healthcare system must realize that a development is now underway which cannot be halted. It is therefore necessary to think carefully about how the implications of that development are to be addressed. Organizations which fail to respond adequately will find themselves in a very difficult position. In the best case scenario, they will take full advantage of the opportunities offered by Health 2.0. Their communication and information strategy will be revised and updated so that the social media can be used in pursuit of their (policy) objectives. They will examine ways of involving healthcare consumers in formulating new policy, and they will strive to achieve far greater transparency in order to retain (or regain) public confidence.

*What must the government do?*

**Valuable innovations must be rewarded**

The government must examine how it is to deal with information and misinformation within the social networks. It must also restructure the funding of the healthcare system in such a way as to ensure adequate resources for innovations intended to enhance the role of the patient. This will entail financial incentives to promote a culture of innovation. 'Perverse' incentives which do nothing to encourage professionals to adopt innovations of added value, or which actually encourage the retention of outdated structures and procedures, must be abolished.

*What must healthcare providers do?*

Healthcare providers should examine how they can use the social media to optimize contact and interaction with their patients. Those patients require reliable information, and expect their healthcare professionals to provide it. This demands both a

| | |
|---|---|
| Use the social media to arrive at optimum health services in association with patients | Healthcare 1.0 approach (the ability to offer reliable information) and a Health 2.0 approach, whereby the professionals benefit from feedback from patients themselves. Patients and professionals must work together to create a system of 'shared care'. This may entail the joint development of care standards whereby self-management is actively encouraged. After all, self-management offers a number of interesting possibilities. It is a question of lifestyle management, of prevention rather than cure, and of patient autonomy. As stated above, self-management can also serve to reduce costs. |

*What must health insurers do?*

<table>
<tr>
<td style="vertical-align:top">Use customer experiences</td>
<td>Health insurers also have a part to play in achieving a 'healthy' Health 2.0 situation. They must offer their policy-holders certain facilities, such as the ability to report back on their experiences with certain healthcare providers. This will enable the insurers to contract better products and services. Insurers should consider funding (some of) the running costs of online communities, and if those communities are subject to a subscription charge ('fee for membership') the insurers should reimburse the patient, just as they already reimburse membership of certain patient organizations.</td>
</tr>
<tr>
<td style="vertical-align:top">Impose Health 2.0 conditions when contracting health services</td>
<td>In the contractual terms and conditions under which they purchase products and services from healthcare providers, insurers can demand that self-management becomes a significant component of the overall treatment protocol or standard. They can encourage healthcare providers to make use of the social media in their communication with patients, and can set deadlines by which all such conditions are to be met.</td>
</tr>
</table>

*What must the public and patient organizations do?*

<table>
<tr>
<td style="vertical-align:top">An active role in the healthcare process</td>
<td>The public will play a significant part in bringing about the shift in responsibility from professional to patient. First and foremost, people must embrace lifestyle management and preventative measures to ensure that they are less likely to require the services of the healthcare professional. In addition, there are a number of 'administrative preparations' that can be made prior to a consultation, such as forwarding personal information and completing the intake questionnaires online. Last but not least, new technology has opened up many more opportunities for patients (such as those suffering from diabetes or COPD) to treat themselves at home without the intervention of a medical professional.</td>
</tr>
<tr>
<td style="vertical-align:top">Support á la Health 2.0</td>
<td>Patient organizations also have a role to play. They can encourage the proper use of personal health records for the purposes of self-management, and by working together they can ensure that patients suffering from a number of conditions ('co-morbidity') enjoy an integrated rather than a fragmented approach. Patient organizations should also undertake activities to ensure that the 'digital divide' between those who have internet access and those who do not is narrowed, particularly in terms of access to Health 2.0 applications.</td>
</tr>
</table>

The adoption of Health 2.0 will mean that patients and healthcare providers will work actively together. This will enhance both the effectiveness and quality of care services.

# 1 Terms of reference

## 1.1 Introduction

The internet: part of everyday life

Since the late 1980s, the internet has come to play a very significant role in society. In the early days, use of the internet in relation to health and health care was limited to the publication of general information which readers would access in a passive manner, just as they might consult a medical encyclopaedia. Later, specific 'e-health' applications emerged, some of which were set up and run by professional practitioners. Examples include sites to which users could submit digital photographs of skin conditions for assessment and diagnosis by a dermatologist, and online therapy courses for people suffering from post-traumatic stress disorder, run under the guidance of psychologists or psychiatrists.

Today, many non-professional internet users have become active in providing information and taking part in forums, discussion groups, online communities, etc. They enable fellow internet users to manage their condition more effectively, and hence to take control of their own health.

Will Health 2.0 influence the traditional relationships in the healthcare system?

Previous advisories produced by the Council for Health and Health Care focused on the opportunities and threats of internet use in terms of public health and health services for consumers (e.g. *Patiënt en internet*[1]) and the implications for the healthcare profession (*e-Health in zicht*[2]). These advisories examined what the government can do in order to exploit the opportunities, minimize the potential risks, and to offer incentives where necessary.

On 10 April 2008, the Council organized a meeting to discuss new developments in healthcare-related internet usage, and in particular the Web 2.0 applications. During this meeting, it became clear that the developments could well lead to a shift in the traditional relationships between the three parties involved in the healthcare process: consumer, provider and financier. This prompted the Minister of Health to include the topic of Health 2.0 in the working programme of the Council for Health and Health Care for 2009 (see Appendix 1).

This advisory therefore examines the influence that the developments, grouped under the general heading of 'Health 2.0' will have on the relationships between the three actors within the healthcare system, and hence their impact on the role of the government itself.

## 1.2 Policy questions

This advisory addresses the following three questions:
- What are, or what may be, the consequences of Health 2.0 for the actors in the healthcare system, specifically, the healthcare consumer, the healthcare provider and the healthcare financier?
- What will be the consequences in terms of the (administrative) relationships between the three parties' roles, tasks, rights and responsibilities?

- What will be the consequences in terms of the government's role as legislator, regulator and facilitator?

This advisory forms a review and survey of the developments in health-related internet use, and the likely consequences of those developments. The relevant aspects include:
- the significance of the developments in terms of the current administrative structure of the healthcare system and the extent of government involvement;
- the willingness (and ability) of healthcare providers to take advantage of the developments;
- the knowledge and skills that consumers will need to help steer the developments, and the measures required to narrow the divide between those who can and those who cannot (or do not wish to) do so.

The primary focus of this advisory is on the field itself: the consumers, providers and financiers of health care. However, the findings will also give rise to consequences for the government.

## 1.3    The purpose of this advisory

This advisory sets out to offer a better understanding of:
- the effect of Health 2.0 on the current administrative philosophy within the healthcare system: will the relationships between parties change?
- the opportunities and threats that Health 2.0 brings in terms of government policy objectives (ensuring affordable and accessible healthcare services of high quality);
- the opportunities that Health 2.0 will offer individual healthcare consumers and organizations in terms of autonomy and self-management, while public interests are safeguarded.

How will Health 2.0 affect health services?

It is hoped that this report will create greater awareness among government and the various stakeholders with regard to current developments in internet usage, and more specifically usage relating to health care ('Health 2.0'), and the opportunities that exist. The advisory is in the nature of a review and forecast, while also offering a number of recommendations.

## 1.4    Domain

The term '2.0' is currently being applied to many fields of endeavour: Politics 2.0[3], Science 2.0[4], Trendwatching 2.0[5], Education 2.0[6], Police 2.0[7], Consultancy 2.0[8], Civil Service 2.0[9], etc. Within the health and welfare sector we see the terms Health 2.0, Healthcare 2.0, Care 2.0, Welfare 2.0 and Medicine 2.0, to name but a few. All are derived from the term 'Web 2.0', which was coined by Tim O'Reilly and Dale Dougherty to refer to collaboration within networks which rely on 'collective intelligence'. The more people involved, they contend, the greater the effects will be.[10]

Many definitions of the term '2.0' refer to the new generation of websites which are more dynamic and interactive than earlier (Web 1.0) examples. Rather than a 'solitary web experience' such as reading an online newspaper or corporate brochure, Web 2.0 users communicate with each other, and can even determine the type and form of the information which appears on the monitor before them.

A significant component of Web 2.0 is therefore 'the wisdom of crowds'. The more people who take part in a social network, the greater the value they create.

> The website Innocentive.com was founded for the benefit of companies who are facing complex and unusual problems. If there is a major oil spill in a polar region, for example, how can one separate the oil from the ice? Such problems are put to the general public who are invited to suggest solutions. There is a cash reward for a successful solution: anything from five thousand US dollars to a million dollars depending on the size of the company concerned. To date, roughly one in three problems submitted to the site have actually been solved in this way. Some had occupied the minds of experts for many years. It is interesting to note that approximately eighty per cent of the problem solvers are from an entirely different walk of life to that of the company seeking solutions.[11]

Two minds are better than one

According to James Surowiecki in his 2004 book The Wisdom of Crowds: why the many are smarter than the few and how collective wisdom shapes business, economies, societies and nations, a group of people is remarkably intelligent, more so than even the most intelligent individual within that group.[12] This phenomenon is now generally known as 'the wisdom of crowds', from the title of Surowiecki's book. According to the theory, the input of several users leads to a decision which is based on as many individual opinions as possible. Examples of the concept in practice include websites on which people describe their holiday experiences[13] or review the products they have purchased.[14] The more contributors, the more valuable the website becomes to other users.[15] Web 2.0 can therefore be seen as an admixture combination of new developments, both technological and social.[16]

It is therefore possible to contend that, when patients with a chronic condition share their experiences, the result will be a combined 'wisdom' which is greater than the wisdom of any individual patient. The same will apply to medical practitioners who share their knowledge and experience. This process, in which patients can discuss the condition and the treatment options on a more equal footing with the doctor, alters the nature of the relationship between layman and professional. The 'wisdom of crowds' can be used to support the decision-making process. It may result in different choices being made, perhaps an alternative hospital, specialist or therapy.

Participation is therefore one of the key concepts of Health 2.0, for which various definitions have been proposed.[17] They include:
- "participatory healthcare characterized by the ability to rapidly share, classify and summarize individual health information with the goals of improving health care systems, experiences and outcomes via integration of patients and stakeholders," [18], or (a refined version of the same definition): "participatory health care. Enabled by information, software, and community that we collect or cre-

ate, we the patients can be effective partners in our own healthcare, and we the people can participate in reshaping the health system itself."[19]

- "[A] new concept of healthcare wherein all the constituents (patients, physicians, providers, and payers) focus on healthcare value (outcomes/price) and use disruptive innovation as the catalyst for increasing access, decreasing cost, and improving the quality of health care." [20]

**Apomediation: the 'invisible' interne diary**

Whichever definition we apply, we see a constantly developing cycle of healthcare innovation which is made possible through the empowerment of patients, professionals and researchers and a process of ongoing cooperation, participation, apomediation, feedback and transparency with regard to healthcare interventions.[21] 'Apomediation' refers to persons or internet applications (the 'apomediary ') which assist the user in finding good information and services without actually playing a direct part in providing the information or services. This is in contrast to the traditional '*inter*-mediary' who stands between the consumer and the information. The quality of the intermediary will therefore determine the quality of the information.[22]

The term apomediary was coined by the Canadian researcher Dr Gunther Eysenbach, who prefers the term 'Medicine 2.0'. His definition refers to "applications, services and tools [which] are Web-based services for healthcare consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies as well as semantic web and virtual reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups."[23]

**Health 2.0: active participation**

The authors of this advisory have opted to use the term Health 2.0, doing so in preference to alternatives such as 'Healthcare 2.0'. Healthcare is provided by others, while the essence of the envisaged Health 2.0 situation is the active participation of the consumer or patient himself. It is a social development, whereby the users of online social networks (often based on Web 2.0 applications) determine the strength of those networks. A key feature is the absence of any central control.

**Patients define their own indicators**

In the Health 1.0 situation, it is the healthcare provider such as the general practitioner who oversees the continuity of care on behalf of the patient. Performance indicators now play an increasingly important role in defining the quality of the services to be provided and the amount to be paid (usually by insurers) for those services. These indicators are frequently regarded as overly 'bureaucratic'.
Social networks might well arrive at entirely different conclusions with regard to appropriate indicators. They can define their own indicators, being the factors upon which the network members base their healthcare choices. In the Health 2.0 situation, the continuity of care is no longer the sole responsibility of the healthcare provider. Part of that responsibility passes to the consumer (or his partner, a parent or child), whose decisions are supported by a multidisciplinary network of professionals and 'experience experts' such as fellow patients and their carers.

**Social contacts are of vital importance**

Social contacts are important to good health. In 1979, Berkman and Syme published an article based on a nine-year study that revealed that the (early) mortality rate among people with few social contacts was between two and four-and-a-half

times greater than among those with large social networks.[24] In the 1970s, of course, the researchers were not discussing online networks.

The key feature of Health 2.0 is therefore the use of social networks which enable patients and their care providers to work together. Control shifts in part from care provider to care consumer. The exchange of information gives rise to a learning curve about the condition itself, treatment options, decision-making and support. This advisory is mainly concerned with the social developments which are made possible through the use of online social media. Such use will support both personal and professional decisions relating to health, care options, information exchange, cooperation and community building, all with a view to improving individual performance and that of the healthcare system as a whole.

## 1.5    Methodology

This advisory has been produced under the auspices of two Council members, Henk Bosma and Prof. Didi Braat. As part of the preparations, Prof. Valerie Frissen produced a background study entitled *Health 2.0: It's not just about medicine and technology, it's about living your life,* which examines how the new media are likely to affect the relationships between the various actors within the health system. The study and the advisory are published simultaneously.

