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## Consultation on the Development of Patients' rights in Europe

Report on a WHO Meeting

Gothenburg, Sweden  
18-19 August 1997

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### HEALTH AND ETHICS

*By the year 2000, all Member States should have mechanisms in place to strengthen ethical considerations in decisions relating to the health of individuals, groups and populations.*

#### ABSTRACT

An extensive and powerful movement for patients' rights and citizens' empowerment has emerged in the European Region. One of the fundamental challenges is to understand that citizens' participation in the planning and management of their own health care services is critical.

The consultation established a network on patients' rights and citizens' empowerment lead by the WHO Regional Office for Europe, and decided that the network would meet yearly to debate developments in the field of patient's rights.

#### Keywords

PATIENT ADVOCACY – trends  
HEALTH CARE REFORM  
EUROPE

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## **Consultation on the development of patients' rights in Europe Gothenburg, Sweden, 18-19 August 1997**

### **Introduction**

The Consultation on the development of patients' rights in Europe was organized by the WHO Regional Office for Europe in collaboration with the Nordic School of Public Health in Gothenburg, which hosted the meeting. It was attended by participants from Bulgaria, Estonia, Hungary, Finland, Iceland, Israel, Netherlands, Norway, the Russian Federation, Sweden, and the United Kingdom. The following organizations were represented at the consultation: the Council of Europe, Public Services International, the Swedish Association of Health Officers, and the Swedish Medical Association.

The meeting was opened by Dr. Mikko Vienonen, Regional Adviser for Health Services Management on behalf of the Regional Director for Europe and by Mr Lars Fallberg from the Nordic School of Public Health. Dr Vienonen and Mr Fallberg were elected as Chairpersons of the meeting and Dr Iliev as Rapporteur.

### **Scope and purpose**

Since the late 1980s an extensive and powerful movement for health care reform has emerged in Europe and elsewhere, as part of a broader process of change. One of the fundamental challenges is to understand that citizens' participation in the planning and management of their own health care services is critical when it comes to setting up services which meet the needs of the actual consumers. In the same way when it comes to the actual delivery of health care services, patients must be entitled to human rights and values, to essential information, to their consent, to confidentiality and privacy, and to appropriate care and treatment. Patients' rights and citizens' choice are issues which need to be taken into consideration whenever the health care system is under reform.

The WHO European Consultation on Patients' Rights, Amsterdam 1994, endorsed the *Declaration on the Promotion of Patients' Rights in Europe*, setting the principles for the implementation of patients' rights in WHO's European Member States. The meeting gave detailed consideration to a wide range of possible strategies. The WHO Conference on European Health Care Reforms, Ljubljana 1996, endorsed the *Ljubljana Charter on Reforming Health Care*. This document further elaborates the concept of patients' rights and citizens views by stating as one of its fundamental principles that health care reforms must address citizens' needs taking into account, through the democratic process, their expectations about health and health care. They should ensure that the citizens' voice and choice decisively influence the way health services are designed and operate.

Furthermore, the Ljubljana Charter in the principles for managing change, says that the citizen's voice and choice should make as significant a contribution to shaping health care services as the decisions taken at other levels of economic, managerial, and professional decision-making. The citizen's voice should be heard on the issues such as the content of health care, the management of waiting lists and the handling of complaints. The exercise of choice and of other patients' rights, requires extensive, accurate and timely information and education entailing access to publicly verified information on health services performance.

The conclusions and recommendations presented in the Ljubljana Charter were based on wide consultation and work of experts and published as *European Health Care Reforms: Analysis of Current Strategies* (preliminary version June 1996; final publication April 1997) and in the book *European Health Care Reforms: Citizens' Choice and Patients' Rights*.

The WHO Regional Office for Europe Action Plan for the support of health care reforms is supported by four main pillars:

- 1) setting up a health care reform observatory/clearing house to follow up, analyze and report on the European development;
- 2) studying the impact on selected priority issues (patients' rights and citizens' views included);
- 3) setting up networks between countries, organizations, institutions, experts, etc. to find new solutions and disseminate information; and
- 4) doing specific development work in the Member States.

Following the valuable work already made in the field of patients' rights and citizens' views on health care, the WHO Regional Office for Europe calls for the start of a new phase in this important work. We aim to set up a Network for the promotion of patients' rights and the Nordic School of Public Health in Gothenburg, Sweden, has agreed to host its initial meeting. Experts who have previously assisted WHO in this field and participants from countries where patients' rights have been actively promoted will be invited to this workshop.

The purpose of the meeting was to:

- review shortly the development of the patients' rights movement in Europe;
- discuss the need for a WHO Network for the promotion of patients' rights in Europe and, if considered feasible, to establish this network proposing terms of reference and an action plan for its future operation;
- elaborate on how patients' rights develop in European Member States, and to set up a regular monitoring mechanisms to follow it up;
- discuss the content of a possible manual/tool kit for governments, organizations and individual citizens to enhance the promotion of patients rights in countries. Some country examples are used as thought provoking examples;
- identify the priority issues that a WHO network for the promotion of patients' rights in Europe should focus and elaborate on;
- discuss the need and possibility of organizing a new Europe-wide Consultation on Patients' Rights, following the example of Amsterdam in 1994;

The workshop was informal and interactive. The work consisted of short introductory presentations, group work and concluding panel discussions. The workshop was scheduled for two full working days and the working language was English without interpretation into other languages.

