The Patient and the Internet
The Patient and the Internet

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Summary

The Internet is becoming increasingly popular. Consumers are now using the Internet to obtain or exchange information on health, sickness and healthcare. More and more websites with this kind of information are appearing on the World Wide Web. These are now already estimated to exceed 100,000. In addition there are thousands of chat and on-line support groups and mailing lists on a wide range of health topics.

The Internet would appear to give citizens, consumers and patients all sorts of new opportunities. It provides an abundance of information and makes it possible to exchange experiences with fellow-sufferers and to support one another in dealing with health problems. Other new or better opportunities include anonymous communication and seeking a second opinion. All these new opportunities are leading to patient empowerment: strengthening the position of the patient and producing a new partnership between patient and care-provider.

At the same time the use of the Internet involves threats. In fact these are not new threats but a rapid increase in the extent to which already existing risks are incurred. These risks of harm to health arise when consumers/patients undertake action on the basis of unreliable information or the incorrect interpretation of inherently reliable information. A particular risk is the ordering and use of drugs without consulting one’s own doctor.

Four clusters of problems arise in encouraging the opportunities and reducing the risks which the Internet brings. Not everyone who so desires has access to the Internet or knows how to use it. Not all the information that is of importance for consumers/patients is available on the Net. Not everyone knows how to distinguish between reliable and unreliable information. And finally not everyone knows how to deal properly with the range of products and services available on the Internet.

The government and parties in the field must undertake joint efforts in order to eliminate or at least reduce these problems. Important elements include the setting up of a health portal (providing reliable information and links to Internet becoming popular
Internet offers new opportunities
Patient empowerment by the Internet
There are also threats
Risk of harm to health
Opportunities must be encouraged and threats reduced
The government and parties in the field must undertake (joint) action

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reliable sites) and the promotion of this site by the government, the provision by organisations of care-providers and patient associations of information of relevance for consumers/patients and the provision of access to the Internet in healthcare institutions.

If the parties concerned do not themselves ensure that reliable information is readily available on the Internet, third parties will emerge offering their services on the Internet. This could result in less or unreliable information, to the disadvantage to the parties concerned (or at least the patient and care-provider).
1 Advisory assignment

1.1 Terms of reference

The advisory programme laid down for the RVZ in 1999 by the Minister of Health, Welfare and Sports states that the RVZ is required to advise on the subject of 'The Patient and the Internet'. The relevant section from the RVZ Programme of Work 1999 is included at Annex 1. Annex 2 provides the composition of the RVZ.

1.2 Reasons for this report

The immediate grounds for this report have been provided by the increasing extent to which the Health Inspectorate is confronted by the procurement of drugs abroad on the Internet. Where these are drugs which are solely available on prescription in the Netherlands, this may result in damage to health. In the first place this is a problem for the individual in question and his or her environment; secondly it involves possibly avoidable costs for society. At the same time it may be noted that the Internet provides new, unknown opportunities for the consumer and the patient – opportunities with a positive effect on health, healthcare and welfare.

Against this background the RVZ examines the value of the Internet for the consumer/patient as a medium. The concern is with the new opportunities afforded by the Internet for improving the health of individuals and the care to be provided to them, the threats which the use of this new medium involves and the question as to whether the government and parties in the field should undertake any action to encourage the new opportunities offered by the Internet and to limit possible risks and, if so, what action.

1.3 Function of this report

This report is designed to help ensure that the Internet is used to best effect by Dutch citizens as actual or potential healthcare consumers, thus improving the efficiency and effectiveness of healthcare and the accessibility of such care.
This can be achieved by exploring the threats and opportunities created by this new medium and by identifying action points. Indirectly this can be achieved by using this report to promote public debate about the Internet.

1.4 Policy issues

A broad indication of the policy issues in question has already been provided. These are now examined in more detail, in the form of facts, analysis and recommendations. The issues are:

- **Facts**: in what form is the Internet used for healthcare purposes, by whom and for what reason?
- **Analysis**: how should this situation be assessed; what threats and opportunities does the Internet bring?
- **Recommendations**: what activities should be undertaken to increase the opportunities and limit the threats? What role does the national government have? What should other actors do?

1.5 Advisory domain

As the title of this advisory report indicates, the report is concerned with the citizen as consumer and the latter's actual or potential use of the Internet. The Internet is generally defined as a global network of networks based on society without any one person or organisation being the owner of that complex of networks or information. This report is concerned not so much with the technical infrastructure - although the quality of that infrastructure is a decisive factor, for example for the nature of the application - as with the user and the opportunities which the user is offered. This means that the advice relates in particular to the information coming from and going to the consumer/patient. Where relevant other actors are also dealt with, for example the use of the Internet by care-providers: for certain applications not just the patient but also the care-provider needs access to the Internet.

There are of course many other important data flows related to the patient for which the Internet can be or is used, especially the information on patients exchanged between care-providers themselves and between care-providers and insurers, etc. This report is not concerned with such
information and communication. It is not therefore concerned with electronic medical records, except where the use of those records by patients themselves is concerned. It does however deal with information derived from data exchanged between care-providers and/or healthcare institutions and which are made available to patients, such as waiting list data.

The Internet also facilitates developments such as telemedicine. This report deals with the latter only in passing. The topic will be examined in more detail in the survey of new technologies to be published by the Council in 2001. The report has interfaces with earlier reports by the Council, in particular 'Towards a more demand-led care' and 'Self-testing'.

Terms such as citizen, consumer, care-consumer and patient are used in this report. In many cases they are synonymous but this is not always the case. The Internet may for example be used by citizens in order to find out whether they are (or to prevent them from becoming) a patient.

Finally a qualification is in order. Although the Internet is an important and indeed ever more significant medium, there are also numerous other media. Generally speaking it is the mix of media in conjunction with other factors which affects human behaviour.

1.6 Working methods

This report was prepared under the direction of Council members J.C. Blankert and E.H.T.M. Nijpels. A large number of people both in the Netherlands and other countries were consulted in the preparation of this report. In addition The Decision Group/Nijenrode University and the Department of Communication and Innovative Studies of Wageningen University provided assistance. A detailed account of the participants is included in the annexes.

1.7 Structure of the report

This report is arranged in terms of the three-fold classification in section 1.4 (Policy issues). Chapter 2 discusses the facts; Chapter 3 provides an analysis of the
facts and Chapter 4 provides recommendations based on that analysis. The report has been kept limited in size. Background information and substantiation may be found in the background study 'On E-health and cyber-medicine' published simultaneously with this report.
2 What can one do with the Internet: the facts

2.1 Introduction

This chapter provides an answer to the questions: what can one do with the Internet, what do citizens/consumers use the Internet for in the health sector and on what scale does this occur. The following are examined in turn:
- Internet applications;
- Use of the Internet in general;
- Applications in healthcare;
- Use of the Internet in the healthcare sector.