*Zorgbelang Nederland*, the federation of patient and healthcare consumer organizations in the Netherlands, conducted a survey on behalf of the Council to gauge the effect of the new media on consumer behaviour. Three follow-up meetings were then held at which patients were invited to discuss their role within the healthcare system, and the ways in which internet applications can help them to fulfil that role. Reports of these meetings can be found (in Dutch) at www.rvz.net.

Further information was obtained by means of a Flycatcher survey of over two thousand internet users.[25]

Three meetings were held (in April, June and September 2009) with experts from the field. The topics discussed included likely future scenarios, the obstacles and problems in adopting Health 2.0 and possible solutions to those problems. The meeting reports (in Dutch) are also available at www.rvz.nl.

An online community (rvz-health20.ning.com) has been set up and remains open to the public. The discussions to date provided input for this advisory.

Council staff held a number of interviews with experts and stakeholders, and conducted a desk study of the current literature.

The results and a preliminary draft of the advisory were discussed with experts and stakeholders at two meetings, held on 30 November and 7 December 2009.

A brief account of the manner in which this advisory has been produced can be found in Appendix 2. A more detailed description can be found on the Council's website (www.rvz.net) and the online community homepage at www.rvz-health20.ning.com.

## 1.6    The structure of this document

Following this general introduction, Chapter 2 provides a description of the setting, ongoing social developments and the positions of the various actors.
Chapter 3 describes the possible future form and implications of Health 2.0, and what might be expected if we fail to make the transition but remain in the current Health 1.0 situation, or a development thereof. This comparison allows the possible impact of Health 2.0 to be deduced. The chapter goes on to consider the likelihood of a full transition to Health 2.0 in view of the various obstacles that must first be overcome. It concludes with suggestions for ways in which the obstacles can be removed or mitigated. The final chapter, Chapter 4, presents a number of recommendations for each of the stakeholders involved.

## 2 The setting

### 2.1 Society

Social relationships are changing. The mayor, the local priest, the head teacher and the lawyer are no longer accorded the same deference. Government organizations and large corporations do not command the same authority. This is largely due to the 'democratization of information'.[26] In the past, a relatively small number of organizations were able to generate and distribute information. Today, absolutely anyone can do so. Of course, this is not to say that the information will actually be 'consumed' by others. Nevertheless, information generated by the individual is gaining in importance, primarily because information from various sources is being collected and collated. While our communication used to be confined to a small circle of friends and acquaintances, it is now possible to share knowledge and experiences with large groups. We have a global audience. The possibilities offered by the internet have encouraged people to take more heed of their fellow citizens' opinions rather than information provided by the government, corporations or other professional organizations.[27] The low take-up for the HPV vaccination among teenage girls illustrates the effect of this trend.[28] Knowledge and opinions that were once confined to a small circle of school friends were exponentially 'upscaled' to include that of teenage girls throughout the Netherlands and far beyond.

New technology has made news available practically anywhere at any time. Moreover, the internet enables the news content to be 'customized' to the individual user's preferences. It is now relatively easy to find people with similar interests to one's own and to form or join an online community.[29] The newspapers seem to have recognized the value of this 'niche profiling' and have created communities on their own websites.[30] The general public, and young people in particular, are now accustomed to using the media in a far more interactive manner.

The internet has penetrated Dutch society to such an extent that those on the 'wrong' side of the digital divide are now in a tiny and shrinking minority. Nevertheless, there are still some who have no internet access or who lack the required skills. According to statistics, 90% of Dutch households have internet access.[31] This means that almost two million people do not. In some clearly defined groups, including seniors and the ethnic minorities, internet penetration is significantly lower than the average, although once again we can see a rapid diffusion to redress the balance.[32] Not having access to internet is now seen as a distinct social disadvantage. It is assumed that everyone can make use of the new media. We should remember that doing so entails not only having physical access to the infrastructure, but also the required skills. Some 1.5 million adults (over the age of 16) in the Netherlands have only a very basic level of education and many can be classed as functionally illiterate: they have great difficulty in reading and writing.[33] They are therefore not able to make use of printed or written information, and inevitably function less well in society, at work and at home. It is important to realize that only one third of this group belong to the ethnic minorities: the remainder are of 'native' Dutch origin. Seniors also lag behind in terms of internet usage, but seem to

be rapidly catching up. There is a growing band of 'silver surfers'. Even so, the internet skills of seniors and those with relatively little formal education are generally not as well developed as those of the younger generation and those who have completed at least a secondary education.[34] The ethnic minorities are at a particular disadvantage. All actors – and especially the government – must take this fact into account. They must ensure that the disadvantage is not carried over into the healthcare domain simply because these groups cannot make full use of the new opportunities. Specific attention must be devoted to these groups and any obstacles to full 'digital inclusion' must be removed.

## 2.2    The information consumer

The internet is an important source of healthcare information

Over the past ten years, it has become a matter of course to seek information online. Information relating to health and health care is in particular demand. In 2007, almost half of all internet users sought health-related information on one occasion, and over one third did so on several occasions. Just one in five internet users did not seek health-related information at all.[35]

As the following table illustrates, internet users find the various online facilities of increasing importance, alongside the traditional sources of assistance.
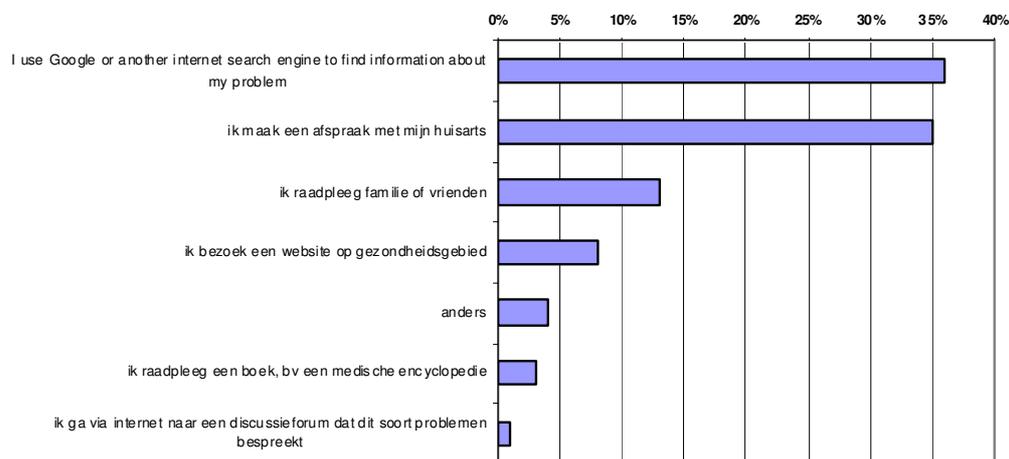
**Table 2.1**

| | |
|---|---|
| Google or other general search engines | 53% |
| Consultation with GP | 31% |
| Wikipedia | 23% |
| Patient association websites | 23% |
| Talking to family and friends | 21% |
| Specific health-related search engines | 21% |
| Contact with those in a similar situation (peer communities) | 17% |
| Health-related newsgroups and forums | 16% |
| Medical television programmes | 14% |
| Government websites, e.g. www.kiesbeter.nl | 13% |
| Information about the quality of health services (AD, Consumer Society, Elsevier, etc.) | 12% |
| Medical professionals' blogs | 10% |
| Newsletters | 8% |
| Books (medical encyclopaedias, etc.) | 7% |
| Social networking sites (Hyves, Facebook, etc.) | 7% |
| Pharmaceutical companies' websites | 6% |
| (Medical) journals | 6% |
| Videos (e.g. on YouTube) | 3% |
| Medical radio programmes | 2% |

% that state that this source of information has become more important to them during the past three years.
Source: RVZ/Flycatcher survey, 2009.

When someone develops a health problem, the most common first response is to use Google to find further information.

**Figure 2.1**



Source: RVZ/Flycatcher survey, 2009.

The internet is also widely used in conjunction with a visit to the GP:

**Table 2.2**

|  | Always/often | Sometimes/rarely | Never |
|---|---|---|---|
| a. Do you consult the internet to find information about your complaint/symptoms *before* visiting your GP? | 29% | 55% | 16% |
| b. Do you discuss the information you have found on the internet with your GP? | 22% | 66% | 12% |
| c. Do you consult the internet *after* visiting your GP? | 25% | 44% | 31% |

a. Percentage of all respondents (N=2145)
b. Percentage of those who do consult internet prior to visiting their GP (N=1803)
c. Percentage of all respondents (N=2145)
Source: RVZ/Flycatcher survey, 2008.

Sometimes the patient knows more about his or her condition than the doctor

The internet has played a very significant role in narrowing the 'information divide' between professional and layman. In the early years of the internet, information was restricted to a small number of sites, most created and maintained by medical specialists. More recently, it has become possible for absolutely anyone to publish

information, the process having been facilitated by social networking websites and the wide availability of technical resources such as webcams, mobile phones with built-in cameras, etc.

## 2.3  The participative citizen

In 2009, some 375 million unique users accessed YouTube (founded in 2005), and between them accounted for 75 billion downloads of the video clips on the site.[36] Facebook now has some 66 million users worldwide, while MySpace has 54 million. Research by Nielsen Online reveals that social networking is now more popular than using e-mail: 67% of internet users regularly visit social networking sites, while 65% communicate using e-mail.[37]

Social media gaining in popularity

Hyves, currently the most popular social networking website in the Netherlands, has seven million registered members with a Dutch (IP) address.[38] As on Facebook and MySpace, users create a 'profile' with personal information about themselves. If they wish, they can add blogs, music, photos and videos. Hyves now has scores of communities dedicated to health-related matters. The majority of Hyves users are aged between 15 and 35, and female users outnumber males by 56% to 44%.[39]

The ways in which members of the public can share information with each other using the internet include:
- *Weblog* (or simply 'blog'): a diary or logbook of information which the author wishes to share with visitors to his or her site. The information need not be pre-sented as text; it can be in the form of photos (a 'photoblog'), videos ('vlog') or audio (a 'podcast'). Weblogs generally allow other users to respond.
- *Internet forum or discussion group*: online public discussion pages.
- *Microblog*: a textual blog limited to a certain number of characters (e.g. Twitter).
- *Podcasts*: audio files of discussions, radio programmes, music etc., made available through the internet.
- *RSS* (Really Simple Syndication): websites send out 'feeds' to automatically no-tify users of updates and breaking news.
- *Social Network*: an online network providing social contact (support for personal welfare and wellbeing of its members), or for business purposes (e.g.) LinkedIn).
- *Video-sharing*: sharing videos through a website, the best-known being YouTube.
- *Wiki*: an online document that can be edited by users who check and amend the content as required.
The above applications are classed under the general heading of 'social media'.

On 25 February 2009, a Turkish Airlines plane crashed just short of the runway at Schiphol Amsterdam Airport. Even before the mainstream media could report the incident, members of the public were using Twitter to 'tweet' each other about the crash and distribute photos of the wreckage. As television presenters claimed that 'no further information is available at present', eye-witnesses at the scene were describing the arrival of the emergency services and could report that survivors were exiting the aircraft. One Tweeter (Twitter user) had actually been inside the plane assisting the passengers.

Product comparison sites, wikis and online social networks such as Hyves, MySpace and Facebook are the most popular websites on the entire internet.

**Table 2.3**

|  | Usage | | |
| --- | --- | --- | --- |
|  | Active | Passive | None |
| Online social networks | 45% | 20% | 34% |
| Comparison sites | 22% | 51% | 27% |
| Wikis | 14% | 51% | 34% |

Source: Ruigrok – NetPanel focus group survey, The Next Web 2009

Health-related discussion platforms are popular

The social media are used to a somewhat lesser degree with respect to health-related matters, as shown by the table below. However, search engines (which are not a social medium) are indeed widely used for this purpose, as are online forums (peer group contact). Given that a significant number of 'Googlers' are looking for health-related information, it would be reasonable to assume that a similar proportion of social media usage would also be health-related. However, this does not appear to be the case.

**Table 2.4**

| Which of the following media do you (sometimes) use for: | General topics | Healthcare-related topics | Ratio general to health-related use |
| --- | --- | --- | --- |
| Search engines: Google | 87% | 75% | 0.86 |
| Wikis (e.g. Wikipedia) | 52% | 33% | 0.63 |
| Consumer review sites (e.g.Kieskeurig.nl) | 38% | 9% | 0.27 |
| Online communities (Hyves, Facebook) | 37% | 5% | 0.14 |
| Photo and video sharing sites (YouTube, Flickr) | 36% | 2% | 0.06 |
| Forums and discussion groups | 35% | 25% | 0.71 |
| Chatboxes (MSN, etc.) | 24% | 3% | 0.13 |
| Social news sites: NUjij.nl | 18% | 4% | 0.22 |
| Blogs | 15% | 4% | 0.27 |
| Microblogs (Twitter) | 2% | 0% | 0 |
| Bookmark sites (Delicious) | 2% | 0% | 0 |

Source: RVZ/Flycatcher survey, 2009.

One reason for this discrepancy is that there are very few review sites which include ratings of individual medical practitioners in the Netherlands.[40] In addition, many people still regard the internet as primarily a tool for 'leisure purposes', such as online shopping, planning holidays, etc., while its use for health-related purposes remains more of a 'necessary evil'.[41]

Of all the social media, the forums and discussion groups are currently the most popular Web 2.0 applications in connection with health-related matters. It is the participants – the members – who generate and share the information. The proportion of internet users who consult wikis is somewhat lower. In any event, this form of usage is more in the Web 1.0-style of passively seeking information rather than producing and contributing it. Research suggests that online communities have the same 'empowerment' effect for both those who actively contribute and those who merely read other users' posts.[42].