## Patients' rights at European level

### Activities of the WHO Regional Office for Europe

Recent developments in the area of patients' rights show the increasing consideration being given to this issue by national legislators, international organizations and the public in general. The World Health Organization, Regional Office for Europe has developed a systematic approach to the issue of patients' rights and conveyed two important events for debating it:

#### Amsterdam Consultation on patients' rights (March 1994)

A European consultation on the rights of patients was held in Amsterdam in March 1994. The consultation endorsed the principle of the rights of patients in Europe, which sets the framework for developing patients' rights at the level of their daily lives. Amsterdam was an important landmark within the landscape of patients' rights movement in Europe. European countries have highlighted several strategies for promoting patients' rights and underlined their willingness to support the promotion of patients' rights across Europe. The Amsterdam Declaration on the Promotion of Patients' Rights in Europe reflects the consensus on how to strength the rights of patients.

The Regional Office has published in collaboration with the Kluwer Law and Taxation Publishers two publications on patients' rights as part of the activities carried out for the Amsterdam consultation: (1) *Promotion of the Rights of Patients in Europe (1993)*, and (2) *The Rights of Patients in Europe: A comparative study (1995)*<sup>1</sup>. Both studies became important references for people interested in patients' rights. However, their costs and limited diffusion make them difficult to obtain.

#### The Ljubljana Conference on European health care reforms (June 1996)

In June 1996, the WHO Regional Office for Europe held a conference on European Health care reforms in Ljubljana, Slovenia. One of the issues debated at this conference was citizens' choice and patients' rights in the context of health care reforms. A review analyzing the trends in and prospects for the development of patients' rights in Europe was published as part of the background documentation of the conference. The Ljubljana Charter on Reforming Health Care in Europe, endorsed at the conference, views patients' rights as a basic element of any health care reform process (Annex). Furthermore, the Charter emphasizes the need for health care systems which focuses on people and allows the "citizens' voice and choice to influence the way in which health services are designed and operate". It sends a global message about how health care reform should be performed from people's point of view.

The Conference offered a platform for lively debate. The issue of patients' rights, although debated in Ljubljana, was overwhelmed by issues such as financing of health care services, health care management and administration. Citizens are, however, the ultimate payers of any health care services they receive, and therefore they should be aware of their rights. The analysis of the current state of affairs reveals that patients' views are not fully acknowledged by the providers of health

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<sup>1</sup> WHO, Regional Office for Europe *Promotion of the Rights of Patients in Europe*. Kluwer Law International, The Hague/London/Boston (1993).

Leenen, H. Gevers, S. Pinet, G. *The Rights of Patients in Europe: A comparative study*, Kluwer Law and Taxation Publishers, Deventer/Boston (1995)

care services. This is due to the lack of knowledge and awareness of their rights. Therefore an expert network on patients' rights has to take up the issue further and elaborate on how health care services could take into consideration the point of view of the rights of patients.

## Activities of the WHO Headquarters in Geneva

WHO Headquarters in Geneva have set up:

1. A steering Group on ethics and Health (Dr Hu Ching-Li) working on:

- cloning;
- reproductive health;
- biologicals;
- xenotransplantation
- medical genetics

2. Health Policy in Development: Human Rights and Health (Dr Aleya El Bindari Hammad)

Regional Adviser Dr Mikko Vienonen (WHO-EURO) has been nominated as the focal point for both of these working groups linking the activities of patients' rights on the European level to these programmes.

## Activities of the Council of Europe

Protecting fundamental economic and social rights is a task of the Council of Europe achieved through the European Social Charter. *Inter alia*, the Charter lays down the right to protection of health, the rights to social security, the right to social and medical assistance, and the right to benefit from social welfare services.

Further to the activities carried out by WHO, the Council of Europe has debated the issue of patients' rights and equity in health at the fifth conference of health ministers held in Warsaw in November 1996. The final text adopted at the Warsaw conference states:

*"A new social deal should therefore ensure that equity and patients' rights issues become an integral part of health care systems and address a number of important issues at the patients' level, at the level of health care delivery as well as at the governmental level: a tripartite social deal between patients, providers and payers."*

The Conference has invited the Council of Europe to build up a network for an exchange of information between member states on patients' rights and participation, the role of lay persons in promoting health in their own environment, the exclusion of certain groups of patients, in particular the chronically-ill and people with disabilities from society, and the involvement of the scientific community in setting effective treatment and procedures.