2.2 Internet applications

The Internet may be used for:
- Electronic mail (e-mail): sending a message from a computer to one or more other computers. Messages may consist of text, image (moving or still) or sound.
- Mailing lists: subscribing to reports on a particular topic for the purpose of group communications.
- News groups: public bulletin boards relating to a particular topic; anyone may send in a message, but it is up to the user to get in touch with the newsgroup and determine whether he or she wishes to look at the particular message or not (in contrast to mailing lists, where the subscriber automatically receives reports in his electronic post-box).
- Chatting: interactive discussion by computer with one or more persons via monitor and keyboard and/or via microphone (sound) and possibly camera (video image).
- World Wide Web (WWW): access via the Internet to a large quantity of information available in all sorts of computer databases throughout the world; this contains text, images, sound and combinations thereof.
- Exchange of computer files: by making use of the File Transfer Protocol (FTP), computer files, including computer programmes, can be exchanged.
2.3 Use of the Internet in general

It is impossible to say precisely how widely distributed the Internet is. The Internet is, however, known to have grown strongly in recent years and will continue to grow strongly in the coming years. This is evident from:
- the increase in the number of users;
- the increase in the number of networks providing access to the Internet;
- the increase in the quantity of data (bytes) being sent by the Internet (number of electronic messages, number of bytes called up on the World Wide Web and so on);
- the increase in the amount of information to be found on the Internet (the number of websites, number of web pages, and so on).

The penetration of the Internet is proceeding much more rapidly than that of other media, such as the telephone, radio and television.

Figure 1 Rate of Internet use among households

Recent market research in the United States indicates that 48% of adults in that country now have access to the Internet. Until recently the Internet penetration in Europe was the highest in the Scandinavian countries, followed by the Netherlands. Since the launch of the ‘free’ Internet subscriptions by various providers the Netherlands has led...
the field in terms of Internet users. In terms of PC use the Netherlands was already at the top. Households with an Internet connection in the Netherlands use the Internet on average for six hours per week. The most commonly used applications are calling up information (76%) and e-mailing (68%). The Internet-user in the Netherlands has a relatively high level of education, is studying or has a job, and is generally younger and has a more extensive social network than those not using the Internet.

2.4 Applications in the health sector

In theory four types of application may be distinguished. The use of these applications more or less runs in parallel with the progression from novice to advanced Internet-user. These four applications are:

- **Consulting files on the World Wide Web**: this concerns the library function, namely looking for, finding and taking stock of information on;
  - health and how to promote it;
  - sickness and how this is to be diagnosed and treated;
  - healthcare facilities, their location, the kinds of services, accessibility, quality, and so on;
  - other facilities of relevance for dealing with a particular disorder or limitation in the field of housing, employment, education, welfare and so on.

Information may be found by the Internet-user without human intervention on the part of those providing the information.

A more advanced application is personal health profiling: by indicating one's personal preferences and wishes as an Internet-user, it becomes possible for the provider of the information to programme in the user's customised requirements for information.

- **Contact with fellow-sufferers**: care consumers/patients can exchange experiences and provide one another with information. Use is more for this purpose of mailing lists, news and discussion groups and chat boxes.

- **Performing transactions**: this concerns the performance of logistical activities, such as making appointments, ordering medical aids and appliances, conventional and alternative drugs, vitamins, food supplements, etc.

- **Consulting care-providers without face-to-face contact**: patients communicate with doctors and other care-providers.
There are various gradations:
- Patients submit requests for advice and the doctor replies without follow-up, i.e. without providing a referral or prescription on the Internet;
- Patients submit requests for advice and the doctor replies with follow-up, i.e. providing a referral or prescription on the Internet;
- E-therapy: the care-provider provides treatment on the Internet; generally this concerns the treatment of psychological problems.

In addition there are other applications of direct or indirect importance for the citizen or patient. These include the monitoring of health status and telemedicine. The latter application may be regarded as the next step within the ‘consultation of care-providers’ cluster. In practice websites provide a combination of one or more of the above applications.

2.5 Use of the Internet in the health sector

According to recent research over 50% of American Internet-users use the Internet in order to look for information in the health field. The figure in the Netherlands is unknown. The number of visitors to the websites of patient associations and organisations of professional practitioners, however, is known to be growing.

On the other hand the patient uses the Internet to a lesser extent than the average citizen. There are two main reasons for this:
- Patients include a disproportionate number of elderly people; PC use and hence Internet use with lower among the elder;
- People with a chronic disorder tend to have fewer financial resources; this obstructs their ability to purchase a PC and bear the cost of the (high) telephone charges.

In this connection reference is made to a growing digital divide in society, under which part of the population does not benefit from the opportunities afforded by the Internet.

Generally speaking care-providers make only limited use of the Internet in their professional activities. Electronic The risk exists of a ‘digital divide’

Care-providers have not yet embraced the Internet
communication between the patient and the latter's care-provider has so far not got off the ground.
3 Where is the Internet leading: the analysis

3.1 Introduction

The Internet is one of the many media including the printed word, telephone, radio and television. Has much in fact changed since Johannes Gutenberg, who invented printing in the 15th century and Leonard Kleinrock, Vinton Cerf, Bob Kahn and Marc Andreesen, the pioneers of the present-day Internet? In some senses it has, in others it has not.

Much has changed in the sense that each invention made the world 'smaller'. With the radio people could hear what was happening elsewhere in the world; with television the impact is even more immediate. Incidents on any scale, wherever in the world reach people in their homes in the Netherlands the very same day. The Internet adds an additional dimension. People can now establish on an individual basis at any moment in the day what is happening elsewhere in the world and can even make contact with others in the world with access to the Internet.

On the other hand, nothing has changed: each time a new medium is introduced this generates a debate about the possible dangers of that medium. Particularly in the early stages there is a fear of anarchy and subversive activities. There is a desire to regulate the new medium; think of censorship in the case of printing, the issuing of broadcasting licences and stipulations concerning the content of radio and television programmes. Some - perhaps many - people perceive new technological possibilities for providing information and communication across borders as a threat. They prefer a safe environment protecting them from confusion and chaos. Once the medium has become established in society, it proves to be more interesting and less 'dangerous' than initially thought. The penetration of the Internet in society has taken on a life of its own. The question is how this development can be put to best use in the health sector.

This advisory report needs to be read in that context. Needless to say the use of the Internet involves risks. The new opportunities opened up by the Internet are, however,
much more important. This is illustrated in the following sections in this chapter, which concern:
- differences from and similarities with other media;
- opportunities offered by the Internet;
- threats posed by the Internet;
- legal aspects;
- problems;
- possible solutions;
- the Internet in the healthcare society.