## 2.4    The patient

There is no such thing as 'the patient'. However, it is possible to identify certain categories of patient or 'healthcare consumer'. Approximately half of all patients are 'not fully self-reliant healthcare consumers', some 40% are 'pragmatic healthcare consumers' and 10% are 'socially critical healthcare consumers'.[43] Those in the largest group are generally least satisfied with their health status. They place a relatively heavy demand on the healthcare system and any information addressing this group must be simple and readily understandable. They have a passive attitude to healthcare, preferring to leave all decisions to the professionals. They are not particularly interested in self-management.

'Pragmatic healthcare consumers', on the other hand, are reasonably self-reliant. They are also demanding and expect to receive the very latest treatment that modern technology can offer. They actively seek out reliable information about healthcare services and avail themselves of the greater freedom of choice in the sector. They wish to be well informed and to be consulted on all aspects of their treatment. These 'vocal' patients are not a new phenomenon: they have been around for several decades.[44]

The third and smallest group is more critical and more outspoken than the main group of 'less self-reliant healthcare consumers'. Most lead a healthy lifestyle and are generally satisfied with their state of health. They too seek reliable information; they demand freedom of choice and the right of co-determination. In fact, they wish to retain full control over their condition and its treatment.

It is the 'pragmatic healthcare consumers' who will be most interested in Health 2.0. They will contribute to health-related wikis (and indeed are already doing so in the case of fertility treatment), and to the various ratings and reviews. They are active within various social networks simultaneously.

You would enjoy searching for a good holiday destination but you might begrudge the time spent looking for a good doctor

Passive participation also leads to empowerment

Health 2.0 may not be appropriate for all patients

| | |
|---|---|
| Older chronic patients are primarily infor- mation consumers | Most chronic patients over the age of 50, even those with a higher standard of education, are still in the Health 1.0 situation. They consume far more information than they produce. Because they can now access far more information than in the pre-internet era, they are seeing a shift in the patient-doctor relationship. In the past, the doctor was the expert. Today, the GP will find it perfectly normal for the patient to have formed his or her own opinion, perhaps even a tentative diagnosis, based on information gleaned from the internet. Similarly, most doctors are now more prepared to discuss matters such as test results with the patient. This group tends to take a rather less favourable view of specialists. Those who are under the care of several specialists complain about the lack of communication between them, which is a major source of frustration.[45] |
| Declining interest in belonging to a patient organization | This group of healthcare consumers nevertheless recognizes the growing importance of the social media, which are coming to replace the traditional peer group meetings at which patients actually meet face-to-face. They see the younger generation using the new forms of contact, and they also see that young people have far less interest in joining a patient organization, and in many cases no interest at all. |

Those who maintain contact with fellow patients are more active in several areas than those who do not, as shown by the table below.

**Table 2.5**

| Activity | Peer contact | No peer contact |
|---|---|---|
| Sharing experiences with professionals and fellow patients | 55% | 9% |
| Discussing information found online with the healthcare provider | 55% | 30% |
| Using the internet to compare the quality of doctors and hospitals | 44% | 24% |
| E-mailing the care provider with questions | 44% | 20% |
| Self-diagnosis using the internet | 33% | 22% |
| Maintaining personal health history/medical records | 20% | 10% |

Source: RVZ/ Zorgbelang Nederland survey, 2009 (N=1317).

| | |
|---|---|
| The members of social networks trust each other | Healthcare consumers are generally far less willing to share information with fellow patients if they believe their privacy will be compromised. Transparency helps to reassure them that they can trust each other and the social networks. The advantages of sharing information will then weigh more heavily than the interests of privacy. |

## 2.5    The healthcare provider

| | |
|---|---|
| Specialists are lagging behind | Information and Communication Technology (ICT) has found many applications in the healthcare system. The GP's traditional written patient notes (the 'green cards') have been replaced by the Electronic Patient Dossier (EPD), while the administra- |

tive and financial aspects of running a general practice have also largely been automated. Specialists have yet to follow suit. There are relatively few who record patient information in digital form. Although there have been many attempts to digitize medical practice (in the broadest sense of the term), many of which are still ongoing, it is fair to state that 'e-healthcare' has yet to become the norm in the Netherlands. There are, however, some notable exceptions such as the initiatives in dermatology and mental health services.[46]

Despite the possibilities now available, the use of the social media remains limited. Some specialists do indeed use the internet to disseminate knowledge, and this practice is on the rise.[47] However, relatively few doctors offer patients the possibility of contacting them by e-mail. According to an estimate made in 2008, only 9% of Dutch GPs offered 'e-consultations'.[48]

Doctors do however communicate with each other through various online forums, discussion groups and so forth. In the United States, Sermo is an established medium for professional discussion.[49] This type of platform is now gaining ground in the Netherlands too.[50] The internet also offers doctors the opportunity to keep abreast with the latest clinical development by means of such sites as UptoDate.com, to which over four thousand medical professionals contribute.[51]

Hospitals are making growing use of the internet to communicate with their patients. The Flevoziekenhuis in Almere enables patients to make appointments online. Using a secure and personal section of the website, they can also view test results and any correspondence between care providers.[52] The Haaglanden Medical Centre in The Hague offers patients full access to their medical records.[53] However, Dutch hospitals are still making very little use of the social media compared to their counterparts in the United States.[54] This remains unexplored territory which seems to offer some interesting possibilities. A hospital can profile itself as a reliable authority on certain conditions and therapies, sharing its knowledge and expertise with the rest of the field and the general public. During discussion sessions with patients, it was discovered that this function is actually expected of the hospitals.[55] Moreover, interaction can help to strengthen the doctor-patient relationship, as well as promoting communication between professionals.

Recent years have seen a number of initiatives designed to bring the knowledge and experience of doctors and patients together within networks which will then provide support to other users. One example is the Digital IVF Clinic run by Radboud University Medical Centre in Nijmegen.[56] By means of a secure site, network members can access relevant information, share knowledge and experiences with each other, and receive advice and support from specialists. Similar Health 2.0 applications have been trialled in several other countries, meeting with a positive response from doctors and other healthcare professionals.[57]

Online patient forums are not only a source of information: they can assist the patient in accepting and coping with his or her condition. The use of social media changes the role of actors such as doctors and hospitals within the process of information provision. The social media themselves become an integral part of the

information flows and other communication. Apart from the isolated initiatives mentioned above, the actors have yet to exploit the full potential of the social media. This is due to lack of knowledge, time, financial resources and appropriate strategy.[58]

Patients to rate care providers

The emergence of review and comparison sites on which patients report their experiences with care providers and award them 'marks out of ten'[59] is likely to influence the way in which those care providers work.

## 2.6    The healthcare insurer

Healthcare insurers are already more active in Health 2.0 than healthcare providers

Healthcare insurers have long since set up websites to inform their (prospective) policy-holders about the insurance cover they offer, as well as information on a wide range of health-related topics. Some now use the social media to maintain contact with their clients, to gauge public opinion and to attract new customers.

Many health insurance companies (CZ being just one example) allow policy-holders to log in to a personal account on the corporate website, where they can access information about their policy and past claims. Some companies have gone even further and allow clients to view details of payments made directly to the healthcare provider in respect of treatment. The sites invite clients to comment on the quality of the care services offered. Information obtained in this way, aggregated across all policy-holders and presented in the form of rankings, can be used to support the insurance company's own contracting decisions as well as helping policy-holders to select the best care provider.
Healthcare insurers, alongside other stakeholders such as patient organizations, are partners in the creation and maintenance of websites which assist patients in selecting the most appropriate care provider, hospital, course of treatment, etc. based on the actual experiences of other patients.[60]

## 2.7    The government

The government finds it difficult to keep pace with Health 2.0

The government applies a number of instruments in pursuit of its policy objectives, which include ensuring the accessibility, affordability and quality of healthcare services in the Netherlands. In doing so, the government must constantly adapt to the changing setting and circumstances. It sometimes has some difficulty in keeping up with the pace of change. This is certainly true in the case of Health 2.0, which entails exploiting the new possibilities offered by the internet to promote the accessibility, affordability and quality of care by focusing on the patient.

The public demands transparency

Increasingly, the public demands transparency from all organizations, including the government. Transparency will serve to enhance public confidence in the government; failure to provide information which people consider relevant will have the opposite effect, fostering only suspicion and mistrust.

The American website www.data.gov went online shortly after Barak Obama's inauguration as president of the United States. It sets out to offer as much 'raw data' about public administration as possible. Anyone can use the information collected by the government for any purpose. The information is not filtered or processed in any way: it is open, transparent and universally available. The website is in keeping with President Obama's policy statement in which he called for fully open government.

Legislation 2.0 is not yet with us

It should be noted that there are several ongoing government initiatives whereby the social media are being used in pursuit of policy objectives. One of the most significant is the *Ambtenaar 2.0* (Civil Servant 2.0) project.[61] However, the government has yet to apply the 2.0 concept within healthcare-related legislation to any significant degree. As a result, the main focus of healthcare funding continues to be the relationship between care provider and insurer. The opportunities to support cooperation between healthcare provider and healthcare consumer by means of financial incentives remain extremely limited.

## 2.8    Moves towards Health 2.0

*More rankings*

Ranking the stars

The Dutch current affairs journal *Elsevier* and the national newspaper *Het Algemeen Dagblad* were among the first media to produce 'league tables' of hospitals in the Netherlands. They have since been emulated by many other organizations. Some, such as *Stichting Consument en de Zorg* (the Consumer and Healthcare Foundation) have opted to focus on collecting and publishing patient experiences. It may be expected that a balance will eventually be struck between empirical data, the subjective information provided by patients and the ratings of fellow care providers.

*'Crowdsourcing'*
Organizations are increasingly tapping the knowledge of a large group of random individuals,  which may include professionals, laymen volunteers and those with a passing interest in the topic under discussion. The tasks traditionally performed by an employee or contractor are thus 'outsourced' to the group or community. This practice has been termed *crowdsourcing* (a portmanteau word combining 'crowd' and 'outsourcing') and is based on the 'wisdom of crowds' philosophy.

Following the devastating earthquake which struck Haiti in January 2010, hundreds of volunteers translated please for help which were received by mobile phone into English and passed them to the international disaster relief teams at the scene. Thanks to their efforts, a hospital was able to obtain fuel for its generators within twenty minutes. Similarly, thousands of volunteers joined forces to produce a detailed map of Haiti showing the locations at which assistance was most urgently needed. The rescue teams could then download the maps onto their mobile GPS systems and knew exactly where they had to go.[62]

*Personal Health Record (PHR)*

Personal Health Records introduced

Dutch healthcare providers have been using the 'Electronic Patient Dossier' (EPD) system for some time. A number of organizations, both in the Netherlands[63] and major international companies such as Microsoft and Google[64], have also introduced a system of 'Personal Health Records' (PHRs) which are maintained by the

individual user. The PHR can facilitate communication with professionals, particularly in terms of direct patient experiences. Portals are being set up (possibly as an intermediate phase) to provide patients with online access to their own personal information, general information about health and healthcare services, appointment diaries and online contact with care providers.[65]

*Network integration*
Many consumers are members of more than one network, since chronic patients often suffer from several conditions simultaneously ('comorbidity'). New technology enables those consumers to integrate their various networks into one user-friendly interface.

*New 2.0 services*
There are new organizations which bring together healthcare providers and healthcare consumers to offer patients greater freedom of choice. One example is www.zoekPGBZorg.nl.

*First MOLs, now POLs*

At present, it is the Medical Opinion Leaders who command greatest authority (and whose voice is particularly important to the pharmaceutical industry). These 'MOLs' are the doctors who are seen as the leading experts in their field. They tend to publish most frequently in the professional journals and, more often than not, they hold a seat on the committee of the relevant scientific organization. They are often invited to speak at medical congresses and their opinions are also sought by the 'lay press', i.e. newspapers and general interest magazines.[66] Alongside the MOLs, a new breed is emerging: the POLs, or Patient Opinion Leaders. These are patients who have considerable experience of living with a particular condition. They know the practical solutions to the problems and inconvenience which a chronic condition can entail. They will have considerable influence on public opinion, especially that of fellow patients, and within the organizations which provide patient care.

*Increase in mobile communication*
By late 2009, the penetration of mobile internet in the Netherlands was almost 20%. Some 2.8 million Dutch consumers regularly access the internet using their mobile 'smartphone'.[67] This represents the continuation of a trend which has been ongoing for some years. People now have unfettered access to the social networks, including health-related networks, at any time and from any location. This can be important in terms of self-management. In many conditions, personal behaviour has a significant effect on health and wellbeing. This advisory does not examine specific mobile applications in depth, but must at least mention this 'm-Health' phenomenon.[68]

*Web 3.0*

Web 2.0 remains a largely unorganized collection of files, be they text, audio, graphics or video files. Web 3.0 will bring order to the chaos by means of metadata: information about information. The web itself will then be transformed into a 'dataweb', also known as the 'semantic web'. Because items can be tagged and linked on the basis of their content and relevance, it will be possible to create a

system of fully personalized care. It will also be possible to quantify the risk of developing a certain condition on the basis of genetic profiling, with lifestyle recommendations made accordingly.