In November 1996 the Committees of Ministers of the Council of Europe adopted the Convention on Human Rights and Biomedicine. The Convention is the first internationally binding legal text addressing bioethical issues and will have a clear impact over the health legislation in the member states of the Council of Europe. In January 1997 the Council of Europe Health and Social Policy

Division convened the first meeting of the coordinated research group on the development of structures for patient/citizens' participation in the decision-making process affecting health care. It was set up by the Council of Europe European Health Committee for preparing a study concerned with the development of institutional structures for democratic citizens' and patients' participation in the decision-making process affecting health care. The next meeting of the above mentioned group is scheduled for 4-5 March 1998 in Strasbourg.

Finally, the Committee of Ministers adopted on 13 February 1997 a recommendation No. R (97) 5 on the protection of medical data.

Dr Piotr Mierzewski from the Council of Europe Health and Social Policy Division said that the link of patients' rights programme of WHO with the European Health Committee (CDSP) would be most welcome. Usually Dr Richard Alderslade from WHO- EURO Coordination and Humanitarian Assistance (COR) unit has represented EURO, but perhaps sometimes the responsible adviser for patients' rights (Dr Mikko Vienonen) could attend the meetings as well. In any case, collaboration with the above mentioned ad hoc network of the Council of Europe would be most welcome.

The WHO and the Council of Europe share common concerns as regards to patients rights. Both organizations might benefit from a co-ordinated collaboration in that area avoiding duplication of work and insisting on shared values. The Council is organizing in 1999 a ministerial conference on patients' rights, elderly and Health in Kos, Greece in which WHO will have an important input.

### **Activities of the European Union**

The activities carried out by the European Union in the area of patients' rights could not be presented, due to the absence of representatives of the EU.

It was recommended that renewed effort should be made in order to establish good working relations with the EU DG XXIV (Mr Jens Ring) dealing with consumer issues including the health care services consumers (the patients).

## **Patients' rights on the European scene today**

### **Citizens and patients: who represent them and how?**

In the discourse relevant to patients' rights and citizens' empowerment, the use of the words *citizens* and *patients* need to be clarified: what makes the difference between citizens and patients? In which circumstances a citizen becomes a patient? How to define a patient and to what extent his/her choice matters more than the health care services he/she receives? In some countries patients value more the fact that they are taken care of rather than the freedom of choice they have.

Patients are reliant on the health care system and health care professionals and therefore vulnerable, they may not express their views and opinions regarding the health care they need and receive. Furthermore they have little knowledge about their health status and health risks. Patients are likely to organize themselves in groups in order to bring about desired consequences. Some patient groups are more active and use the influence they have in a more effective way. The question is then how to ensure that all expressed views are equally taken into account? This might cast a shadow on other less visible group of patients.

Patients' satisfaction studies are a tool for taking into account patients' views and listening to their voice. However, studies focused on patients' satisfaction have two serious methodological problems:

- the measurement of patients' satisfaction is subject to continued methodological debate and is far from an exact science. Indeed, many instruments tend routinely to produce high levels of reported satisfaction – such results, when considered in isolation, may therefore be of limited use to health care professionals, patients and researchers;
- the measurement of "satisfaction" does not always encompass the sometimes very different components of a patient's experience and personal background that influence reported satisfaction and dissatisfaction.

Improving the asymmetry inherent to the health sector requires to educate patients to become more aware of their rights and especially working with the chronically ill patients. In the Netherlands many organizations of the chronically ill patients play an important role in educating their members. Moreover, patients in this country take an active role in deciding what are the best options for their treatment.