3.2 Differences from and similarities with other media

The Internet has a number of unique features, especially:
- it is a mass medium, but also an individual medium which everyone can in principle use at any time and in any place as they see fit;
- it is interactive and multi-media: in an interactive environment combinations of text, sound and moving or still images can be used;
- the costs of publishing are very low when compared with other media;
- it is easy to modify information quickly.

There are however similarities with other media:
- they serve a library function;
- they contain not just reliable but also incorrect information;
- they have an influence on citizens/consumers/patients.

The use of the Internet greatly enlarges both the positive and the negative aspects. This is for example reflected in the following:
- the Internet provides access to unlimited information;
- a high proportion of that information is misinformation;
- drugs are being ordered abroad on a bigger scale than would be the case without the Internet.

3.3 Opportunities offered by the Internet

The Internet offers the following opportunities:

a. Improved access to information for the individual citizen/patient: the Internet provides rapid access to a large body of information on health, sickness, health facilities and
other relevant provision.

b. Better opportunities to contact fellow sufferers: the consumer/patient can share experience with fellow sufferers on treatment, living with the illness, treatment side-effects, etc.; place and time do not play a role, which is particularly important for patients lacking mobility and patients suffering from a rare disease.

c. Lowering the threshold for seeking a second opinion: e-mail provides a comparatively simple way of approaching doctors and institutes both at home and abroad.

d. Possibilities of anonymous communication: certain patients prefer to call up information anonymously or to seek advice from a doctor they do not know (for example out of feelings of embarrassment or shame).

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**Figure 2** Opportunities, impact and effects of the Internet

![Diagram of Opportunities, Impact, and Effects]

- **Opportunities:**
  - much information
  - fellow-sufferer contact
  - easier second opinion
  - anonymous communication
  - new patient-care-provider communication
  - lower threshold for contact with care-provider
  - e-therapy
  - better health information

- **Impact:**
  - patient empowerment
  - new patient-care-provider partnership

- **Effects:**
  - customized care
  - better handling of illness/disability
  - prevention of harm to health

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e. Strengthening the position of the patient by such means as improved access to much more information and contact with fellow sufferers; the patient's comparative lack of information - particularly in relation to the care-provider - is reduced (and in certain cases even converted into a lead).

The Internet promotes patient empowerment
f. **New opportunities for communication between patient and care-provider:** e-mail in particular provides a new opportunity that can have added value in an existing doctor/patient relationship (in the same way as a telephone consultation).

g. **Lowering the threshold for making contact with the care-provider:** certain patients prefer electronic communication (e.g. for certain problems) to face-to-face communication.

h. **New treatment possibilities,** for example the treatment of mental problems (E-therapy).

i. **New opportunities for health information and prevention:** interactive counselling and support for changes in behaviour (giving up smoking, losing weight, etc.), providing warnings about health risks, communicating messages by use of moving or still images and sound, and so on.

j. **New partnership between care-provider and patient:** care-providers increasingly become advisers, not just on health promotion, sickness, treatment and so on but also on how to deal with information.

k. **New employment opportunities for patients:** the Internet provides new possibilities for education and employment; this can be particularly important for patients lacking mobility.

A new partnership is generated between care-provider and patient

### 3.4 Threats posed by the Internet

The Internet creates the following threats:

a. **The patient acts on the basis of unreliable information:** a good deal of information is incorrect, incomplete, out of date or in a word unreliable; there are many unfounded claims about 'miracle cures'; assessing what information is reliable and what is not is not straightforward.

b. **The patient acts on the basis of incorrectly interpreted information:** in itself correct information may be incorrectly interpreted by placing that information in a different context.

c. **The patient becomes agitated and confused** by the large volume and sometimes conflicting nature of information.

d. **The patient orders and uses prescription or over-the-counter drugs without consulting his or her doctor:** using these drugs can be risky if there are contraindications or the drug interacts with other drugs, etc.

e. **Risk of harm to health** as a result of the factors noted in points a-d above.

There are also threats

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f. *Lack of data protection* can result in the infringement of privacy; in the absence of security measures others can gain access to data on/messages from Internet-users.

g. *Internet addiction* may result in family and financial problems, social isolation, and so forth; other forms of addiction may be encouraged, such as on-line gambling.

**Figure 3 Threats, impact and effects of the Internet**

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<th>Threats</th>
<th>Impact</th>
<th>Effects</th>
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<tr>
<td>unreliable information</td>
<td>incorrect decision by patient</td>
<td>loss of health</td>
</tr>
<tr>
<td>incorrect interpretation</td>
<td>confusion, agitation</td>
<td>loss of quality of life</td>
</tr>
<tr>
<td>unsupervised taking of drugs</td>
<td>direct harm to health</td>
<td>higher costs</td>
</tr>
<tr>
<td>infringements of privacy</td>
<td>other tangible and or intangible harm</td>
<td>inefficient care</td>
</tr>
<tr>
<td>unethical behaviour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>undesired influence</td>
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h. *Industry (especially pharmaceutical companies) influences consumers and patients in a manner considered undesirable by other parties* (for example, the government, care-providers and health insurers): the boundaries of public advertising (Direct-To-Consumer) designed to encourage sales of prescription drugs become blurred (partly as a result of the differing attitudes in this area between the United States and Europe).

i. *New opportunities for unethical activities, for example offers of bodily materials (organs, sperm and ova, etc.)*.

### 3.5 Legal aspects

The speed with which the Internet is becoming an established part of public life raises the question as to whether the existing legislation and regulations are or can be an entirely
geared to this new medium or whether a new set of statutory instruments is required. In the government policy document *Wetgeving voor de elektronische snelweg* (Legislation for the Electronic Super Highway) the line is taken that what applies off-line should also apply on-line, in other words existing legislation and regulations are in principle applied to the Internet, although this may require amendment in so far as technology-dependent terms are used. New legislation and regulations are solely deemed necessary where the specific nature of the Internet so requires. This point of departure is shared at both European and international level. It means that legislation in the healthcare field also applies to activities conducted via the Internet. One problem in this regard concerns the enforcement of such regulations, which remained highly tied to national borders.

Under the Advertising Act, the advertising of prescription drugs is prohibited in the Netherlands. If prescription drugs are advertised on a foreign site, the Netherlands may claim legal jurisdiction as the advertising also has an effect in the Netherlands. The Netherlands may therefore proceed to prosecution. In doing so it will however be obstructed by the fact that investigation abroad is impossible without a request for international legal assistance, since such information may well be permitted in the country in which the provider of the information is established and/or because it is often difficult to determine the identity of the information-provider on the Internet. Another problem concerns the sale and delivery of drugs that are not registered in the Netherlands and not allowed to be marketed there. The unavailability of a drug in the Netherlands may create a need to buy it on the Internet. Drugs available on the Internet in one of the other member states of the EU will generally be registered in the Netherlands. If the buyer and seller have declared the law of the country in which the seller is established to apply to the contract of sale, a valid agreement may arise under private law. The seller is however unable to comply with the agreement in these circumstances: the law prohibits him from delivering drugs on Dutch territory.
The chances are that the package will be intercepted by the customs. In many cases the patient/consumer will by then already have honoured his part of the bargain, namely payment of the purchase price. It is reasonable to assume that the supplier must refund the purchase price and bear the cost: it was his responsibility to be familiar with the ban to deliver drugs in the Netherlands and to advise the patient/consumer accordingly.