## 2.9 Conclusion

The USA leads the way

Although the internet offers many opportunities for social interaction, those opportunities have yet to be fully exploited by the healthcare field. There is very little interactive communication between professionals and patients, whereupon the sector can be seen to be lagging behind many others. This situation is not unique to the Netherlands[69], although the use of the social media is certainly far higher in the United States than it is here.[70]

Enterprising care providers are leading the way

At present, we are still in the Health 1.0 situation, in which the internet is primarily seen as source of information rather than a platform for social interaction and for exchanging information using the various new media applications (video, audio, etc.). The sole exception to this statement are the online patient communities.
To date, hospitals have made scant use of the new possibilities. Most innovations are the result of individual action on the part of motivated, enterprising professionals.

# 3 The significance of Health 2.0

## 3.1 Introduction

In Chapter 2, we examined the general setting and a number of ongoing developments. What will be their implications in terms of Health 2.0? In this chapter, we first present a number of key features of the possible future scenario for Health 2.0. However, we cannot claim that this scenario will become reality within the foreseeable future. This will depend on a number of factors. An alternative scenario is therefore described in Section 3.3. It is one which represents the further development of the current Health 1.0.

Section 3.4 is concerned with the impact of Health 2.0. The likelihood of Health 2.0 actually becoming reality is the focus of Section 3.5. There are, after all, certain obstacles. The final section of the chapter suggests various measures by which these obstacles can be removed or alleviated.

## 3.2 Key features of Health 2.0

This scenario is based on the background study, *Health 2.0: it's not just about medicine and technology, it's about living your life',* produced by Prof. Valerie Frissen. The ideal Health 2.0 situation will be that in which all the opportunities described in the study's concluding chapter are fully exploited. However, there are also risks. It is possible that the 'digital divide' will widen, and with it the gap between the socio-economic groups in Dutch society. There is a risk of misinformation, and a risk of personal information being misused. All such threats are also present in the alternative scenario described in this chapter. The only differences are the likely severity and the speed at which they will make themselves felt.

Patient-centric care, transparent care, demand-led care, efficient and effective care: these are the objectives of the scenario described here. We have therefore clustered the key features of Health 2.0 accordingly.

### Patient-centric care
*Dignity and respect*
Patients must be treated as individuals, with dignity and respect. The patient is a full partner in the care process, and that process must be appropriate to his or her personal identity. Patients must retain full control over their own lives. They must enjoy freedom of choice with regard to treatment and therapy, the timing of the various care services and the manner in which the therapy is offered (face-to-face, e-health applications, etc.). If he wishes, the patient must be able to base his decisions on the experience of patients who are, or have been, in the same position.

*The professional as coach and advisor*
Healthcare providers practise the profession for which they have been trained. They must have enough time to answer the patient's questions and explain matters, building on whatever knowledge the patient has been able to glean prior to the

consultation. The professional and the patient have different roles, different responsibilities and different types of knowledge. The practitioner can increase his professional knowledge by taking part in networks of fellow doctors; the patient can increase his or her knowledge by taking part in the patient communities and drawing upon the experiences of people in the same position. Health 2.0 offers the means for both parties to benefit from each other's new knowledge, thus creating added value which will enhance the quality of the treatment process. The traditional, paternalistic 'do what I tell you' doctor will become a coach and advisor. Patient and doctor will join in a process of shared decision making. The doctor-patient relationship will be built on mutual trust.

Shared decision making

**Transparent care**
*Ratings of practitioners, therapy teams and care institutions*
Those who have received healthcare services will report their experiences of those services in a structured and standardized way. Systems worthy of consideration include the Consumer Assessment of Healthcare Providers and Systems (CAHPS) method[71] and the CQ Index[72]. The aspects most important to patients themselves, such as the experiences of others and the nature of interaction with professionals, should be included. Based on such 'consumer reviews' in combination with empirical and statistical information, patients will be able to make an informed choice of doctor or treatment team.

Shared responsibility

*Regulation and supervision*
Consumers will be able to report irregularities and shortcomings, such as poor hygiene, using the internet. They can do so through the platforms in which they take part or using rating sites and suchlike. Healthcare providers will be keen to ensure that their name does not appear in a negative light on such sites. At the same time, the providers must enjoy the right of rebuttal or the opportunity to state what measures have been taken to prevent a recurrence of the situation. This form of 'social control' will make the work of the Health Care Inspectorate, the regulatory body in the Netherlands, somewhat easier. The Inspectorate will no longer have to investigate quite so many reports, nor take action to encourage care providers to resolve undesirable situations quite so often. However, it must also remain possible for healthcare consumers to report situations directly to the Inspectorate, which will remain able to impose corrective measures as necessary. Patients will also play an important part in defining quality indicators.

Healthcare consumers and providers together in the same network

**Demand-led care**
*Networking*
There will be (dynamic) networks for various conditions, each including doctors, nurse practitioners, pharmacists, patients, etc. Information will be provided, exchanged and shared within these networks, perhaps by scientific organizations which produce 'user-friendly' laymen's versions of their standards and guidelines, and by patients who share their experiences and opinions of treatment options, practitioners and healthcare institutions. Pharmacists will be able to answer questions about the side effects of prescription drugs and any drug interactions. Both treatment teams and patients will take an active part in these networks, all members

acting as 'information brokers'. The documents and websites they consider relevant will be tagged so that others can find them easily using social bookmarking sites.

## (Medical) profiles

Personalized information

Healthcare consumers will be able to produce a medical profile which includes relevant information about themselves and their condition. They can, should they wish, make the profile fully public or may opt not to do so. There will also be the option to reveal only selected information. Based on this profile, they can be automatically informed of any new medical advances or new experiences reported by fellow patients with a similar (risk) profile. This process will gradually lead to fully personalized advice on lifestyle, treatment and care, and eventually to personalized treatment in which the patient's genetic profile is also taken into account. The anonymized collation of large numbers of profiles could greatly facilitate medical research dealing with the incidence and prevalence of certain conditions within a patient population.

## Self-management

Patients will become their own doctors (to a degree)

Chronic patients will become responsible for (part of) their own treatment, which can be undertaken in the home setting with the support of the professional treatment teams and online platforms. Patients will record information about their health status (e.g. the results of the daily blood sugar test) and about their therapy (e.g. medication use), which is then shared with others through the networks described above. This will enable patients to compare their situation (including the therapy) with that of others in the same phase of the condition, the same risk profile or the same comorbidity (e.g. patients with diabetes, depression and heart failure). The data can be aggregated and anonymized for use in medical research.

## Control

The patient takes control

Control and direction of the patient's case used to be the sole responsibility of the doctor. In Health 2.0 this is no longer the case. Healthcare consumers and professionals will work together as equals with a single objective: to protect and improve the health of the individual. If the situation demands that someone does indeed take control and make an 'executive decision', the patient himself or herself should be the prime candidate. If he wishes, the patient can of course delegate this role to a member of the treatment team, a relative or some other third party.

## Creating strength of demand

Strength in numbers

Networks of healthcare consumers may well join forces to form a 'purchasing organization', as indeed some patient organizations such as the Netherlands Diabetes Association have already done. They operate webshops from which members can obtain medical aids at a discount.[73] Such purchasing organizations will be in a position to impose additional requirements in terms of quality and service from suppliers. They will be able to change the tide from supply-led health services to a fully demand-led system.

## User organizations

Healthcare consumers will assume certain tasks from the established representative organizations. They will exercise a form of supervision of healthcare services by publicly reporting on their experiences of those services. The traditional role of the

patient organizations in providing information, representing members' interests and promoting peer contact will change. They must offer added value over and above that of the networks if they are to survive.

## Efficient and effective care

*Professional interaction*

Practitioners in the field will use internet forums, discussion groups, etc. to ensure that their knowledge is up to date, and to call upon the help and advice of colleagues when dealing with particularly complex cases. They might, for example, discuss the most appropriate form of treatment for a patient with special needs.

*Electronic Patient Dossiers and Personal Health Records*

The patient will maintain a Personal Health Record

Professional practitioners will continue to maintain patient records, as required by law. Those records will be in the form of the standard 'Electronic Patient Dossier' (EPD). Patients who wish to do so can maintain their own Personal Health Record (PHR), which might include information about the non-prescription (OTC) drugs they have taken, the results of tests they have conducted themselves (weight, blood pressure, blood sugar levels, etc., all of which will eventually be entered into the PHR automatically by the monitoring devices concerned), and their experiences in coping with their condition. The Electronic Patient File will be 'synced' with the Personal Health Record, whereby data can be combined and collated. The patient will have access to all information in his or her medical records, while the information in the PHR will enhance that held by the doctor.

*Decision Support Systems*

The computer as advisor

Both doctors and patients will have access to automated systems which will assist in the decision-making process. Doctors will use such systems in combination with guidelines and standards made available in digital form, and the patient's EPD. Patients might use them to decide whether they should consult a doctor about a particular symptom, and for the purposes of general self-management. A decision support system of this type is already in use at the heart failure clinic of the Martini hospital in Groningen.[74] Moreover, such systems can draw information from EPDs and PHRs to identify patterns, whereupon it will be possible to offer early treatment or advice to patients with a particular risk profile.

*Guidelines and standards*

Wild-based standards

Guidelines and standards will be established by the relevant parties, including doctors, nurses and patients. The process will make use of various resources, including wikis. The development and use of 'best practices' will rely on a participative model which centres around the healthcare consumer. This will lead to the best practice which is indeed *best* from the patient's point of view. All team members will work together to produce the desired result.

*Innovative treatment options*

Even small groups of patients will combine forces to raise money for research into rare conditions. They will commission scientific institutes to pursue activities which, hopefully, will bring the cure for those conditions somewhat closer.

### 3.3 An alternative scenario: further development of Health 1.0

One alternative to the scenario outlined in the foregoing section is that in which the current Health 1.0 situation develops in the direction it has followed thus far, whereby:
- the healthcare consumer largely limits internet use to obtaining information about health and health care;
- the healthcare consumer who does share information does so within the context of a peer group, and mainly with regard to ways of coping with a condition;
- case management remains the responsibility of care providers.

This scenario has the following implications:

**Transparency**
*Factual information about health services*
Health services will be made transparent in a 'top-down' manner. Information about the quality of each hospital's care will be published on the internet, to include mortality rates and the prevalence of infections such as MRSA, etc. For each practitioner or treatment team there will be details of training and qualifications, how often they perform certain interventions, and the success rate of those interventions (expressed as a percentage, corrected for population).
The existing institutes will make every effort to collect and publish statistical information about health services. National projects such as *Zichtbare Zorg* ('Visible Care') will be particularly important in this regard.

*Ratings of practitioners and healthcare institutions*
'Business as usual'
The existing media, such as *Het Algemeene Dagblad*, *Elsevier* and www.independer.nl will continue to collect and publish information relating to healthcare institutions and providers.

*Regulation and supervision*
The Health Care Inspectorate (IGZ) will continue to supervise health services. Quality indicators will be devised by the government and professional federations.

**Demand-led care**
*Patient organizations*
The institutionalized patient organizations will represent their members' interests and provide relevant information, such as news of alternative therapies, drugs and so forth. They will facilitate communication between patients, enabling them to support each other in coping with the condition in question.

*Treatment*
The passive patient
Patients will undergo whatever treatment has been prescribed by the healthcare provider, which may or may not include a 'remote care' component. Insofar as there is any question of self-management, it will be limited to simple undertakings and reporting self-administered test results to the physician, with a view to arriving at the best possible health status.

*Control and case management*

The doctor is in charge

In principle, the care provider will be in sole charge of the patient's case. Where several specialists are involved, one will be expected to assume the role of case manager. There are, however, certain categories of chronic disease (such as diabetes) in which the patient does have a more significant role to play.

**Efficient and effective care**

*Professional interaction*

In their treatment of patients, care providers will seek insight and guidance through attendance at conferences and symposiums, the traditional (refresher) training courses, and from written sources, both printed and in digital form. In complex cases, they will consult colleagues within the same organization or personal acquaintances.

*Electronic Patient Dossiers and Personal Health Records*

Patient does not provide information

Practitioners will maintain patient notes (as required by law), doing so in the form of the EPD. This will be the central source of information. Patients may be allowed to view the contents of the file, perhaps through a secure website. Patients who wish to do so will maintain a Personal Health Record (PHR).

*Decision Support Systems*

Doctors will have automated systems to support decision-making.

*Guidelines and standards*

Guidelines and standards will be devised by the scientific organizations and professional federations. Input from patient organizations may be invited.

*Innovative treatment options*

Top-down innovation

Anyone with a project proposal relating to innovation in health care must apply for funding to organizations such as ZonMw, the Ministry of Economic Affairs, the Dutch Healthcare Authority's Innovation Programme, or one of the other traditional project financiers.

## 3.4    The impact of Health 2.0

Based on the scenarios outlined above, it becomes possible to answer the policy questions formulated in Section 1.3 with regard to the impact of Health 2.0 on care services in the Netherlands and the roles of the various actors.

The patient is in charge of his or her own health

The well-informed patient

A comparison of the key features of each scenario produces a good impression of the likely impact of Health 2.0. The most notable aspect of the new situation is that the patient really is the focus of all activities. This is no longer an empty promise. The patient is very much in charge of his or her health, supported by a network of professionals and fellow patients. This entails a different type of doctor-patient relationship, one which will benefit both parties. The doctor is now dealing with a well informed patient and no longer has to explain simple, basic matters. This

makes his work somewhat more attractive. The patient will have acquired this basic information from the internet prior to the consultation. He knows at least the outline of what is in his medical records, he knows what treatments are possible and what they entail, and has read about the experiences of patients who are, or have been, in the same position. Armed with this information, the patient will ask about any matters which require further explanation. The patient and the doctor can then make a joint decision with regard to the most suitable treatment plan.