### **Directions for the Promotion of Patients' Rights**

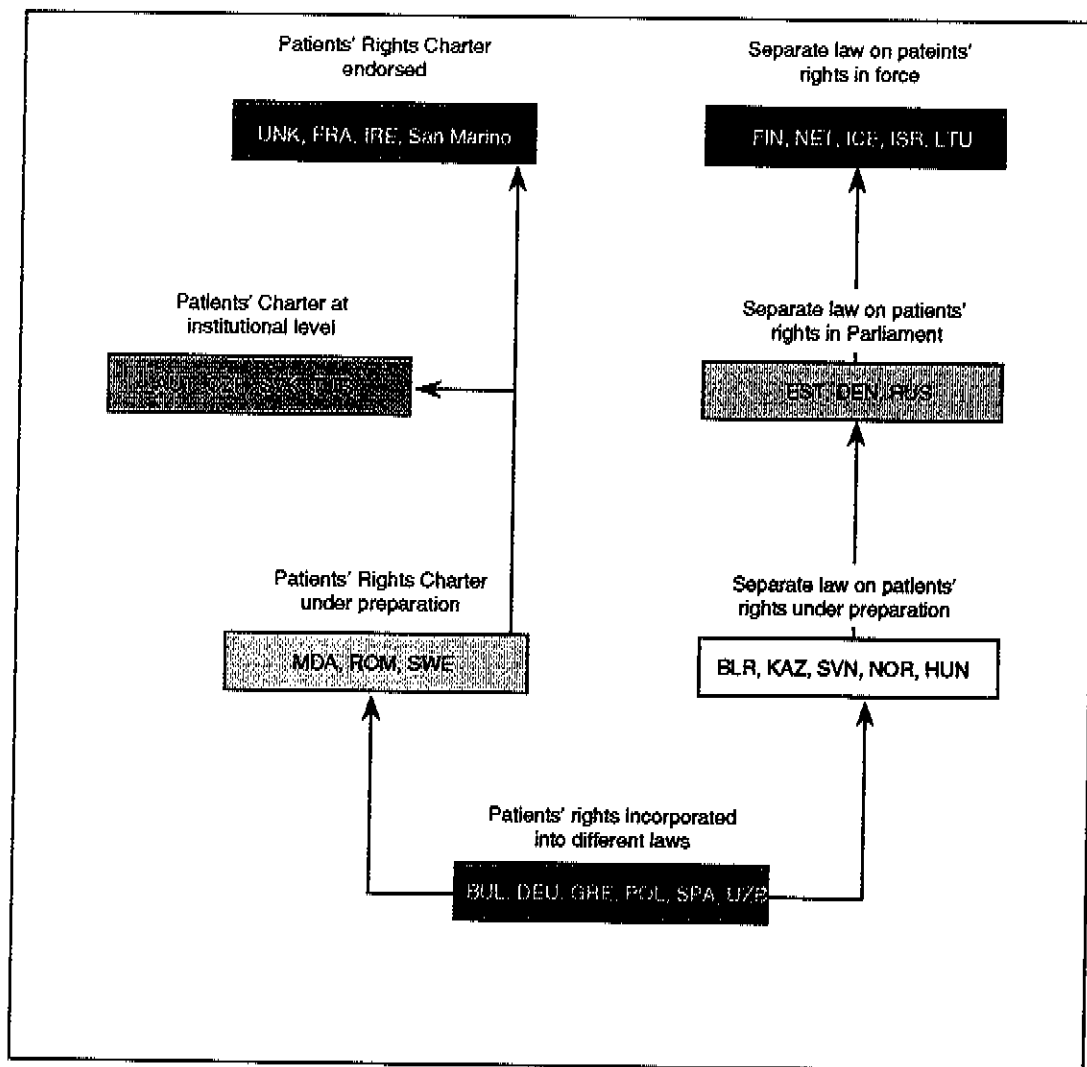
European countries have moved towards elaborating or implementing patients' rights legislation (Fig. 1). In this view it is important to know what constitutes a law on patients' rights, what is the appropriate role of a charter on patients' rights and which should be the components of a good law or charter in this matter. The pattern viewing patients' rights' developments as presented in Figure 1 was considered appropriate by the meeting participants.

In **Denmark** a patients' rights law is now being drafted. The Danish patients' organizations were involved in its preparation but they could not reach a consensus about which patients' rights should be added to the draft law.

In **Finland** one of the goals of the Finnish health policy is a greater participation of citizens in decision-making at local level. Finland enacted the *Act on the Status and Rights of Patients* in March 1993. Before that the health care legislation applied mainly to the administration of health care, provision of services and the status of health care professionals. Only a few provisions were defining the status and the rights of patients. In Finland a consensus was reached between the patients' organizations and the health professionals about the need of patients' rights legislation.

Bringing the patients' rights into one single law has proved to be a good solution. The *Act on the Status and Rights of Patients* stresses the patients' active participation, self-determination, the right of access to care and information. It lays down several other rights:

- the right of access to health care provided within the framework of society's resources;
- the right to high quality of care and good treatment;



It also prohibits discrimination in medical care and requires that patients have to be given information about their health status, illness and different treatment options in order to consent. The Act has introduced the mandatory patient ombudperson in Finland and requires that each health care unit must have a patient ombudsman.

The Finnish experience in implementing the patients' rights legislation reveals that health care professionals and patients need education about the basic provisions of the Act which has had a positive effect over the health care field and the Government considers a bill of the same type on the status of social welfare clients. The weak point is that the patients' ombudsperson is a staff member of the health care institution and is sometimes known as being on the side of the service provider

In Israel before the *Act on the Rights of Patients* entered into force, patients' rights were incorporated in different laws. The Act (1996) came as an addition to the existing legislation dealing with patients' rights. Patients in Israel have understood the law as a mechanism of protection against the medical profession instead of forming the basis of a partnership. On their side, the health professionals have sometimes felt offended and insulted by the law as it lays down the way they should act. The Israeli experience reveals that there are three important points to be taken into account :

- efforts should be targeted towards explaining to people what is the purpose of a patients' rights law;
- the media have a clear role to play in this process;
- the partnership philosophy of such a law has to be put forward

Nevertheless, the overall assessment of the patients' rights legislation in Israel has been positive.

In **Norway** a proposal for a new law on patients' rights passed through the government in August 1997, and will be submitted to public hearings. The draft law on patients' rights goes together with three other law proposals:

- Law on health personnel;
- Law on specialist health care services;
- Law on compulsion against psychiatric patients.