As the two above examples indicate the regulations concerning the advertising, sale and deliver of drugs can be difficult to enforce in practice.

A development still in its early stages and raising certain legal issues is that of obtaining services on the Internet, such as consulting a doctor. Although the possibilities of providing and receiving medical treatment on the Internet remain limited at this stage, they will expand with technological progress. This will also place the liability issue in sharper relief. At present, an electronic medical consultation consists primarily of requests for and the provision of advice. Under Dutch law the provision of advice comes under the Medical Treatment Agreement Act (WGBO). Dutch law does not, however, automatically apply to the consultation agreement. If the doctor is established abroad, the parties - the doctor and the patient/consumer - may declare that the agreement is subject to the law of the land in which the doctor - the service-provider - is established. This does not eliminate the fact that under the Convention on the Law applicable to Contractual Obligations, the consumer/patient may invoke coercive provisions that have been included for his or her protection in the law of the land in which he or she is normally resident. This means that the consumer/patient may invoke the rights arising under the WGBO. It also means that the doctor - even if established abroad - cannot exclude or limit liability for a shortcoming on his or her part. In principle the patient appears to be well protected legally. It will, however, need to be shown in practice whether the law can also be adequately enforced.
3.6 Problems

On the basis of the preceding sections the problems may be reduced to the following four categories:

- access to the Internet: people must have access to the Electronic Super Highway in order to exploit the opportunities;
- availability of relevant information: relevant information must be available;
- dealing with information: it must be possible to draw a distinction between reliable and unreliable information;
- dealing with the supply of services and products: measures must be taken to prevent harm to health from the provision of services and/or the sale of products on the Internet.

Access to the Internet

In order to benefit from the opportunities offered by the Internet it is important for everyone who so wishes to have access to the Internet. Particularly important is physical and financial accessibility. Both in the United States and the Netherlands reference is made to the 'digital divide' in society. There are various factors at issue here. The penetration rate of the Internet among patients is lower than the average penetration rate. Large groups of patients do not have access to the Internet. Causes include the cost of Internet use (in particular the costs of the necessary hardware and the telephone charges) and computer illiteracy (especially among the elderly). People with a chronic disease are several hundreds guilders worse off per month than the average Dutch person.

Another factor concerns the ability to understand the information offered on the Internet. At present most of the information on the Internet is textual. In many cases the text is written from the viewpoint of medical/paramedical staff and much of the information is in English. There are various gradations: a (small) element of the population is illiterate; a larger proportion is partially illiterate (i.e. are able to read but do not understand what they read) and a higher proportion again get lost in the medical jargon.

Existence of relevant information

Much information is available; in many cases it is largely the same. Organisations and individuals placing information on the Internet often do so on the basis of what they, as
information-providers, consider important. For citizens, consumers and patients, however, it is important for the information-provider to work on the basis of meeting the information-demanders needs.

Among other things the consumer needs information on:
- health and how to promote it;
- sickness and how to diagnose and treat it;
- care facilities: where are these located, what services do they provide, when and how are they available, what is the quality, and so on;
- other facilities (housing, employment, education, welfare) are relevant for dealing with a particular disorder or handicap.

Important problems are that the desired information is not available or cannot be found. In both cases it may be asked who should ensure that the desired information is made available and that it can be found without difficulty.

*Dealing with information and communication*

In principle anyone is at liberty to offer information on health and healthcare on the Internet. As against the advantage that a lot of information has become available quickly, cheaply and easily there is the disadvantage that the information offered is often not correct or complete and/or is dated and in certain cases even misleading. Remedies and therapies are lauded on the Internet as miracle cures while the providers are not in fact able to substantiate their claims. It is not easy for the consumer/patient to assess whether the information on offer is reliable. Information may be conflicting, causing confusion and agitation for the patient. In addition the patient/consumer may interpret the correct information incorrectly or place it in the wrong context and so draw erroneous conclusions.

*Dealing with the supply of services and products*

Although e-commerce has not yet really taken off - 9% of households on the Internet order or make reservations from time to time on the Internet and 3% sometimes make payments via the Internet - the ordering of products abroad by this medium is growing. At present this largely concerns the ordering of drugs that are unavailable in the Netherlands or available only on prescription. The uncontrolled use of the drugs can result in harm to health. A well-known example of a drug procured abroad is Viagra. In some cases however the pills supplied are bogus; in this case the loss is 'confined' to financial loss.
Broadly speaking customers may be divided into the following categories:

- consumers who are financially better off by ordering drugs abroad; this of course depends on the extent to which the consumer is required to pay for the drugs in the Netherlands and the price of the drug elsewhere;
- consumers who are only able to obtain the drug abroad (because it is not on the market in the Netherlands);
- consumers for whom the doctor does not wish to prescribe the drug in question;
- consumers who wish to remain anonymous or do not wish or dare to discuss their problem with their own doctor or pharmacist;
- members of ethnic minorities who value their own medication/packaging or their own traditional remedies;
- last-resort patients: patients whom mainstream medical have nothing further to offer and who keep hoping for a miracle cure;
- life-stylers: customers of smart drugs, such as people who order Prozac even though they are not suffering from depression.

In a number of cases - especially in the United States - suppliers will ask for a prescription before supplying a prescription drug. The prescription will generally be obtainable from a cyber-doctor (working for the supplier). After a questionnaire has been completed a prescription will be provided, generally in return for payment. It can therefore happen that a doctor prescribes drugs on the Internet without ever having physically seen the patient. Not just the delivery of products (drugs, vitamins, self-testing kits, appliances and so on) but also the delivery of services is likely to expand. This includes the treatment of psychological problems, diagnosis at a distance (on the basis of material supplied by the consumer or otherwise) and so forth. The consumer/patient will need to deal sensibly with these new opportunities. Other actors will need to make efforts in order to ensure that incorrect use of the Internet does not result in loss of health.
A pessimistic view
The citizen/consumer/patient does not know that
the Internet exists. Where they do, they lack
access. Where they do have access, they lack the
skills to handle the Internet. Where they do have
the skills, the information they want is not
available on the Internet. If the information is
available on the Internet they are unable to find it.
If the information can be found, it proves to be
unreliable. If the information is reliable, it is then
interpreted incorrectly. If the information is
correctly interpreted, the individual concerned will
then act unadvisedly and will decide to take Viagra
ordered abroad on the Internet without consulting
his doctor. The individual concerned suffers from
heart complaints, for which he takes Nitrovate. He
receives and takes Viagra. The individual
concerned is ‘lucky’: he does not die but ends up in
hospital.