For the patient, it is important that there is a network which includes professionals and whose members can provide support as and when it is needed. The funding structure must encourage professionals to take part in such networks. This is a matter to which the government must devote attention.

If the patient is in charge of his own health and can largely determine how the care services he needs are to be organized, the structure and funding of the healthcare system must undergo changes.

> In the past, patients with (or at risk of) thrombosis had to report to the clinic for tests, usually once every two weeks. Based on the patient's INR ('internationally normalized ratio': an indication of how quickly the blood clots), the clinic would determine and prescribe the correct dose of anticoagulants. Today, the patient can perform the same test at home. Moreover, because he can do so more frequently the results are more accurate. The patient's INR is therefore more likely to remain within the target range than when relying on the fortnightly tests at the clinic. Patients do require some prior training in how to perform the test and interpret the results. They must be able to phone for assistance if necessary. This demands adaptations to the current organizational structure and funding arrangements, but there is no longer any need for a fully staffed thrombosis clinic.

Self-management: better for the patient and better for society

There are a growing number of technological aids which enable patients to manage their own condition. Greater patient control and self-management means a shift in the tasks and responsibilities, not only between professionals (e.g. from specialist to nurse practitioner) but from professionals to patients or home carers. This clearly benefits the patient, since care can now be tailored exactly to requirements and he is less dependent on others. It also benefits society at large, since the costs will be somewhat lower than when all care is provided by highly-trained professionals. It also presents a solution to the impending staff shortage in the healthcare sector. Although it will remain necessary to recruit staff, the number required will be lower than originally forecast.[75]

> According to figures published by the American Agency for Health Care Research Quality (AHRQ), seventy per cent of all healthcare costs are incurred further to the management of chronic conditions.[76] The number of chronic patients is rising. Within the next few years, the Netherlands will see a significant increase in cases of diabetes. By 2025, an estimated 1.3 million people will have either type 1 or type 2. By comparison, in 2007 there were 740,000 known diabetics (the diagnosis having been confirmed by a GP), although at least another 250,000 people were suffering from diabetes without being aware of it.[77]

If the individual is given the opportunity to take charge of his own health, he must assume greater responsibility for prevention and for treatment of any condition.

Based on the care plan agreed with the professional provider, he might for example regulate the dose of his medication or adjust his diet based on the results of tests he himself performs at home (e.g. blood pressure, weight, blood sugar level, creatinine level, etc.). This will foster greater personal involvement and hence lead to better patient compliance. The various additional aids, such as the Personal Health Record, online communities and other sources of information (e.g. Wikis) will form an integral part of this model. The information available serves to educate the patient and develop skills such as the interpretation of test results. Communication with regard to self-management will revolve around the Personal Health Record (PHR), in which the patient records the test results and other relevant information.[78] The PHR may also draw upon the information contained in the doctor's records – the EPD – such as the results of hospital tests.[79] Because both patient and care provider have access to all test results, the patient can implement the best possible self-management regime. The care provider's role is one of 'coach', guiding the process from a distance. This model includes various feedback moments which result in a particularly flexible system able to provide fully personalized patient care.

Figure 3.1 (below) shows how the various elements might be combined.

**Figure 3.1**
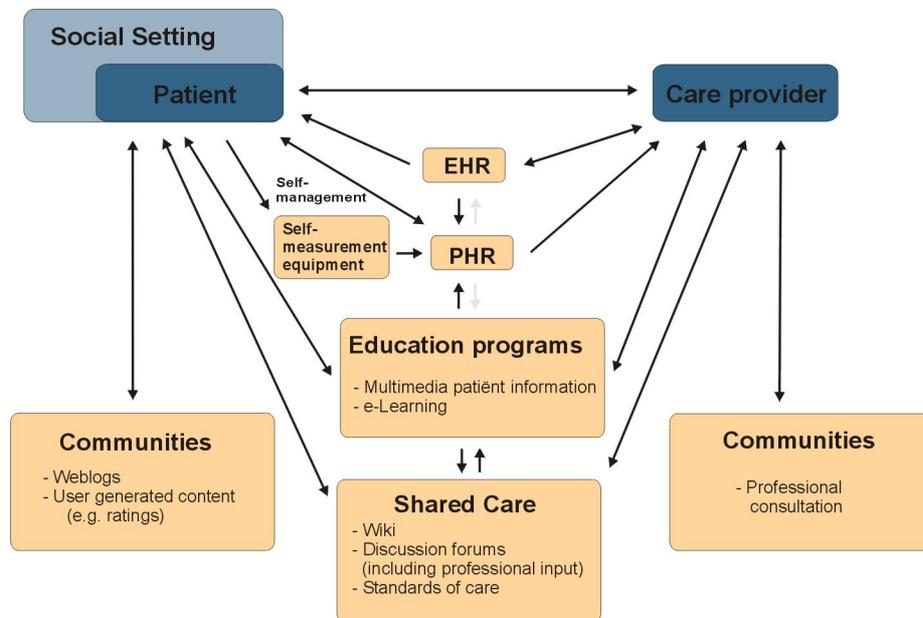


Source: adapted from P.J.M. van der Boog, *Gezondheidsmanagementmodel, de patiënt centraal.*

If the government does indeed wish to place the focus on the patient, it must facilitate a number of changes. At present, the structure and funding of the healthcare system are based exclusively on the 'fixed' relationship between healthcare provider and healthcare insurer, with little or no opportunity for new market entrants. One

positive development which has been introduced by the Ministry of Health is the 'functional' funding system based on output criteria. It is no longer necessary to determine in advance exactly who is to provide treatment and where, provided it can be offered in accordance with the established care standards.[80] Where the patient has an 'in natura' insurance policy (under which insurers pay the care provider directly) it usually falls to the insurance company to select the care provider. Patients with a 'restitution' policy (under which the insurance company reimburses all or part of the expenses incurred by the patient upon presentation of invoices), the patient is able to choose.

Amendments to current legislation can facilitate the entry of new parties to the market. According to Christensen *et al.*, unnecessary costs will be removed from the equation entirely if the funding system is geared towards the optimal (organizational) setting in which the care services are to be provided. To achieve this situation, 'disruptive innovators' must be allowed to become involved. Experience has shown that many existing organizations have difficulty in implementing rigorous innovations.[81]

In a Health 2.0 situation, the government will involve the public fully in its work and deliberations. In regulation and supervision, it is now recognized that the public can be given a role as the 'eyes and ears' of the authorities or as 'watchdogs', even though regulation and supervision would appear to be a task for the government alone. Dutch police already use the new media to involve the public in law enforcement, with videos on YouTube and appeals for tips on sites such as Hyves.[82]

---

The social media have proven themselves an effective tool in law enforcement. Nevertheless, many police stations prevent staff from accessing websites such as GeenStijl.nl and YouTube when on duty. In June 2008, there was a hostage situation and siege in Almelo. The name of the person responsible and his motives were published on GeenStijl.nl while the police were still plodding the streets looking for clues. Messages on Twitter revealed that the man had obtained the weapon he used from his own son. The police nevertheless had to prepare a press conference to appeal for information.
Source: report of Regional Security Day, 19 November 2009.[83]

---

**Health 2.0: patients to report inadequacies**

Similarly, it will be appropriate to examine which aspects of the Inspectorate's work can be shared with, or delegated to, the public. In some cases, individuals are likely to take action on their own initiative, 'supervising' the quality of care and more especially the information relating to that quality. The Inspectorate must devise an appropriate strategy, acknowledging the role of the public and stating the manner in which the social media can be put to best use.

**The public joins the discussions about new legislation**

In other cases, the government itself must take the initiative in using the social media to support the legislative process. It seems only reasonable that 'patient laws' are framed with the input of the patients themselves. The process might rely on a wiki, similar to that used to invite public input on a new police act in New Zealand.[84] Recently, the Dutch government implemented a passive form of public participation. In this trial project, in which individuals, companies and stakeholder groups are invited to discuss new regulations in an online forum. The site will remain open for two years, during

which time everyone can offer their opinions on certain selected proposals.[85] The aim is that all ministries should open at least ten per cent of their proposals for new legislation for consultation in this way.

---

The government's communications about the HPV vaccination were restricted to a 'one-way traffic'. There was a website which presented information but which did not invite comments or questions. The communication about the H1N1 flu vaccine took a very different approach, with the government taking a full part in the social debate. The Minister of Health made personal appearances on television discussion programmes and answered questions submitted by the public by e-mail. The government also set up a supporting website and even a Twitter account. In future, the government is likely to use viral campaigns and sponsored links on Google, where-upon a search for certain keywords will result in the governmental sites being shown first among the results.

---

**Care providers who perform poorly will face a hard time**

In recent years, accountability, transparency and adequate communication have become very much more important. If organizations fail to function as they should, they must face the consequences. This is also true within the healthcare sector, as illustrated by the publicity surrounding hospitals and homecare organizations which fail to meet the standards expected of them. When an organization is seen to be performing poorly, its customers or the general public will demand that the situation is rectified forthwith. They will use 'naming and shaming' techniques which are largely beyond the influence of the offending organization itself. It is therefore in the organization's own interests to preclude this type of reaction by maintaining consistently high standards.

---

Can the collapse of a bank be attributed solely to loans made to 'sub-prime' customers five years ago and a range of dubious financial products? In 2009, the social media played a significant part in the demise of the Dutch DSB Bank. The victims of the bank's practices could locate and contact each other very easily using online forums, weblogs, etc. They could then form a joint opinion and take joint action against the bank. They could also contact the mainstream media very easily, and *vice versa*, using resources such as Twitter. As a result, the entire Dutch public could follow the discussions and form an opinion. When it was announced in July 2009 that the financial services regulatory authority (AFM) had fined the DSB Bank for mis-selling mortgage products, there was little or no public reaction. It would seem that warnings from the regulator have very little impact on consumer behaviour.[86] However, when a single individual (one Pieter Lakeman) called on all customers to withdraw their money and close their accounts, thus forcing the DSB into bankruptcy, there was indeed a massive response. The suggestion spread rapidly via the social media. Within ten days, customers had withdrawn some 600 million euros. According to media experts, the DSB bank had failed to communicate, or did too little too late.[87] While in the past it may have been possible to sweep shortcomings under the proverbial mat, this is no longer the case. Accountability, transparency and adequate communication are essential in maintaining public confidence in an organization and its products and services.

### 3.5 Is Health 2.0 feasible in practice?

*Will Health 2.0 become reality?*

The possibilities of 1.0 must also be better exploited

In the alternative Health 1.0 scenario, the existing facilities will be subject to some further development. A greater number of hospitals will enable patients to book their own appointments online (for reasons of both customer service and efficiency: the system reduces staffing costs), hospitals and specialists will allow patients to consult their own medical records online, and the hospitals will make greater use of the social media, largely for the purposes of promoting their services in an increasingly competitive market.

At the same time, it is inevitable that even in this scenario some consumers will embrace the Health 2.0 concept, encouraged and/or facilitated in part by the new possibilities offered by internet technology, and in part by the healthcare professionals. Unless appropriate measures are taken, this situation could lead to the risks which accompany Health 2.0 overshadowing the advantages.

---

"The HPV vaccine has already killed dozens of people and caused adverse health impact in many thousands more. In literally hundreds of cases, the side effects have been extremely serious and permanent in nature. From 2009, Ab Klink [the Dutch minister of health] plans to test an HPV vaccine on *your* daughters at a cost to the taxpayer of thirty million euros a year. Secret FDA documents reveal that HPV does *not* cause cancer! On the other hand, the HPV vaccine alters your DNA, damages the immune system and does cause cancer as well as infertility. Vaccines contain mercury, aluminium, sodium borate (rat poison) and many other substances which damage brain cells."

This message[88] and many like it calling for people to refuse the HPV vaccine, can still be found on the internet. Teenage girls have flocked onto Hyves and MSN to discuss the pros and cons of vaccination. Having read such misinformation (which has no basis in truth whatsoever), many decided not to have the vaccination. The experts who could have provided correct information did not become involved in the debate, at least not to any significant degree. The take-up rate for vaccination was less than 50%, compared to the prognosis of 70% to 75%.

---

Health 2.0 will also encourage healthy lifestyle choices

It is therefore important that incentives to achieving the Health 2.0 scenario are put in place wherever possible in order to ensure that full advantage is taken of the many opportunities. Those opportunities can be seen in terms of prevention as well as curative care. Health 2.0 applications can be used to promote a healthy lifestyle.[89] First, however, it is necessary to resolve a number of obstacles, most of which are the result of the current organization and funding of the healthcare system.

*Obstacles resulting from the organizational structure*

Christensen states that there are, in principle, three organizational settings in which care services are provided.[90] The existing hospitals are organized in such a way as to solve unstructured problems. To do so, they use the services of specialists who, by virtue of their training, experience, analytical thinking and problem-solving ability, can identify the cause of health problems and arrive at a diagnosis. Payment is made as 'fee for service', since the subsequent processes are not known in advance, nor how much time and money will be involved. This is, after all, a 'personalized' service.

However, it is not only unstructured problems which are solved in those very same hospitals. There are also a number of routine interventions which could be performed more efficiently if grouped together in a logical fashion. This approach has been adopted by the independent clinics offering laser eye surgery, hernia repairs, etc. The processes are then rule-based or evidence-based. Payment is in the form of a 'fee for outcome', whereby a guarantee can also be offered, since all required interventions are known in advance as is the end result. These are routine activities which do not differ from one patient to another. Given the nature of these activities, it is often unnecessary to have them performed by specialists who have undergone years of extensive (and expensive) medical training.