The draft law on patients' rights contains the first complete description of the general patients rights for all patients and all people demanding health care services. It is believed that the law will help people to know better their rights and will improve the access to health care of vulnerable patients. It lays down the right to be a patient and to receive necessary health care services under the following conditions:

- the illness must be serious;
- the actual treatment must be efficient;
- the costs of the treatment must be reasonable compared to its the benefits;

If the patients could not receive the health care they need from the public sector, they may go to the private sector or even abroad. In this case the health authorities will have to bear the costs. The draft law contains also provisions for receiving a second opinion, the right to consent to any health care, to refuse or stop life-lengthening treatment, and the right to refuse blood transfusion. According to the draft, the patients will have the right to information, choose among different treatment or examination options, and to complain. Provisions are made for introducing an ombudperson in all hospitals of the 19 counties.

In **Iceland** a new law on the rights of patients entered force on 1 July 1997. The main goal of the Icelandic legislation was to put the patients' rights previously incorporated in different pieces of legislation together in one single law.

In the preparatory process the group responsible for the drafting of the legislation, which included a representative from the Consumers' Association of Iceland, held several meetings with representatives from the numerous patients' organizations in Iceland. The purpose of these meetings was to obtain information from the patients on what they felt should be included in the law. These meetings were of great importance for the development of the work with the draft legislation.

From the outset the legislation was intended to deal mainly with individual rights of patients, such as informed consent, access to medical records and the right to complain. Consequently the patients' organizations' request of specific legal provisions on increased access to health care, priority settings and waiting lists could not be met. Nevertheless the law includes provisions stating that

patients shall be given explanation if they have to wait for a proposed medical procedure. Furthermore it states that in the cases of priority settings these shall be based on medical reasons and no others.

There is a governmental patient policy reflected in the following laws in **the Netherlands**:

- Patients' rights (*Act on medical treatment and the Medical Contract Act*);
- Complaints procedures (*Client complaint Act*);
- Empowerment (*Client participation Act* and an extensive network of patients' organizations)

*The Medical contract law* from 1995 was preceded by a series of articles in local journals and newspapers that have informed the public about the forthcoming law, its main tasks and features.

In the Netherlands there are more than 300 patients' organizations. Their activities are mainly focused on patients' education, information, sharing experience, and lobbying. At the national level, they are represented in the Federation of Patients/Consumer organization which has 4 sections:

- mentally-ill patients;
- chronically-ill patients;
- regional platforms;
- general consumer/patients' organizations,

The development of patients' rights might be driven by a major ethical concern: the lack of trust in the health care system and its professionals. In **Sweden** studies revealed that people's trust in general towards the publicly funded health care system is high. However people place more trust on health care professionals rather than on health care establishments. The lack of trust towards "faceless" institutions may be behind the desire of more rights through laws or charter of patients' rights. Thus, it may change the way patients behave: increasing or regaining back the trust in health care systems will make patients more active and interested in health related matters. Getting patients to participate in health related matters depends on the education patients have in health issues.

Despite the differences inherent to each country, there is a set of questions common to European countries engaged in the development of patients' rights:

- Is it the lack of ethical standards and trust that force countries to draft laws on patients' rights;
- How to achieve a balance between the higher public expectations and meet patients' demand for better quality of health care?;
- How to educate patients better in order to enable them in understanding the philosophy a patients' rights law?

The representative of Public Services International (PSI) has approached the issue of patients' rights from a different point of view. Patients' rights should be based on values enshrined in the Ljubljana Charter:

- human dignity;
- equity;
- solidarity; and

- professional ethics.

PSI considers the right to good health care as an essential right. Furthermore, people are entitled to accessible health care services provided to everybody in full transparency. In this connection, current trends in some central and eastern European countries (CCEE) where unofficial payments for health care are operating, may challenge the provision of health care.

There is a clear link between the rights of patients and the rights of health care professionals: e.g. the providers of health care have the right to receive their salaries in time and measures should be taken to cope with current practices in CCEE where public employees, including health care professionals, have not been paid for months. A major problem in fulfilling the rights of patients could be the lack of trust in the health care systems in CCEE. Health care professionals in these countries feel they are not involved in the ongoing health care reforms that have to change the basis of the health care systems. On the other hand, patients do not trust the quality of care they receive. Trade unions work together with their members in order to restore mutual trust and recognition.

### **Priority setting v/s patients' rights: is there any conflict?**

The discussion about the trends in patients' rights developments in Europe has revealed that the fulfillment of some social rights might be brought into question because of:

- A potential conflict between the provisions for social and resources' scarcity; and
- The priorities setting in health care services and narrowing of the basket of health care services.

A study on incorporating public views into the health services purchasing process was carried out in the **United Kingdom**. The study is mainly concerned with the involvement of patients and communities in the identification of health care priorities and it has three main objectives: (1) obtaining a regional picture of local participation initiatives, (2) identifying factors which obstruct or foster local "participation" in purchasing, and finally (3) producing "good practice guidelines".