3.7 Possible solutions
If the problems referred to in section 3.6 are reduced or
resolved, the opportunities afforded by the Internet are
enhanced and the threats limited.

Access to the Internet
Important factors in this regard are technology, awareness and
education, and affordability. Technological developments will
ensure that the Internet becomes faster and so offers greater
opportunities for moving images and sound. Whereas now
computers are still generally operated by means of a keyboard,
voice-activation will become possible in due course. Activities
being conducted in the United States (funded by the Federal
Government or otherwise), the incentive programmes
operating in the EU and market forces render it unnecessary
for this subject to be examined in this report. Technological
progress will enable certain target groups, such as the illiterate,
to be served more effectively. Education is important in terms
of awareness (for example, the issue of dealing with health
information, obtained on the Internet or otherwise, needs to
form part of ‘care’ as a subject); awareness also needs to form
part of the follow-up training for professional practitioners
(for example how to deal with patients who visit their doctor

The Patient and the Internet  26
armed with information obtained on the Internet needs to form part of medical/paramedical training).
In addition it is important for elderly people to be made aware of the possibilities afforded by the Internet and to try and reduce any computer-inhibitions. Access to the Internet must in principle be available where required. People will of course need the necessary skills but, if certain groups in society are unable to afford access to the Internet, they should not be excluded from that medium. In that case the government has a duty to find a solution.

Existence of relevant information
Every actor (the government, institution, insurer, professional organisation, professional practitioner, or patient association, etc.) is required to inform the citizen/consumer/patient properly about the way in which they handle their tasks. In many cases multiple actors will be involved in the handling of certain tasks. The quality of professional practice will for example be primarily of relevance for the care-provider and the patient. In such a case a natural partnership arises in which both parties jointly provide adequate information. If they fail to do so, third parties will emerge and offer information on the Internet. This may result in less or unreliable information, with adverse consequences for both parties (in this case the care-provider and patient). If information of relevance for the citizen/consumer/patient is lacking, it is primarily the task of the actor carrying out the activity which the information relates to provide such information. Making the information available on the Internet accessible along straightforwardly structured lines goes one step further again. Making such arrangements is a matter for nation-wide organisations, including the national government.

Dealing with information and communication
There are various ways of ensuring that citizens/consumers/patients deal sensibly with information obtained on the Internet. These are:

a. Information: provision of information to those concerned so that they are able to recognise and use the possibilities and limitations of the Internet more effectively. They must be provided with the necessary means for assessing the reliability of information.

b. Open a health portal: the provision by the Dutch government of a generally recognised Internet address on which reliable information is made available, with

Everyone has a right to access the Internet
Information on the Internet must be readily accessible
There are various options for helping the consumer deal effectively with information
links to sites of organisations regarded as reliable. (The 'Healthfinder' website provided by the US government is an example).

c. **Certification of websites:** the awarding of hallmarks to reliable websites (as the Consumer Association has done with its 'Webtrader' hallmark for e-commerce sites); one problem is that a certified site can and will alter its content: one of the advantages of the Internet is that information can be rapidly amended and updated.

d. **Certification of organisations or individuals providing reliable information on the Internet:** the problem here is that there are many providers, including some outside the national borders; it will not be possible to certify these, or only with great difficulty; if a provider is not certified this does not mean that its information is necessarily unreliable.

e. **Active identification:** for example by the sponsorship (by the government) of banners, linked to search engines, referring to the importance of reliable information with a link to a short list of points indicating how the information offered should be dealt with.

f. **Filtering of information:** development and provision of software with which 'unreliable' sites can be screened out means of filters); the problem here is that there must be an organisation awarding labels for reliable information; labelling calls for a major effort, meaning that only a small proportion of the information available on the Internet could be classified.

*Dealing with the supply of services and products*

Some of the procurement from abroad cannot be prevented; this applies for example to the lifestyle category. Nationally it is all but impossible to take action against the advertising and delivery of prescription drugs on the Internet if the provider is established abroad; the regulatory instruments no longer apply to this new medium.

There are various alternatives:

a. Blocking access to information on prescription drugs and the ability to order these and other risky drugs at the Dutch border. Within Europe this would be at variance with the principle of the internal market. Furthermore, many such providers are established outside Europe. Nor would blocking at the European border be a feasible option.

b. Prohibiting deliveries to suppliers offering products on the Internet at variance with Dutch legislation. This
option is not particularly realistic as it would require international agreement.

c. Pursue self-regulation at global level, for example by seeking to ensure that no treatment involving drugs is provided solely on the basis of an Internet consultation. This is strongly advocated by the American Medical Association; other national medical associations would need to fall in line. This does not eliminate the fact that there will always be individual doctors who would evade such codes of conduct.

d. Expand the investigation service (customs) in order to intercept deliveries of such drugs. This costs money. Because the harm to health that is sustained cannot generally be traced to the use of drugs ordered abroad it may be expected that this will not be assigned high priority.

e. Placing the consequences of irresponsible use of such drugs with the consumer in question; this would mean that the latter would have to bear the costs of his behaviour himself. This is ethically unacceptable (particularly in those cases where the consumer has been misled) and also difficult to enforce on account of the burden of proof. Politically this option may be regarded as unfeasible.

f. Providing information by drawing the attention of the consumer/patient to the risks associated with the use of such products and services.

g. Making it unattractive for the consumer/patient to seek his or her 'salvation' abroad. Where the wishes of the consumer/patient can be met in the Netherlands, there would be little incentive to go further afield. In the case of prescription drugs it is important that these be reimbursed in the Netherlands. Apart from a few exceptions the present insurance package provides little incentive to order prescription drugs abroad.
An optimistic vision

The consumer has access to the Internet and knows how to deal with the Internet. He has a health problem and seeks up-to-date information in order to decide whether he should consult his GP about his disorder. He finds the information he wants, thinks it is advisable to consult his GP, but is not quite sure where he stands. On the Internet he seeks advice from his GP, from the web consultant of the Medical Association or from his insurer's web consultant. He receives confirmation of the conclusion he had drawn himself and visits his GP. The latter makes the (likely) diagnosis and refers the patient to a specialist in a hospital. After examination the specialist suggests an operation to the patient. The patient is hesitant; he is afraid of the operation. The specialist asks his assistant to print out information of relevance for the patient from the hospital's Intranet and to give it to the patient. Among other things this information contains the World Wide Web address of a patients' association with an Internet support group, where experience is regularly shared on such operations.