A third type of activity is that of networking, whereby people share their knowledge and activity. There are some foreign healthcare organizations which provide facilities for certain patient groups, such as the American companies dLife.com and SugarStats.com (for diabetics).[91] Dutch counterparts include the Digital IVF Clinic run by Nijmegen University Medical Centre and ParkinsonNet.[92] In general, these are disease management applications, whereby patients play a significant role in managing their condition. Payment is usually in the form of a subscription charge ('fee for membership'). In the United States, however, other business models have been applied. Some sites (e.g. PatientsLikeMe.com) are sponsored by the pharmaceutical industry, which can then obtain aggregated data about patients' experiences with their products.

Unnecessary costs can be avoided if the funding mechanism is matched to the optimal organizational setting in which the care services are provided.[93] At present, the Dutch healthcare system does not have an 'optimal organizational setting', and hence the funding system is also not ideal, as discussed in the following paragraphs.

*Obstacles resulting from the current funding system*
In principle, the 'functional descriptions' included in the *Zorgverzekeringswet* (Health Care Insurance Act) enable various types of medical intervention to be included in the basic (mandatory) insurance cover. The main criteria for inclusion are that the therapy:
- must be provided in accordance with the latest scientific insights and practice (i.e. evidence-based);[94]
- must be of the nature usually provided by a qualified medical practitioner, such as a doctor.[95]

Within this framework, some 'innovative' shifts in the actual provision of health services are possible. For example, treatment 'usually provided by a qualified medical practitioner' need not be provided by a fully qualified doctor but by other professionals such as nurse practitioners or physician assistants, provided this leads to comparable or better results. The same would apply to self-management.

However, this does not mean that the dividing line between what can and what cannot be included in the basic cover becomes any clearer. It was necessary for the Health Insurance Board (CVZ) to issue a formal ruling with regard to whether 'chain care' qualifies for inclusion, since there is no mention of the term in the Act itself. By recognizing chain care as a cohesive, multidisciplinary method of case

The nature of activities should determine the organizational and funding structures, not vice versa

Eligibility for inclusion in the standard insu-rance cover is not always clear

management, or an organizational 'shell' embracing all the care services required by the patient, the CVZ established that it was indeed eligible for inclusion in the standard insurance cover.[96]

It is appropriate to note that, despite the inclusion of 'functional descriptions' in the Act, the freedom to differentiate levels of fees is relatively restricted. For example, the essence of the policy introduced by the Netherlands Health Authority (NZa) with regard to the funding of chain care (as assessed by the CVZ) is that the GP must continue to play a key role in chain care for diabetes, vascular risk management and COPD, even though the terms of the Act itself allows insurers to enter into contracts with new market entrants, whereby nurse practitioners would work alongside other relevant medical specialists.

There are many organizational aspects involved in Health 2.0, but the concept is not the same as chain care given that in many cases there is not only a one-to-one relationship between care provider and patient but a relationship between several care providers and patients. The current healthcare funding system is not entirely appropriate to Health 2.0, in which patients themselves have a significant part to play. The implementation of Health 2.0 calls for a different infrastructure and different business models, both of which will be difficult to attain unless the current funding arrangements are radically overhauled.

All hospital processes in the Netherlands now fall within the *diagnosis-behandeling combinatie* (diagnosis-treatment combination) or DBC system. All required activities, from diagnosis to final outcome, are charged as an all-in 'package deal'. In fact, the fee is made up of two main components, Segment A and Segment B. The level of Segment A charges is set by the NZa; Segment B charges are set by the hospital itself and there is room for negotiation in the interests of competition.

At present, the freely negotiable Segment B accounts for some 34% of the total DBC charge. The government wishes to increase this percentage to 65% to 70% by 2011 in order to allow market forces to play an even greater role in the health system.

Indivisible diagnosis and treatment combinations

Current funding arrangements form an obstacle to Health 2.0

If this DBC system is retained, the existing institutions will continue to receive the same financial rewards, even though they will be required to provide fewer services. This is because the DBC is indivisible; the health insurer buys it as a package and cannot opt to buy one component of that package elsewhere, even if that component is of the same quality but less expensive. Accordingly, new market entrants can only serve to push prices up when people opt to make use of their services.

A patient who has undergone a kidney transplant must return to the hospital around twenty times to have his or her blood pressure and creatinine levels tested. However, it is perfectly possible to measure one's own blood pressure at home, and there are now do-it-yourself creatinine tests too. When responsibility for testing shifts to the patient, the income of the professionals will fall – *unless* the specialist is paid for the tests anyway as part of the 'diagnosis-treatment combination'. This is clearly unjust when the patient is doing all the work.

| | |
|---|---|
| Establishing a perma-nent source of fund-ing is often a problem | Innovations can be funded under the existing NZa incentive scheme, provided the innovation relates to care provision itself. New products, medical aids, organiza-tional costs and ICT do not automatically fall within the scope of that scheme, unless they are an integral part of an innovative form of care provision. Note that the funding is not in the form of a grant: it entails an agreement between health insurer and healthcare provider whereby the latter may experiment with a new form of service and charge the costs to the insurer. Moreover, such funding is temporary in nature, offered for no more than three years. It will only be granted to projects which involve a direct partnership between health insurer and healthcare provider. The two parties enter into a contract at the local level. Once the three-year period has elapsed, further funding of the new service is likely to be problematic, as even the General Court of Audit notes in its report *Zorg op afstand* ('Remote care'*).*[97] The majority of projects to date have been concerned with diabetes. |

Cooperation and coordination, as in chain care or network care, can in principle be funded in one of two ways: via the existing innovation incentive scheme (insofar as the project falls under the heading of 'healthcare services'), or by means of a per capita payment, being the maximum fee (established by the Ministry of Health and NZa) which the contractor may charge a health insurance company for providing all necessary care services to one patient for the period of one year, provided such services fall under the established definition of 'care' provided by the *Wet Marktor-dening Gezondheidszorg* (Health Care Market Forces Act; WMG). The per capita pay-ment is therefore another form of all-in fee. The CVZ is currently examining whether cooperation between several parties within this system can be defined as 'care' in the meaning intended by the Act. If so, it seems likely that cooperation in the context of Health 2.0 would also fall under the same definition. However, this remains to be seen.

| | |
|---|---|
| The patient has no place within innova-tion funding | The only form of cooperation which is recognized under the current innovation scheme is that between registered care providers. Cooperation between doctor and the lay patient is therefore excluded. Of course, all contacts between them can be legitimately regarded as a 'consultation', whereupon the doctor can charge the usual fee. However, it would be appropriate to establish a scale of fees depending on the intensity of the contact. This seems a particularly awkward construction, not least because within networks there is no clear one-to-one relationship between doctor and patient. Rather, there is a 'many-to-one' relationship. |
| Shifts in funding arrangements | Prevention is an important component of the network care which typifies Health 2.0. Where prevention measures are directly related to health care, they do indeed fall within the scope of the Health Care Market Forces Act. When prevention measures address the population as a whole, they do not and the NZa is not able to set performance targets or indicators. Prevention measures within Health 2.0 must therefore be funded, at least in part, under other regimes. |
| Healthcare insurers often ignore the financial benefits of innovation | It is uncertain whether healthcare insurers are genuinely interested in innovation. In most cases, it seems likely that they are not since innovation will lead to additional costs: there is no substitution possible. The DBC therefore remains indivisible, even though it may be possible to contract one or more components elsewhere at |

lower costs for the same quality. Similarly, the fact that policy-holders are able to move from one insurance provider to another each year is a perverse incentive for the insurers. Why should they invest in prevention if their customers are going to take their business to a competitor? Of course, one reason for doing so would be market differentiation – to stand out from the competition – but then the returns must outweigh the costs.

<div style="float:left; width:25%">DBC system chokes innovation</div>

The current transition phase, in which funding relies partly on the DBC system and partly on the old budget parameters, stands in the way of new developments. Even if some components of the diagnosis-treatment combination could be provided in a different way (more patient-friendly, more cost effective, etc.) by a new market entrant or by the patient himself, this would have no effect on the cost price of the DBC (except in the negotiable Segment B) or the budget. Take the example of laboratory testing by a new market entrant unconnected with the hospital itself: this would not affect the price of the DBC in the hospital, which is cast in stone. It is currently not possible for a GP to open a DBC case and contract a certain service from an institution without that institution also opening a separate DBC for the same patient and the same condition. The professional organizations are unwilling to rectify this situation, since it would erode their members' income.

The NZa has proposed that proportion of the DBC fee which falls within the negotiable Segment B should be increased to 50% in 2011.[98] In fact, it is the care services within this segment which represent the best opportunities for patient choice, and in which Health 2.0 applications are particularly relevant. This applies to a lesser degree to the A segment, which is more concerned with acute care and clinical care at the very highest level.

Current legislation provides too much protection to the 'traditional' care providers

The NZa is constrained by the Health Care Market Forces Act, a fact which severely limits its scope. In practice, the NZa can do little or nothing to empower the patient (financially or otherwise) with regard to the regulatory principles. Under current legislation, the NZa must limit its activities to regulating the fees charged by healthcare providers and setting the performance levels which qualify the institution to receive those fees. As a market party, the care providers retain considerable influence. Innovations on the part of new market entrants will not be in the best interests of the professional organizations if tasks and responsibilities shift from one specialist to another, to the GP, nurse practitioner, physician assistant or patient. Such innovations would erode both income and status. The relevant policy still includes 'face-to-face' contact, which therefore becomes the definition of a professional consultation. The established care providers do not wish to alter this situation. In any event, it is likely to be a very long time before the professional organizations agree to even consider doing so.

> 'MinuteClinics' are walk-in centres offering first-line healthcare services in the United States. They are staffed by nurse practitioners and physician assistants who use digital patient files and decision support systems to provide evidence-based first-line care at a very much lower cost. Patients rate both the quality and the 'patient-friendliness' of the clinics as excellent.[99]

To summarize, 'disruptive innovations' in the healthcare sector are virtually impossible under current legislation and regulatory arrangements, given the power and influence they accord the professional organizations. We may conclude that any change to the situation forms a threat to the established order and vested interests. Any shifts in responsibility, and hence income, are bound to meet with opposition from the groups which have most to lose in terms of money, status, etc. In a broader context, we can also state that the culture of the entire Dutch healthcare system is not geared to change.

On the demand side, healthcare consumers are still uncertain what new possibilities can or will be offered by the internet. It is essential that public awareness is raised and that people acquire the skills required to take advantage of the new opportunities. They must also be taught to cope with the limitations of the medium: how to recognize misinformation and how to prevent any personal information they entrust to the internet being misused, for example.

*Obstacles*
The obstacles to the development of Health 2.0 may therefore be listed as follows.
- The current organizational structure and funding arrangements are geared to the current Health 1.0 scenario and are inadequate to meet the requirements of Health 2.0.
- The institutionalized professional organizations, which are not inclined to adapt to new circumstances, have much to gain from retaining the Health 1.0 situation. The Health 2.0 situation in which the consumer is in charge would render the organizations 'surplus to requirements' if they fail to amend their strategy accordingly.
- Field parties (hospitals, doctors, the Health Care Inspectorate) seem disinclined to promote transparency.
- The culture within the healthcare system is not geared to change.
- Healthcare consumers are not fully aware of the opportunities and threats represented by Health 2.0.
- Patients take greater heed of the threats rather than the opportunities:
  . Accountability and responsibility do not appear to be adequately defined in the Health 2.0 situation.
  . Because everyone and anyone can become an information provider in the Health 2.0 situation, there is a greater likelihood of misinformation being published.
  . The added value of Health 2.0 outweighs the interests of personal privacy. As people forgo part of their privacy as a result, others may misuse personal information.
  . In practice, only a small proportion of healthcare consumers will become fully active participants in Health 2.0 by generating content. They will indeed benefit from the new possibilities, but this will be at the cost of other groups such as those with a lower socio-economic status. It is essential to ensure that the digital divide is not widened by Health 2.0.

*Conclusions*

If the advantages offered by Health 2.0 are to be exploited, certain measures must be taken. Those measures will affect the feasibility of the entire Health 2.0 scenario.

If the measures are not introduced, the alternative Health 1.0 scenario appears to be more likely. However, certain measures will also be required in this scenario in order to preclude the negative effects of a partial and fragmented implementation of Health 2.0.

## 3.6    Possible measures

In principle, it is for the participants themselves - the general public – to realize Health 2.0. By taking part, people will gain authority and responsibility. Unfortunately, participation is not an option for everybody. Some people will be excluded due to poor (computer) literacy while, ironically, others will be unable to take part for health reasons.

The government must remove the obstacles to Health 2.0

It is not in keeping with the '2.0' philosophy for the government to impose, or even actively promote, Health 2.0. This is a matter for society itself. Nevertheless, the obstacles must be removed, and this is indeed a government responsibility. The prime requirement in this respect would seem to be the introduction of an appropriate funding structure.

Prevention is better than cure

The manner in which doctors are paid is currently concerned with the curative process. Insurance companies will pay for an amputation as a result of diabetes, but they devote little or no attention to promoting the health of their policy-holders to prevent the situation from getting this far. Patient compliance and lifestyle are widely believed to have little short-term effect, but can be extremely important in the longer term. Networks of patients, private individuals and doctors can offer a solution. However, the services have to be paid for, in most cases by means of a subscription ('fee for membership').

In practice, prevention meets cure when the healthcare insurer is also the healthcare provider, as in the case of Kaiser Permanente in the United States. Another possibility is to call upon a 'disease management network' which takes responsibility for the health of its member patients, as in the case of another American organization, Healthways.[100] Healthways employs a team of nurse practitioners who maintain contact with patients and teach them how to monitor their own condition. Employers hire Healthways to keep their chronically ill staff in the best possible state of health, paying a set annual premium for each employee registered on the scheme.