Existing local needs and future local needs, geographical limits in purchasing services were found to be among the main factors influencing the process of health authorities taking into account the views of local people on health care priorities. The study also has found that there is a perceived need for greater provision of information to the local community and brought up the question: "*Is information provided to empower patients and local people or is it only to inform them of what the health authority has already done on their behalf?*" In a second respect, emphasis was placed on dissemination and communication between health authorities around the theme of public participation. Here the family doctors could play an important role as channels for patient views but the use of such proxies is not a substitute for direct discussion with patients and citizens.

A possible mismatch between public "perceptions of need" and "actual need" has been reported to be a reason for concern among health authorities: people's interest in health issues often does not go beyond a concern with their own experience of treatment. A more systematic approach to inform and educate the public about issues of priority setting is needed. People seem not to be willing to get involved in decision-making unless it has a direct bearing on them.

Finally, the project carried out by the University of Kent has emphasized that there is a very limited scope for radical change in health services as a result of discussing with local people. A very

technical approach to involving local people in setting health care priorities will simply miss a lot of what people can say and think about it. It is therefore also necessary to make use of qualitative approaches and ongoing formal and informal dialogue when discussing health care priorities and related matters with citizens and patients.

The Medical Associations, e.g. in Israel, report that there is an inherent conflict between patients' rights and the reality of limited resources which leads to prioritization and allocation of resources. In-practice patients and physicians are unwilling to accept the necessity of taking into account economical restraints due to the need of providing health care with limited resources and rising costs. On the other side, in some circumstances physicians will prescribe only the treatment, which is recognized by the Sickness Fund, even if it is not the best treatment for their patients.

Physicians apply prioritization by making clinical judgement. At present, it is rather difficult for any society to answer questions such as:

- Can we ethically allow prioritization/rationing?
- Should rationing be implicit or explicit?
- Who should decide on this matter?
- Should the public take an active part in the debate concerning rationing?
- What method should be used to achieve public involvement?

On the other side one of the missions of the Swedish purchased organizations is to establish priorities in health care from the point of view of the local community. Sweden has 25 County Councils that have adopted to split the purchasers and providers of health care services. However, there is no conflict between the priorities setting and the patients' rights in Sweden. Patients' rights and empowerment are way of influencing the political decision affecting health care.

The representative of the Ministry of Health from Finland has reported that over the past few years there has been more lively debate about priorities in health care than there was before. Priorities in health care have been regarded as necessary but concerns have also been expressed about certain patients or patients groups being deprived of the health care they need. Despite a special project designed to consider the priority setting in Finland, there is no method allowing to start running the process at national level.

The following conclusions have closed the debate about patients' rights and priorities setting:

- there may arise clear conflict between setting priorities and safeguarding the entitlements to care and treatment that can be inherent to the explicit rights of patients and citizens;
- narrowing the basic basket of health care services does not seem to be a suitable political solution in a number of countries;
- efforts should be targeted towards educating patients;
- the issue of priority setting should be brought into the debate with the public.

## **Towards networking for patients' rights**

The participants in the informal consultation on patients' rights have considered:

- the establishment of a network for the promotion of patients' rights supported by the WHO Regional Office for Europe and the possible main tasks to be carried out by the Network;
- the setting up of a clearing house for regular monitoring and following up of the patients' rights developments;
- the key issues to be taken up by the Network; and
- the appropriate role for the international bodies and countries.

Three working-groups were set up for discussing the above mentioned topics. Their findings were then reported and discussed (Table 1).

The discussion that followed the reports of the workgroups has pointed towards extension of the network to other potential participants:

- participants from southern European countries;
- representatives of Consumer International;
- representatives of the Red Cross.