The support group is expertly moderated, so that the specialist is sure that problems are seriously handled. The specialist has drawn the patient's attention to this support group. Back at home the patient explains his problem to the support group the very same evening. He rapidly receives a number of reactions, in which fellow-sufferers explain that they had the same problem and ultimately decided to undergo the operation. They indicate what they found difficult in reaching their decision. In retrospect they are positive about their decision, for the operation was successful. On his next visit to the specialist the patient says that he has decided to undergo the operation. In his case too the operation proves successful.
3.8 The Internet in the care society

The possibilities offered by the Internet, the opportunities and threats and a number of possible approaches for tackling identified problems were set out above. This section outlines the impact of the Internet as a frame of reference for assessing the above and recommendations are made, as discussed in the next chapter.

The Internet is a technology with a major impact. In the same way that the steam engine played an important role in the Industrial Revolution in the 19th century and the combustion engine was a major factor in the 20th century in relation to mobility, information and communication technologies - especially the Internet - and biotechnology may be expected to have a major impact on social change in the 21st century. The Council will be issuing an exploratory study on technology in the field of care in the broad sense in early 2001.

The Internet is more than just a new information medium. It is a communications network which, on account of its worldwide nature, has given rise to new phenomena. A number of these have been discussed above. A characteristic feature of the Internet is its dynamism. Much of the information included in the background study accompanying this advisory report, for example, was already dated at the point at which this study went to print. New possibilities are created every day. This means continuous change. It remains difficult if not impossible to indicate precisely how this technology will continue to develop and what the exact consequences will be.

As noted the Internet is changing the (Western) world. This also applies to healthcare. The roles and relationships between the various parties - patients/consumers, care-providers and health-insurers - will change. The patient empowerment referred to previously, which is facilitated by the Internet, will play an important role. The Internet means that patients are better informed. Patients want the best treatment. In the past they were heavily dependent on the care-provider. The latter largely determined which diagnostic investigations and treatments were carried out. The patient can now find information on the Internet concerning the diagnosis and treatment of his or her symptoms or illness. If the care-provider is unable or unwilling to provide such

ICT and biotechnology are changing society in the 21st century

The Internet is changing continuously

Relations between the care-seeker, care-provider and care-insurer will change radically
diagnosis or treatment the patient is able to find out on the Internet where this is possible. This is not confined to the Netherlands. As noted in the RVZ report on Europe and healthcare, European developments are giving the patient greater freedom of choice; they no longer need to remain confined to their national borders.

The position of the patient will change as a result of the Internet and traditional care will come under pressure. Whereas until recently the patient was at the end of the chain, in the future he or she will be at the beginning and will influence the chain. The position of care-providers, health institutions and health-insurers will consequently change markedly. The health-provider will become more of an advisor who is hired by the patient. The patient may contract elective treatment out (at European level). The care-provider will obtain the role of contractor. Examples already exist in the United States, where patients/consumers can place requests for an operation - primarily cosmetic surgery on an ‘auction site’ on the Internet where surgeons can bid. The patient selects the most attractive proposal.

The citizen/consumer/patient will increasingly bear responsibility themselves. This will have repercussions for the role of the government, including that of State supervision, which will change. Whereas this role was until recently characterised by patronage and protection of the citizen, this approach will no longer be feasible in the future. Greater freedom of choice for the patient will mean that the degree of protection which the government can offer is reduced. The government will need to adjust its ambitions in this field. In the past the government could offer the citizen maximum protection. The fact that the choices open to the consumer are no longer confined to what is on offer in the Netherlands mean that the protection can no longer extend to all the services and products that are consumed. The consumer must be aware that what is obtained outside the Netherlands is not without risk.

Precisely given a greater freedom of choice, the monitoring of quality by the Health Inspectorate, even though necessarily confined to the national borders, is vitally important.
All this has consequences for the health system in the Netherlands. The present system, based on solidarity and the regulation of supply, is coming under increasing pressure. The Council will be examining this problem in greater detail in its advisory report concerning scarcity and the personal responsibility of the citizen which is to be published in October 2000.
4 Using the Internet actively: the recommendations

Take measures to ensure that everyone who wants access to the Internet in order to obtain and exchange health information can gain such access and promote the proper use of information. That in a sentence is the message of this advisory report. That doing so in practice is not straightforward will be evident from the preceding chapter.

This provides the national government with a major opportunity to achieve what it has been calling for many years now, namely strengthening the role and personal responsibility of the patient. It must therefore now be a challenge for the government to realise what it has claimed to be pursuing for many years.

The government cannot do so alone; it also requires a positive approach and co-operation on the part of those involved in the field. In this area too the government can lead by example and needs to do so.

An indication is provided below as to what action needs to be undertaken by whom in order to arrive at the desired situation. The breakdown into clusters of problems provided in the previous chapter provides the frame of reference for doing so.

It should be noted that the use of the traditional means of communication and information transfer would be retained, at least while some of the population do not have access to the Internet or cannot handle it.

4.1 Access to the Internet

Access to the Internet needs to be realised by means of the following measures:

a. The national government needs to ensure that the education system imparts the necessary skills for dealing with the information and particularly the information obtained on the Internet. In the case of children of school-age, for example, this means that dealing with health information should form part of the teaching of

The government must seize the chance to strengthen the position of patients

Improve access to the Internet
‘care’. In the case of care-providers this means that dealing with patients who visit their doctor armed with the information needs to form part of medical/paramedical training/further training. For the elderly the existing range of courses needs to intensified.

b. The government and parties in the field must take efforts to make the elderly aware of the opportunities provided by the Internet and to reduce computer-inhibitions. Government support should be provided for organisations involved in such activities, for example the provision of Internet training for the elderly.

c. Municipalities should provide their citizens with the possibility of obtaining health information on the Internet. They could do so by providing separate access to the Internet for those unable to afford such access themselves. The national government should encourage failing municipalities to do so by means of financial instruments, such as a bonus/penalty scheme.

d. The national government, municipalities and health institutions should jointly ensure that people in residential care have access to the Internet. Sheltered housing facilities, homes for the elderly and nursing homes can do this by providing ‘Cybercafés’, where residents can use the Internet free of charge.

e. Health institutions such as hospitals need to provide an Internet connection at information counters for patients and patient advisory centres, so that up-to-date electronic files can be consulted and up-to-date, customised information can be printed out for patients, while links need to be provided to patient associations. This also applies in principle to waiting rooms in outpatient clinics, where the staff can provide the patient with customised, written information drawn from the intranet/Internet.

f. In so far as this is not regulated by the ‘free market’ itself, the state government needs to promote the competition between Internet providers and between telephone and cable companies in order to minimise the cost to the consumer/patient. There is an important task here for the OPTA and the Dutch Competition Authority.
4.2 Availability of relevant information

Information of relevance to the patient needs to be available on the Internet. The latter already contains a great deal of information, for example on health, health promotion and disease. For certain information, an extra effort is required to provide this on the Internet as well. Examples are listed below.