There are two types of solution: 'rigorous' (the system is radically and immediately altered) and 'gradual' (the existing system is adjusted over time.)

Everything under one roof

Rigorous solutions would include:
1. Introducing market incentives which would enable private sector companies to form integrated healthcare organizations, staffed by all professionals relevant to

the condition(s) being addressed, all of whom will be on the payroll of that organization. This resolves the problem of the benefits being derived by those who do not bear the burdens. The organization will be concerned only with outcomes. This is analogous to Kaiser Permanente in the USA.

2. Giving chronic patients the option of a 'Personal Healthcare Budget', as already available to some categories of patients under the Exceptional Medical Expenses Act (AWBZ). The patient is then in control and decides how and where the budget is to be spent. Of course, the patient will be able to delegate these decisions to someone else, possibly a healthcare provider (with whom agreements will be made with regard to the mutual expectations).
There has already been a limited trial of Personal Budgets under the Health Insurance Act (for the visually handicapped, for example), a report of which has been published by the NZa.[101] The trial was not a success: health insurers imposed so many conditions that it became virtually impossible for patients to exercise any freedom of choice for fear of incurring additional costs.

Gradual solutions might include:
1. Encouraging insurance companies to include the membership fee for a social network in their standard cover, as they already do in the case of membership of a patient association.
2. Setting fees to be paid to professionals in respect of their participation in social networks.

3. Introducing a system of 'functional funding' in the extramural care sector. (In fact, moves in this direction are already ongoing.[102]) Payment is made not for all the various individual interventions, examinations, prescriptions etc., but for an all-in package of care for each type of patient. In the first instance, the system is being introduced with respect to diabetes and cardiovascular risk management. COPD and heart failure will follow. Care providers provide the actual treatment as required. One care provider, perhaps the GP, takes on the role of 'contractor'. He receives the total budget which he then divides among the other providers. This system does attract some criticism. Health 2.0 entails full equality of all actors. In principle, the patient himself should be in charge. This does not mean that he should necessarily receive a personal budget which he himself controls: an individual budget administered by someone else is also an option.
4. Other 'self-management' packages (yet to be defined) could be included in the standard health insurance cover, just as 'prevention of diabetes' and 'prevention of overweight' are now recognized as healthcare interventions in their own right.

5. Extend the current innovation incentive scheme whereby Health 2.0 innovations including projects involving interaction between the patient on the one hand and the insurer or healthcare provider on the other become eligible for funding. Given that the adoption of an innovation often takes over ten years[103] it seems appropriate for the scheme should be extended by a substantial degree.
6. Extend the freely negotiable 'Segment B' category of health services, where-

upon insurers will have greater scope to address the wishes of their policy-holders. For institutions and insurers alike, it will be more interesting to experiment with innovations within the 'B' Segment than in the 'A' Segment, since it will be easier to achieve market differentiation and all benefits flow back into the organization (assuming a successful outcome, of course).

In addition, measures will be required to remove or mitigate the risks that Health 2.0 entails:

Avoid social division

- It is important to ensure that certain groups who are particularly active in Health 2.0 do not enjoy better access to good care services than those who are not. In fact, Health 2.0 need not lead to any greater divide between the 'haves' and 'have nots'. The use of the new media can itself help to reduce this divide.[104] For example, health advice can form part of short films and (interactive) games.

Counterbalance the nonsense promulgated on the internet

- The risk of misinformation must be reduced, as must that of personal information being misused.

It is well known that the internet contains a large quantity of unreliable information. By the very nature of the medium, it is impossible to exclude such information altogether, whereupon it becomes extremely important to ensure that the organizations and people who enjoy public trust – as many healthcare professionals do – participate in the networks and are on hand to offer patients accurate information. Doctors may refer their patients to the websites of such organizations during a consultation, while the health-related networks can include links to the relevant information.

Introduce rules that make the misuse of personal information pointless

It is also important to prevent the misuse of personal information. Members of the public can assist by ensuring that their personal details are not made available to all and sundry. On the other hand, the same members of the public are required to provide personal information to countless organizations, whereupon it is relatively easy for those in possession of the information to collate and combine data. This may be very difficult to prevent, but the government can at least ensure that the information in its possession remains private and secure. Health insurers are obliged to accept any new client, regardless of his or her health history. Even if the insurer has information to suggest that the prospective client has made many claims in the past, that client must be offered cover. As the main collector of sensitive information, the government has a duty to set a good example.

# 4 Recommendations

## 4.1 Introduction

**Health 2.0: the patient at the fore**

Health 2.0 places the patient centre stage: the focus of all activities. Its adoption will fulfil the government's long-held policy objective of a truly patient-centric, demand-led health system.

As we saw in Chapter 3, Health 2.0 offers a potential 'win-win' situation for patients, healthcare professionals and government alike:
- The patient can match healthcare services to his actual requirements. He will enjoy greater opportunities for self-management, with support available as necessary. Through participation in the social networks, he will devote greater attention to prevention, thus reducing the risk of ill health in future.
- The professional will be dealing with a well-informed and committed patient, which will make his work more attractive.
- A more committed patient who adopts healthy lifestyle choices, is more compliant with medical advice and who self-manages his own health will help to stem the ongoing increase in healthcare costs. The demand for new staff will be lower, as will the demands on the time of existing staff.

**The benefits of Health 20. cannot be fully exploited unless certain measures are taken**

As we also saw in Chapter 3, the most likely future scenario is a further development of the Health 1.0 situation *unless* certain measures are put in place. Even so, there will be efforts to implement Health 2.0 on the part of both public and professionals. Patients are already particularly active within online communities and their use of general social media can only increase. They have seen the developments in other countries such as the United States, where numerous Health 2.0 applications are now available, and they wish to help the Netherlands follow suit. Similarly, professionals with an innovative outlook will strive to establish the patient (or the patient's health) as the focus of their activities, and will wish to be compensated accordingly. They will no longer rely on treating those who are ill as their sole source of income.

**Combine the positive elements of Health 1.0 and Health 2.0**

The aim must be to combine all the positive elements of Health 1.0 with those of Health 2.0. In Health 1.0, it is the professional who possesses the scientific knowledge and expertise, and who makes this available by means of the hospital website, videos and podcasts about certain types of operation, and blogs describing new technologies.[105] In Health 2.0, this knowledge can be combined with that of patients themselves, gained through experience. The ideal outcome is a perfect synthesis of 1.0 and 2.0. As it is, patients are now generally far better informed and are likely to become more discerning as a result. They must be able to retain confidence in the healthcare system.

In sectors other than healthcare, the adoption of Web 2.0 scenarios is likely to be more rapid, since new entrants do not face the difficulties created by the complex funding structure of the health sector. However, it is not only the patients and professionals who stand to benefit from Health 2.0. The government will also do so,

whereupon it is in its own best interests to remove or mitigate the obstacles to Health 2.0 and to oversee its smooth implementation.

## 4.2    Recommendations for all actors

Standing still is moving backwards

All actors must realize that a development is under way which demands thought and attention. Those who fail to respond adequately will find themselves in a particularly difficult position. Health 2.0 offers clear advantages which should be exploited.

> **Recommendation**
> Healthcare providers, insurers and the government must make greater use of the social media in order to provide information in a suitably transparent manner.

One of the possibilities open to the government is to publish information, including reports which are relevant to the individual consumer or patient, freely on the internet in a 'user-friendly' form, thus encouraging public debate. By remaining fully transparent and taking part in that debate, the government will retain or regain public confidence.

> **Recommendation**
> Healthcare providers, insurers and the government must make greater use of the social media to involve patients, policy-holders and the general public in the formulation of new policy.

## 4.3    Recommendations for the government

Health 2.0 offers new opportunities to attain the government's stated policy objectives in terms of patient-centric, demand-led healthcare services of extremely high quality, while also gaining possibilities for better cost management. It is therefore in the government's own best interests to act upon these opportunities. If it fails to do so, there could be problems. The HPV vaccination programme provides a striking example. On that occasion, the government was able to learn from its mistakes, as demonstrated by the far more effective communication about the H1N1 flu vaccination.

> **Recommendation**
> The government should take an active part in the social networks, both to demonstrate its involvement and to enrich the discussions by contributing objective information.

The financial opportunities are better than they appear

The healthcare sector has stated that financial obstacles stand in the way of innovation in general, and the adoption of Health 2.0 in particular. The Ministry of Health contends that current legislation allows for far more opportunity for innovation than the field itself seems to believe. There are indeed some real obstacles and

some assumed obstacles. However, the main problem would appear to be a culture which is not geared to innovation. As stated in Chapter 4, the existing institutions seem to have great difficulty in adopting any rigorous innovations. It is therefore important for the government to communicate clear why the supposed financial obstacles are not really obstacles at all. In addition, the existing NZa innovation incentive arrangements should be extended in order to enable the ongoing funding of Health 2.0 applications with clear added value.

---

**Recommendation**
The government should provide ongoing funding for any healthcare innovations with clear added value, whereby the traditional relationships between the actors in the field will change and the focus will shift to the 'empowered patient'.

---

This recommendation entails:
- Encouraging the extension of the NZa innovation incentive scheme, so that Health 2.0 innovations which can create greater patient value by means of patient-centric cooperation between patients and consumers can be adequately funded. It will then not be only projects involving the healthcare provider which become eligible for funding, but also those involving the patient and the insurer, or the patient and the healthcare provider.
- The introduction of financial incentives which will promote a culture of innovation in the healthcare sector. This requires the abolition of the current 'perverse' incentives which discourage professionals from implementing innovations because they derive pecuniary advantage from retaining the traditional, now outdated, procedures.
- Introduce means (in terms of both fees and their inclusion in insurance cover) by which professionals can be properly compensated for their participation in Health 2.0 applications which promote patients' health but which are currently excluded from the definition of 'care services' under the strict letter of the law. This has recently been achieved in the case of chain care.

## 4.4   Recommendations for other actors

Failure to act puts the organization's survival at risk: snooze and you lose!

It is not only the government which must consider the implications of Health 2.0: all other actors must do so and they must decide how to respond. They must determine how they can use the social media in order to attain their objectives. Experience in the private sector demonstrates that failure to respond to social developments can place continuity in jeopardy. **!**

Patients require reliable and accurate information, and expect health professionals to provide it. This demands both a Health 1.0-style approach, with authoritative websites offering factual information about certain health conditions, together with a Health 2.0 approach which also draws upon the experiences of patients themselves.

> **Recommendations for healthcare providers**
> 1. Healthcare providers must use the social media to optimize patient contact.
> 2. Like consumers, healthcare providers will derive significant benefits from the health management model described in Section 3.4 above. Accordingly, consumers and providers must work together to implement a system of 'shared care'. The providers should be encouraged to develop and implement care standards and appropriate self-management regimes.

**Self-management and the reassignment of tasks can serve to reduce costs**

Self-management opens up many interesting opportunities in healthcare. It is largely a question of lifestyle management, of prevention to reduce the demand for professional care services, and of patient autonomy. As we have seen, self-management can also serve to reduce costs. It will clearly be of interest to health insurers if much of the professional support that patients require can be offered by nurse practitioners. Some of that support may even be provided by communications professionals, as interaction becomes more important to both the health system and the individual patient (in terms of personal attention, help in finding the most appropriates sources of information and networks, etc.)

> **Recommendations for healthcare insurers**
> 1. Offer policy-holders appropriate facilities:
> - by providing full and transparent access to information about the services provided, all including payments made in respect of the patient's treatment, so that they have a better understanding of the costs involved and can take appropriate action;
> - by enabling them to share their experiences of healthcare services. This will assist in the insurers' purchasing decisions;
> - by reimbursing the cost of policy-holders' use of Health 2.0 networks (just as membership of patient organizations is already covered).
> 2. When contracting functional care services, impose conditions and criteria with regard to:
> - self management, which should be a substantial component of the treatment protocol of care standard;
> - communication between healthcare providers and consumers which relies on the social media;
> - setting a deadline for full compliance with these and other conditions.

**Patient can do much of the preparatory work**

There are several sectors in which a clear shift in the roles of service provider and client has been observed. Clearly, healthcare professionals will continue to play an extremely important and valuable role. However, consumers can do much to bring about a shift of responsibility from the professional to the individual. Their part will begin with effective lifestyle management to reduce the likelihood of requiring medical care in future. It will also involve certain 'administrative preparations' prior to a consultation, such as completing and submitting standard forms and intake questionnaires online (which is already standard practice in many other sectors.) In many conditions, such as diabetes and COPD, modern technology has greatly enhanced the opportunities for self-treatment at home.

At the end of the day, it will be the consumer/policy-holder/patient who will decide whether Health 2.0 becomes a reality, and how quickly it does so. It falls to the other actors to remove or mitigate the obstacles. Patient organizations also have a role to play in this regard.

---

**Recommendations for patient organizations**
1. Ensure that patients with comorbidity are not treated for each condition separately, but promote cooperation to provide an integrated approach which also interlinks the various condition-specific web applications.
2. Take action to narrow the 'digital divide' between those who have internet access and/or the appropriate skills and those who do not, thus enabling as many people as possible to derive the benefits of Health 2.0.
3. Encourage the use of Personal Health Records for the purposes of self-management.