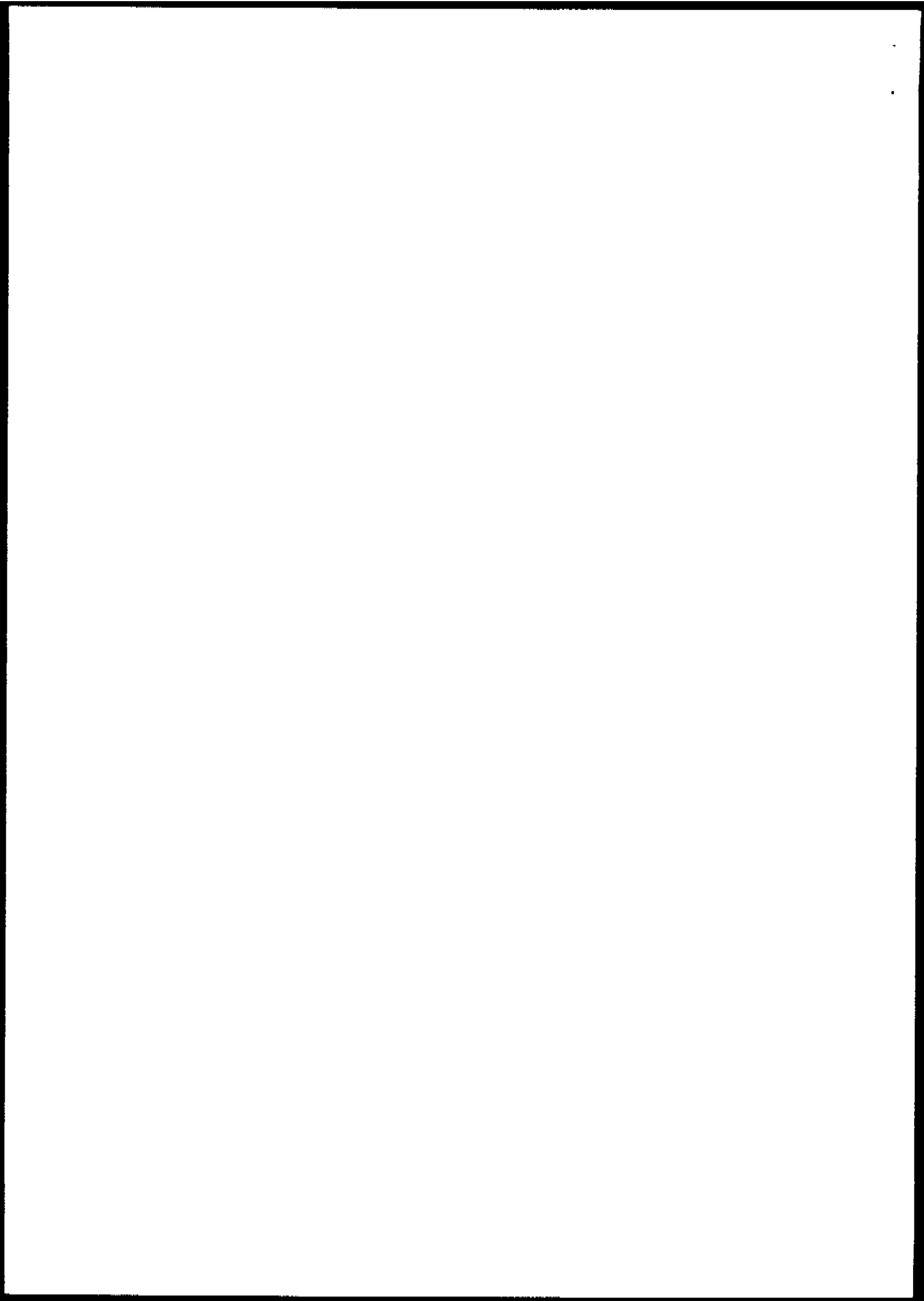
## Conclusions and recommendations

The informal consultation on the development of patients' rights in Europe held by the WHO-EURO from 18-19 August 1997 at the Nordic School of Public Health in Gothenburg is a step towards further development and promotion of patients' rights at European level. The participants have discussed the latest patients' rights developments on the European scene and have emphasized the emerging conflict between patients' rights and priority setting.

Difficulties in monitoring developments in the area of patients' rights highlight the countries need for a suitable platform to discuss, share and learn from each others experience. Three important issues have appeared during the discussions:

- efforts should be targeted towards explaining to people what is the purpose of a patients' rights law;
- the media have a clear role to play in this process;
- the partnership philosophy of such a law has to be put forward.

The informal consultation has recommended the establishment of a network on the promotion of patients' rights to which participants from the southern European countries would be invited, together with representatives from Consumer International and the Red Cross, as members of the network. The network would meet annually and ongoing activities between meetings would be setup. It was pointed out that this informal consultation is not ready to call for organizing a formal conference/consultation on patients' rights. This item should be re-examined again during the next meeting of the new network. In the mean time, the secretariats of the WHO Regional Office for Europe and the Council of Europe European Health Committee should keep contacts and update each other on their respective activities carried out in the field of patients' rights.