a. Care-providers and institutions must provide information of relevance to the patient on their own organisation/practice (accessibility and so on).

b. In consultation with patient associations, scientific associations of care-providers need to provide information on new and existing treatments, relevant research and the risks associated with such treatment.

c. A public/private partnership of government, care-providers and patient associations, organised for example through the CBO, should make guidelines and protocols for the treatment of sickness on the Internet accessible for all, i.e. also – in comprehensible language - for consumers, along the lines in the United States and Canada.

d. Organisations of professional practitioners should provide information in consultation with patient associations on the quality of care. If necessary a public/private partnership of government and parties in the field should take responsibility for this. In this regard the inspection services should provide relevant information for patients on the quality of care.

e. Patient associations and organisations of professional practitioners should draw up public codes of conduct for themselves in order to safeguard their independent position vis-à-vis the financiers of their websites in terms of the information made available on those sites. The observance of such codes of conduct should be one of the preconditions for inclusion as a reliable organisation in a health portal (see below).

It is not just important for the information to be available on the Internet. The information must be readily accessible. This will require the following.

a. The national government should itself or by means of public/private partnership set-up a Dutch-language health portal where reliable information is provided,
with links to the sites of organisations regarded as reliable.

b. The national government should promote this health portal in the media, for example by broadcasting a TV commercial referring people to the name of the website on which information on health can be found. The government should set up an electronic care 'finder', helping people to find their way through the currently unfathomable maze of existing care facilities and services on the Internet, so that they can rapidly find out what facilities are available in the field of care, housing, employment and training and the conditions on which these can be taken up. The Government Counter 2000 project provides an initial step in this direction.

d. Care-providers, patients, health insurers and industry need to co-operate in creating access to information for certain target groups. The Internet 'rheumatism village' and 'diabetes house' are examples. In order to prevent a conflict of interest, a code of conduct needs to be adopted in order to prevent undesired marketing activities.

e. Encouragement of projects aimed at the presentation of relevant health/healthcare information on the Internet to specific patient groups (for example the blind and partially sighted).

f. Responding to the emergence of new possibilities on the Internet, making use of moving images and sound in order to transfer information, for example members of ethnic minorities and illiterate people.

4.3 Dealing with information and communication

It is important for citizens/consumers/patients to deal correctly with the information they obtain on the Internet. This could be encouraged as follows:

a. The actors concerned should all provide information so that Internet users are able to identify and use the possibilities and limitations of the Internet more effectively. They must be provided with means for assessing the reliability of information.

b. The government must actively stress the importance of reliable information. One way of doing so would be to sponsor banners linked to search engines. These banners would need to point to the importance of reliable information and to provide a link to a short list of
points, indicating how the information on offer should be dealt with.

c. The government must ensure that reliable information currently available on other media (for a limited public) - such as the information assembled by the NIZW and provided for example on CD-ROM - is also available on the Internet.

d. Professional practitioner organisations should have web consultants to whom citizens/patients can pose questions concerning health and healthcare, especially the way in which they should deal with information on the Internet. The net-doctor for 12-18-year-olds appointed by the Royal Dutch Medical Association (KNMG) is a good initiative in this regard.

e. If patient associations and professional practitioner organisations consider that the certification of websites in specialist healthcare offers added value they should arrange this jointly, as a form of self-regulation; there is no task here for the government.

f. Insurers should provide an e-mail advisory address from which their policy-holders can obtain advice on health promotion and on decisions as to whether or not to seek medical help, with a view to preventing consumers from seeking medical help too late or unnecessarily.

g. In consultation with organisations of care-providers and patient associations the national government should create a facility where consumers can file complaints concerning the provision of healthcare information, products and services on the Internet. On the basis of this 'cyberwatch' the governments can undertake action, for example by warning consumers. (In the case of complaints about the Internet information supplied by mainstream organisations with customer complaint schemes, the complainant can of course turn primarily to that organisation.)

4.4 Dealing with the supply of services and products

The set of instruments used in the past for supervision and enforcement by the Health Inspectorate is at risk of losing effectiveness. In order to achieve the objectives pursued by the government in the field of health promotion and the prevention of unnecessary harm to health, the following measures need to be taken:
a. The government and other actors must provide information to citizens/consumers/patients concerning the risks associated with obtaining services and products on the Internet. Among other things the government can achieve this by setting up a health portal and by sponsoring banners, linked to search engines, indicating the health risks attached to (for example) the ordering of drugs abroad.

b. All actors must respond to the wishes of those concerned by offering facilities meeting their needs. This means for example that doctors should also be accessible via the Internet.

c. In its decision to include new prescription drugs in the insured package and remove existing drugs from the package and to demand additional payment, the national government should take into consideration that such measures may encourage patients to order such drugs more cheaply and uncontrolled abroad.

4.5 Action plan

This section sets out the activities to be undertaken by each of the actors, in order of importance. The measures proposed in this action plan need to be realised within two to three years.

National government (Ministry of Health, Welfare and Sports)

1. Set up a health portal either independently or by means of a public/private partnership, on which reliable information is provided and enquirers are referred to the sites of organisations that are deemed reliable. The initiatives taken by the national government to set up a 'digital care meeting place' and the compilation of an 'electronic care atlas' provide a good basis.

2. Promote the importance of dealing properly with information obtained by the Internet and - in this context - promote the health portal in the media (radio, television and newspapers).

   Use this health portal and other media to provide warnings about obtaining healthcare products and services on the Internet.

3. Encourage those responsible for the Government Counter 2000 project rapidly to set up an electronic knowledge system, also known as a healthcare finder or social map (i.e. a structured survey of knowledge and
facilities in the field of care, housing, employment and education of relevance for people with a disorder or handicap indicating how and under what conditions these can be used). A link to the care-finder should be provided on the health portal.

4. In consultation with organisations of care-providers and patients set up a facility for the submission of complaints concerning the provision of healthcare information, products and services on the Internet on the basis of which the necessary action can be taken.

5. Funding/co-funding of projects aimed at the presentation of relevant healthcare information for specific ('orphan') patient and population groups.

6. Encourage and facilitate healthcare institutions and individual professional practitioners to make relevant information on their own institutions/practice available on the Internet and to provide patients with the possibility of communicating with them on the Internet (for example by introducing a financial scheme for professional practitioners analogous to the implementation of GP information systems).

7. Encourage organisations in the field to conduct research and development in this area, e.g. through participation in projects financed at European level.

Funds will need to be released for these activities. The cost level will of course depend on the method of implementation.

Organisations of care-providers
1. Encourage their members to have an Internet site and be accessible for their patients by e-mail.

2. Set-up a web consultant facility to which citizens/patients can pose questions concerning health and healthcare and, in particular, the way in which they should deal with information they have found on the Internet.