---

**The Council for Public Health and Health Care**
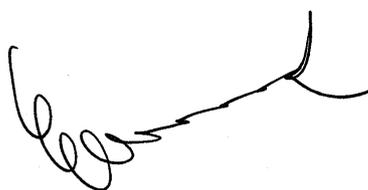
Rien Meijerink,
Chair
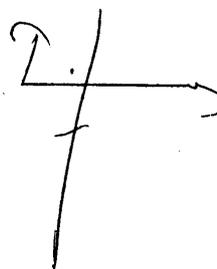
Pieter Vos,
General Secretary

# References / Endnotes

1   Raad voor de Volksgezondheid. Advies Patiënt en Internet. RVZ, Zoetermeer, 2000
2   Raad voor de Volksgezondheid en Zorg. E-Health in zicht. RVZ, Zoetermeer, 2002
3   http://nieuwemedia.web-log.nl/nieuwemedia/2008/06/barack-obama-en.html
4   http://debibliotheek.blogspot.com/2008/06/is-science-20-de-toekomst.html
5   http://trendslator.nl/wordpress/wp-content/trendwatching.pdf
6   http://www.boekcover.nl/1089/onderwijs_2_0
7   http://criminaliteitswijzer.ning.com/
8   http://www.linkedin.com/groupInvitation?groupID=1571547&sharedKey=6B4E38440FEB
9   http://www.ambtenaar20.nl/
10  O'Reilly, Tim. Why Dell.com (was) More Enterprise 2.0 Than Dell IdeaStorm. http://radar.oreilly.com/2008/09/why-dell-dot-com-is-more-enterprise.html
11  http://www.frankwatching.com/archive/2008/06/22/crowd-sourcing-het-publiek-onderschat/
12  Surowiecki J. The Wisdom of Crowds. Anchor Books, New York, 2004
13  Bijvoorbeeld: http://www.zoover.nl/
14  Bijvoorbeeld: http://www.kieskeurig.nl/ en: http://www.vergelijk.nl/
15  Sattler, Bart. Succesfactoren op het Internet: Lessen van Web 2.0. See also: http://www.twanetwerk.nl/default.ashx?DocumentId=6572
16  http://www.brickmeetsbyte.com/berichten/web_20_het_dilemma_van_een_hype_zonder _definitie/
17  http://health20.org/wiki/Main_Page
18  Furst, Ian. 2008. New Health 2.0 Definition, June 13, 2008. http://waittimes.blogspot.com/2008/06/new-health-20-definition.html
19  Eytan, Ted / Sharp, John. Updated Health 2.0 Definition. http://www.tedeytan.com/2008/06/13/1089
20  Shreeve, Scott. http://blog.crossoverhealth.com/
21  http://markhawker.tumblr.com/post/63534151/health20#disqus_thread
22  http://www.jmir.org/2008/3/e22/
23  Eysenbach G. Medicine 2.0 Congress website launched (and Definition of Medicine 2.0 / Health 2.0). Gunther Eysenbach's Random Research Rants. 2008. http://gunther-eysenbach.blogspot.com/2008/03/medicine-20-congress-website-launched.html
24  Berkman LF & Syme SL. Social Networks, Host Resistance, and Mortality: A nine-Year Follow-up Study of Alameda County residents. American Journal of Epidemiology Vol. 109, No. 2: 186-204, 1979 (http://aje.oxfordjournals.org/cgi/content/short/109/2/186)
25  http://www.flycatcher.eu/
26  Nationaal Onderwijsdebat 2009; see: http://www.goedbloed.net/content/view/85/51/

27   http://www.marketingweek.co.uk/home/how-deference-became-
reference/2065417.article, and
Edelman Trust Barometer 2009; zie: http://www.edelmanpr.nl/downloads/
20080128_DEF%20Edelman %20Trust%20Barometer%202009.pdf

28   http://www.nu.nl/algemeen/1930130/opkomst-vaccinatie-
baarmoederhalskanker-valt-tegen.html

29   E.g. http://www.meetup.com/

30   Raad voor Cultuur. Advies Persbeleid; see:
http://www.cultuur.nl/files/pdf/advies/advies_0eabac2c-d09d-4b09-1b8c-
00007f75f068_med-2008.04948-2.pdf

31   Eurostat. Internet access and use in 2009; One person in two in the EU27 uses
the internet daily. News release 176/2009, 8 December 2009

32   http://www.hiil.nl/files.nsf/pages/NWOP_697KFS/$file/MES_verslag_ se-
minar_Social_Policy.pdf

33   http://www.lezenenschrijven.nl/nl/analfabetisme/vragen/

34   Deursen AJAM van en Dijk JAGM van. Using the Internet: Skill related prob-
lems in users' online behavior. Interacting with Computers, doi:
10.1016/j.intcom.2009.06.005, 2009

35   RVZ/Flycatcher survey (N=2080), 2007

36   http://mashable.com/2009/04/17/web-in-numbers-social-media/

37   http://blog.nielsen.com/nielsenwire/wp-
content/uploads/2009/03/nielsen_globalfaces_mar09.pdf

38   http://www.hyped.nl/details/20090111_de_echte_statistieken_van_hyves
/#When:07:15:00Z

39   http://www.nrc.nl/media/article1885705.ece/De_digitale_gezelligheid_van_
Hyves_?service=Print

40   Denk bijvoorbeeld aan: www.zorgkaartnederland.nl,
www.consumentendezorg.nl en www.zoekdokter.nl

41   RVZ/Flycatcher survey, November 2009

42   Uden-Kraan F van, Drossaert CHC, Taal E, Seydel ER & Laar MAFJ. Self-
Reported Differences in Empowerment between Lurkers and Posters in Online
Patient Support Groups. Journal of Internet Research, 2008
(http://www.jmir.org/2008/2/e18/)

43   De Praktijk/Motivaction: http://www.motivaction.nl/downloads/Wat-werkt-
bij-wie.pdf

44   Snelders S en Meijman FJ. De mondige patiënt; historische kijk op een mythe.
Bert Bakker, Amsterdam, 2009

45   Deze bevindingen vloeien voort uit drie discussiebijeenkomsten met in het to-
taal 60 chronische patiënten waarvan het merendeel 50-plusser was en een hoge-
re opleiding heeft genoten.

46   See for example: http://www.interapy.nl/ en http://www.ksyos.org/in
dex.php/telemedicine-diensten/teledermatologie

47   See for example: http://www.radiologyassistant.nl/en/

48   Curavista BV:
http://www.nvfm.nl/images/eConsult%20in%20de%20huisartsenpraktijk_ppt.
pdf

49   http://www.sermo.com/

50 See for example: http://www.mednet.nl/

51 http://www.uptodate.com/home/index.html

52 http://www.MyHealthOnline.nl

53 http://www.medischegegevens.nl

54 http://hospitalseu.wordpress.com/

55 These are among the findings of three discussion meetings attended by a total of sixty chronic patients, most over fifty and most with a higher level of education.

56 http://www.umcn.nl/extern/patfol/CSS0842.pdf

57 See for example: Nordqvist C, Hanberger L, Timpka T & Nordfeldt S. Health Professionals' Attitudes towards using a Web 2.0 Portal for Child and Adolescent Diabetes Care: Qualitative Study. Journal of Medical Internet Research, 2009 (http://www.jmir.org/2009/2/e12/)

58 Lems E. Gezondheid 2.0, onderzoek naart de invloed van sociale media op communicatie- en informatiestromen rondom ziekte, behandeling en geneesmiddelen bij borst- en darmkanker. Amsterdam, 2009

59 Zoals www.zorgkaartnederland.nl, www.consumentendezorg.nl en www.zoekdokter.nl

60 Achmea is a partner in the comparison site www.zorgkaartnederland.nl while De Friesland forms part of the partnership responsible for doejeverhaal.nl

61 http://www.ambtenaar20.nl/

62 http://www.newscientist.com/article/mg20527453.600-how-crowdsourcing-is-helping-in-haiti.html

63 E.g. www.thuisepd.nl en www.medlook.nl

64 http://www.google.com/intl/nl/health/about/index.html en http://www.healthvault.com/

65 One example is www.pazio.nl, an initiative of the University Medical Centre Utrecht, Imtech, VitalHealth Software, Mediportaal, VitaValley and Leidsche Rijn Julius Gezondheidscentrum

66 Bouma J. De MOL is goud waard. Trouw, 15 August 2005 (http://www.trouw.nl/achtergrond/Dossiers/article1431509.ece/De_MOL_is_goud_waard.html?all=true)

67 http://tweakers.net/nieuws/61431/forrester-een-vijfde-nederlanders-gebruikt-internet-op-telefoon.html

68 Zie bijvoorbeeld: mHealth for development: http://www.globalproblems-globalsolutions-files.org/unf_website/assets/publications/technology/mhealth/mHealth_for_Development_full.pdf

69 Lupianez-Villanueva F, Mayer MA & Torrent J. Opportunities and challenges of Web 2.0 within the health care systems : An empirical exploration. Informatics for Health & Social Care, vol 34 no. 3, pag. 117-126, 2009.

70 Chou WS, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social Media Use in the United States: Implications for Health Communication. Journal Medical Internet Research, 2009;11(4):e48 (http://www.jmir.org/2009/4/e48/)

71 http://www.nivel.nl/oc2/page.asp?pageid=8363

72 http://www.nivel.nl/cqi/

73 http://www.dvnwinkel.nl/

74  At the heart failure clinic of the Martini Hospital in Groningen, cardiologist René van Dijk now discharges patients two days earlier, armed with a DSS and self-monitoring equipment. If any abnormalities are noted, the DSS determines whether the patient should contact the clinic.

75  The Council's 2010 advisory on labour-saving technology will examine this matter further.

76  http://www.ahrq.gov/

77  http://www.rivm.nl/persberichten/2009/stijgingdiabetes.jsp

78  See for example: Baardman J, Booys M de, Heldoorn M & Meulmeester M. Zelfmanagement 2.0; Over zelfmanagement van de patiënt en wat eHealth daaraan kan bijdragen. Nederlandse Patiënten Consumenten Federatie, Utrecht, 2009 (http://www.ikregelmijnzorgonline.nl)

79  ChipSoft. CS-EZIS.Net en het Personal Health Record, proefopstelling integratie met Microsoft HealthVault. Amsterdam, 2009

80  Letter from the Minister of Health to parliament, dated 22 December 2008

81  Christensen CM, Grossman JH & Hwang J. The Innovator's Prescription, a disruptive solution for health care. McGraw-Hill, New York, 2009

82  http://www.ambtenaar20.nl/?p=3348

83  http://mobile.emerce.nl/2009/11/23/politie-onderkent-kracht-social-media/

84  http://news.bbc.co.uk/2/hi/asia-pacific/7015024.stm

85  http://www.internetconsultatie.nl/

86  Erp J van. Naming en shaming in het markttoezicht; een onderzoek naar de openbaarmaking van sancties op de financiële markt. Boom, 2009

87  http://www.olafmolenaar.com/2009/12/4-social-media-tips-voor-bedrijven.html

88  http://nederlander.wordpress.com/2008/11/20/hpv-vaccinatie-niet-doen/

89  Wilson K & Keelan J. Coping with public health 2.0. Journal of the Canadian Medical Association, Vol. 180, No. 10, page 1080, 2009

90  Christensen CM, Grossman JH & Hwang J. The Innovator's Prescription, a disruptive solution for health care. McGraw-Hill, New York, 2009

91  http://www.dlife.com/ en http://www.sugarstats.com

92  http://www.parkinsonweb.nl

93  Christensen CM, Grossman JH & Hwang J. The Innovator's Prescription, a disruptive solution for health care. McGraw-Hill, New York, 2009

94  College voor Zorgverzekeringen. Beoordeling stand van de wetenschap en praktijk. CVZ, Diemen, 2007 (http://www.cvz.nl/resources/rpt0711_stand-wetenschap-en-praktijk_tcm28-25006.pdf)

95  College voor Zorgverzekeringen. Betekenis en beoordeling criterium 'plegen te bieden'. CVZ, Diemen, 2008. (http://www.cvz.nl/resources/rpt0811_criterium_plegen_te_bieden_tcm28-26913.pdf)

96  College voor Zorgverzekeringen. Zorgstandaarden, ketenzorg voor chronische aandoeningen en de te verzekeren prestaties Zvw. CVZ, Diemen, 2009 (http://www.cvz.nl/resources/Zorgstandaarden%20ketenzorg%20voor%20chronisch%20aandoening_tcm28-28244.pdf)

97  Algemene Rekenkamer. Zorg op afstand. Tweede Kamer der Staten-Generaal, 31 967 Nr. 2, 2009

98  Nederlandse Zorgautoriteit. Advies uitbreiding B-segment 2011. NZA, Utrecht, 2009 (http://www.nza.nl/7113/10118/84814/Advies_uitbreiding_B-segment_2011.pdf)

99  http://www.innovations.ahrq.gov/content.aspx?id=1772

100  http://www.thisishealthways.com/downloads/Healthways_Fact_Sheet.pdf

101  Nederlandse Zorgautoriteit. Evaluatierapport Het PGB in de Zorgverzeke-ringswet. Utrecht, 2008

102  Brief van de minister van VWS aan de Voorzitter van de Tweede Kamer der Staten-Generaal d.d. 22 december 2008

103  Schrijvers AJP. Tien theorieën om de snelheid van de verspreiding van zorgin-novaties te verklaren. In: Raad voor de Volksgezondheid en Zorg. Weten wat we doen; verspreiding van innovaties in de zorg. RVZ, Zoetermeer, 2005

104  Lamaitre M en Meijer H. Web 2.0 tegen de armoede. Digitaal Bestuur, 16 sep-tember 2009 (http://digitaalbestuur.nl/opinie/web-20-tegen-de-armoede)

105  The Mayo Clinic in the USA is a prime example of a hospital which has em-braced the use of the social media. See:
http://www.mayoclinic.org/blogs/index.html