Consultation on the development of patients' rights in Europe

Table 1 Feedback from Workgroups

Workgroup	Network's Establishment	Clearing House	Key Issues	Role of the Organizations
<p>First working-group</p> <p>Rapporteur: Dr Paul Francissen</p>	<p>To establish a patients' rights network is an acceptable idea.</p> <p>It should include experts who are well informed, give quick answer to queries, and willing to continue participate in the Network</p> <p>WHO should set it up together with the Council of Europe and the Nordic School of Public Health</p>	<p>Clearing house needs a clear definition and well established operational level: national and international.</p> <p>The targeted Public should include patients, health authorities or other special groups (young, elderly, poor)</p> <p>The Network should meet some conditions: flexible structure, responsible officer, quick access and low costs</p>	<p>(a) <b>Information</b> at hospital level, at home, at internet</p> <p>(b) <b>Education of:</b> health care professionals during their early training; and ombudsman</p> <p>(c) <b>Monitoring of:</b> effects of patients rights; best comparative methods; feedback from the patients' satisfaction;</p> <p>(d) <b>Liability/malpractice:</b> patients' involvement; Dutch experiment with small claims (below 4000 USD)</p> <p>(e) <b>Access to health care services.</b></p>	<p>No feedback on this issue</p>
<p>Second working-group</p> <p>Rapporteur: Dr Thomas Linden</p>	<p>The Network will need facilities to communicate between meetings.</p> <p>Its main tasks should be: following up of the implementation of patients' rights; sharing experiences; keeping the process ongoing.</p> <p>Its participants have to be from different backgrounds, different countries, interested in and motivated by the Network.</p>	<p>Suitable idea</p> <p>Co-operation with the Council of Europe and the European Union</p>	<p>Setting priorities;</p> <p>Support information exchange;</p> <p>Investigating support for the Network;</p> <p>Following up of the process;</p> <p>Streamline legislation/implementation;</p> <p>Patients' education;</p> <p>Care-giver education;</p> <p>Promoting patients' rights.</p>	<p>Staff should act as Infobank;</p> <p>Watch and lead development;</p> <p>Organize network meetings;</p> <p>Avoid duplication of work.</p>

Consultation on the development of patients' rights in Europe

<p>Third working-group Rapporteur: Paul Etherington</p>	<p>The group found that a network should be established via WHO. It should include mix of patients' representatives, managers, administrators, academics and politicians. The network should not be too formal and should encourage informal contacts.</p>	<p>To be linked to the network, open to the public but with some restricted areas; To serve for exchange of information.</p>	<p>Further develop the links at country level Promote citizens' voice in policy development Platform for sharing of good practice Exchange information on innovations</p>	<p>No feedback on this issue</p>
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## **Terms of reference**

### **for a network on the promotion of patients' rights**

The World Health Organization Regional Office for Europe—Health Services Management Unit has organized an informal consultation on the development of patients' rights in Europe. The Nordic School of Public Health hosted the event in August 1997 in Gothenburg. The aim is to provide a forum for in-depth discussions about the patients' rights in Europe, identify priority issues on which a WHO network on patients' rights should focus, and consider recent developments in that area. Participants from 11 countries attended the consultation.

The participants have discussed the need of and decided to establish a Network on the promotion of patients' rights in Europe. The Network will be in charge of:

- monitoring of patients' rights developments on a regular basis;
- setting up and maintaining of an appropriate mechanism for following up, analysing, and informing the public about the evolution of patients rights. In this view, the establishment of a "clearing-house" could be an example;
- preparing a manual/tool kit for governments, organization and individual citizens to enhance the promotion of patients' rights;
- elaborating on how to enable people to better understand the philosophy beyond a patients' rights legislation and promote citizens' voice in policy development through their involvement as partners in the process of drafting laws on patients' rights;
- considering the option to organize a new Europe-wide consultation on Patients' Rights, following the example of Amsterdam in 1994;

The Network will meet once per year. The Network should include experts with different backgrounds (patients' representatives, administrators, managers, politicians, and academics) and coming from all parts of Europe. It will seek collaboration with other partners active in the patients' rights area. In this view, WHO-EURO focal point for patients' rights is invited to maintain regular contacts with the secretariat of the Council of Europe European Health Committee (CDSP) as regards activities carried out by the CDSP in the field of patients' rights. Effort should be made to invite the EU to attend the future meetings of the Network.

WHO-EURO will be in charge of organizing the meetings and will take care of their practical arrangements. Furthermore, the WHO Secretariat will provide link between meetings and distribute relevant materials to expert members to the Network.

## Provisional programme

### Sunday 17 August

Registration and get together

### Monday 18 August

Opening

Lessons from the Ljubljana Conference on European Health Care Reforms (June 1996)

*Dr Mikko Vienonen, WHO Regional Office for Europe*

Round table of the Ljubljana citizens/patients team: was the citizen/patient present in Ljubljana? Debate

The role of the council of Europe in the promotion of patients' rights

*Dr P. Mierzewski, Council of Europe*

Debate

Patients' rights on the European scene today

*Mr Lars Fallberg, Nordic School of Public health*

Debate on directions for the promotion of patients' rights in Europe

Group work on the same topic

Group work

Video presentations on issues related to patients' rights in selected countries

### Tuesday 19 August

Feedback from working groups:

- Workgroup I
- Workgroup II
- Workgroup III
- Workgroup IV

Discussion aiming at the setting up of a network and providing advice on its work plan

Patients' rights, priority setting and rationing: mission impossible?

- representative of patient organization
- representative of "purchaser" organization  
*Mr Anders Östlund, Purchaser Network, Bohus County Council, Sweden*
- representative of Medical Association  
*Ms Leah Wapner, Israel Medical Association*
- representative of Public Services International (PSI)  
*Ms Soile Tammisto, PSI Secretariat*
- representative of the Ministry of Health  
*Ms Marja-Liisa Partanen, Ministry of Social Affairs and Health of Finland*

Patients' rights, priority setting and rationing: mission impossible?

Plenary discussion and participation from the audience  
Final conclusions

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