3. In consultation with the national government and patient organisations set up a facility for the submission of complaints concerning the provision of healthcare information, products and services on the Internet.

4. In consultation with patient associations provide information on the World Wide Web concerning existing and new treatments, research into such treatments and the relevant risks.

5. In consultation with the national government and patient associations, place guidelines and protocols for
the treatment of disease on the Internet, in language that
the consumers can understand.
6. In consultation with patient associations provide
information on the quality of care.
7. Draw up public codes of conduct in order to guarantee
an independent position in relation to financiers of their
websites as regards the information provided on those
sites.

In respect of a number of these activities, especially those
referred to in points 2, 4 and 5, the lead needs to be taken by
the scientific associations.

Care-providers
1. In so far as this has not yet been realised, establish an
Internet connection and enable patients to communicate
by e-mail.
2. Provide relevant information for the patient on the
World Wide Web on the practice in question
(accessibility, etc.). The implementation of such
activities needs to be co-ordinated along the lines of GP
information systems (as handled at the time by the
WCIA).

Healthcare institutions
1. Provide relevant information for the patient on the
institution in question (accessibility, etc.).
2. Set up Internet counters linked to information counters
for patients/patient information and advice bureaus (e.g.
in hospitals).
3. Guarantee access to the Internet for patients in
residential care, for example by setting up Cybercafés.

Patient associations
1. Create a website (where not yet done) with which
reliable information on the domain in question is
provided, with links to reliable sites with information on
existing and new treatments, on relevant research and on
the risks associated with the treatment (in consultation
with care-provider associations).
2. Draw up public codes of conduct in order to guarantee
an independent position in relation to financiers of their
websites as regards the information provided on those
sites.
3. In consultation with the national government and
patient organisations set up a facility for the filing of
complaints concerning the provision of healthcares
information, products and services on the Internet.

4. In consultation with the national government and organisations of care-providers, place guidelines and protocols for the treatment of disease on the Internet, in language that consumers can understand.

5. In consultation with organisations of care-providers providing information on the quality of the care.

Health insurers

1. Provide an e-mail consultancy service from which their policy-holders can obtain advice on health promotion and on whether or not to take a decision to seek medical help, in order to prevent consumers from seeking medical help too late or unnecessarily.

2. Make information of relevance to the patient available on the Internet, such as the full policy terms, premiums, information on contracting policy and the results thereof (e.g. contracted parties), waiting lists, etc.

National government (Ministry of Education, Culture and Science)

1. Impart Internet skills and the ability to use information obtained on the Internet discerningly at both primary and secondary level.

2. Ensure that training courses for professional practitioners in the health field, including university courses, pay sufficient attention to communication with consumers/patients on the use of information obtained by them on the Internet.

3. Encourage this type of further training in postgraduate courses.

Municipal authorities

1. Provide access to the Internet elsewhere for citizens who do not have independent access to the Internet (e.g. for financial reasons), for example by:
   - Providing free access to the Internet for people who have wholly or partly left the labour system, for example in libraries (in the same way that the borrowing of books is free for people aged under 18).
   - Provide free access to the Internet for people on low incomes and drawing benefits, for example in libraries.
   - Set-up Cybercafés in community centres and youth clubs.
   - Ensure that there are sufficient technical facilities for access to the Internet so that everyone can in fact be connected.
2. Co-finance Internet use courses for disadvantaged groups, such as the elderly.

Council of Health and Social Services,

[Signature]

Prof. drs. J. van Londen

[Signature]

Secretary general

[Signature]

Drs. P. Vos
ANNEXES
Annex 1

Composition of the Council of Health and Social Services

Chairman
Prof. drs. J. van Londen

Members
Ms. prof. dr. I.D. de Beaufort
Drs. J. C. Blankert
Ms. M.J.M. le Grand-van den Bogaard
Prof. dr. T.E.D. van der Grinten
Ms. prof. dr. J.P. Holm MD
Ms. J.M.G. Lanphen MD
Drs. E.H.T.M. Nijpels

Secretary general
Drs. P. Vos
Annex 2

Preparation of report by the Council of Health and Social Services (RVZ)

Members of the Council
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Drs. E.H.T.M. Nijpels

Project Team
Drs. A.J.G. van Rijen, project-leader
Ms. mr. M.W. de Lint
Drs. L. Ottes, arts
Ms. O.L. Klijn, project-assistant
Annex 3

List of participants in the workshops on 24 and 26 August and 2 September 1999

Drs. R.B.M.R. Bakker  
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M. Butcher  
*The Big Picture*

K. Deijl  
*N.V. Organon*

M.J. Dubbeling, apotheker  
Centrale Apotheek

Drs. A.R. Esch MD  
*Landelijke Huisartsen Vereniging*

J.B. Goutier MD  
*Schoonhoven*

Dr. M. ten Ham  
*Ministerie van Volksgezondheid, Welzijn en Sport*

Dr. E.R. Heerdink  
*Universiteit Utrecht*

J. van der Heijden  
*Cystic Fibrosis Stichting*

C.A.Th. Janssen  
*Pfizer*

J. Kingma MD  
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J. Langenberg
HIV Vereniging

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College ter Beoordeling van Geneesmiddelen

J. Meutgeert
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J. van de Pavert
Spring Communicatie

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Acacia Service Apotheek

E. Rozenbaum
HIV Vereniging

Dr. C.G. van Schagen
Glaxo Wellcome BV

Dr. J.W. van der Slikke, gynaecoloog
Ziekenhuis De Heel

E. van Stokkom
Asthma Fonds

A. Visser
Cystic Fibrosis Stichting

Drs. P.H. Vree
Staatstoezicht op de Volksgezondheid

Ms. drs. A.M. Willems
Consumentenbond
Annex 4

Dutch experts who participated in the patient associations survey

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization and Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Astrid Beenakker</td>
<td>Nationale Vereniging Sjogren patiënten</td>
</tr>
<tr>
<td>Annet van Betuw</td>
<td>European Chromosome 11q Network</td>
</tr>
<tr>
<td>Johan Beun</td>
<td>Nederlandse Vereniging voor Addison &amp; Cushing Patiënten</td>
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<tr>
<td>Gerard Boekhoff</td>
<td>Nierpatiëntenvereniging</td>
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<td>Liesbeth de Boer</td>
<td>Osteoporose Stichting</td>
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<td>Arnold Brabander</td>
<td>Vereniging van familieleden van schizofrene en chronisch psychotische mensen</td>
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<td>Marlies Burghouwt</td>
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<td>Hans Eijsackers</td>
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<td>Lex van der Heijden</td>
<td>Vereniging voor mensen met het Van Lohuizen Syndroom</td>
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<td>Elisabeth Venselaar</td>
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<tr>
<td>Arian Visser</td>
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