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THE RIGHTS OF PATIENTS

Report on a WHO Consultation

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ABSTRACT

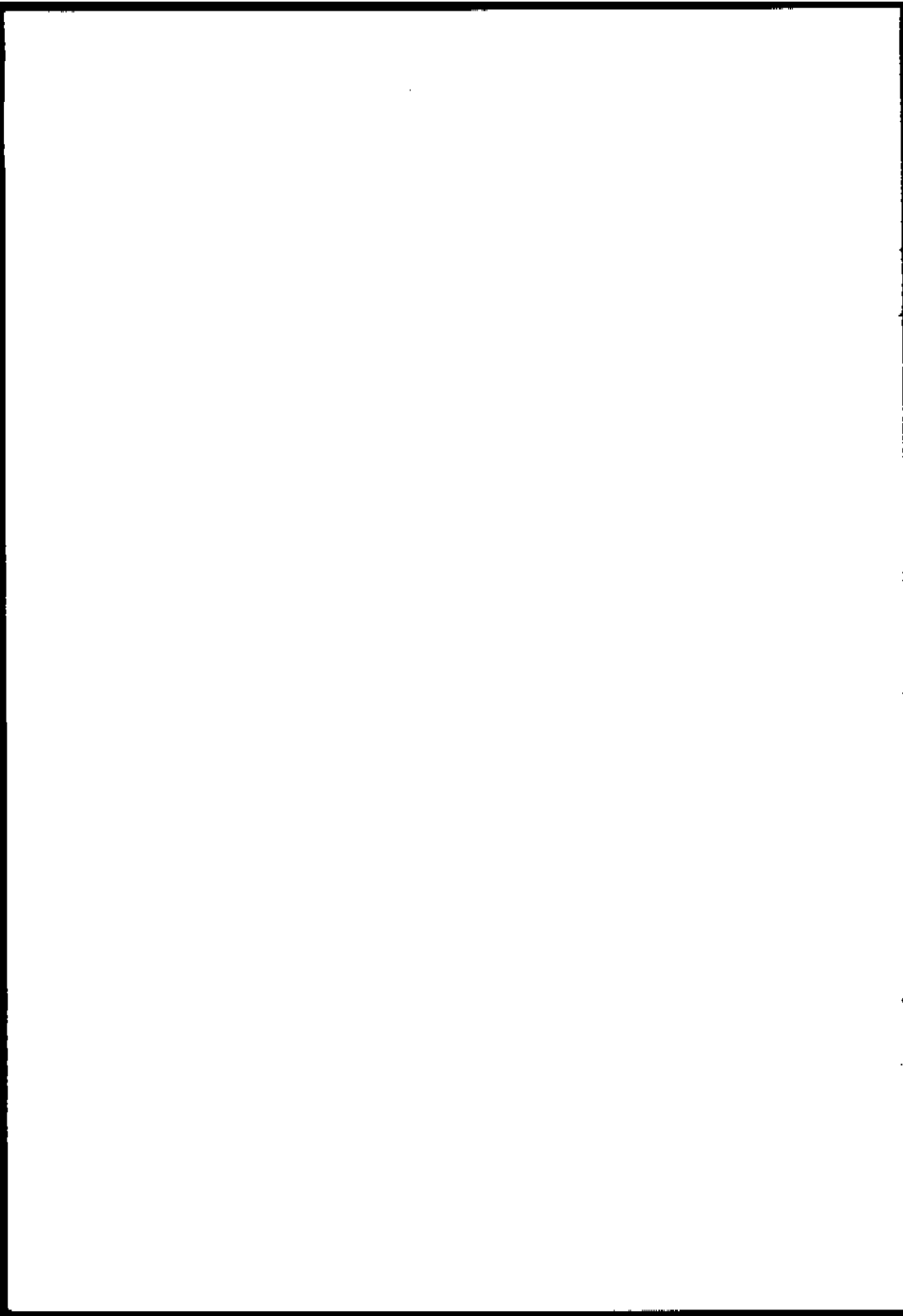
The WHO Regional Office for Europe organized a European Consultation on the Rights of Patients, which was held in Amsterdam on 28-30 March 1994. The participants comprised some 60 people from 36 Member States of the WHO European Region, representing the viewpoints of citizens, patients, health care providers, policy-makers and academics. Their task was to define principles and strategies to promote the rights of patients, as a part of current efforts to reform health care. Discussion centred on a document, prepared by a group of experts convened by the Regional Office, on the principles of the rights of patients. The participants' most important recommendations were incorporated in a Declaration on the Promotion of Patients' Rights in Europe; it endorsed the principles spelled out in the WHO document, commended strategies for action, called for closer cooperation between international bodies and proposed the monitoring of developments.

Keywords

PATIENT ADVOCACY
HEALTH CARE REFORM
EUROPE

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INTRODUCTION

The European Consultation on the Rights of Patients was held by the WHO Regional Office for Europe and hosted by the Government of the Netherlands. The participants comprised some 60 people from 36 Member States of the WHO European Region. The participants represented a wide variety, not only of countries from all parts of the Region, with different processes of health care reform, but also of governmental, intergovernmental and nongovernmental organizations. Thus, they could express the viewpoints and experiences of citizens, patients, health care providers, policy-makers and academics. The participants' task was to define principles and strategy to promote the rights of patients as the first step in a continuing initiative linked to the process of health care reform that was under way in most countries of the Region. Lists of the working papers and participants comprise Annexes 1 and 2, respectively.

The Consultation was the culmination of a long preparatory process. As early as 1986, the Regional Office carried out studies and surveys on the development of patients' rights throughout the Region, concluding with the publication of *The rights of patients in Europe*^a and the distribution of a draft document on the principles of the rights of patients. The strategy of the Consultation was to review patients' rights within the context of other emerging issues and trends, such as patient education, relationships between health personnel and patients, health education and social rights. The intention was to establish a broad rather than exclusively legal conception of patients' rights. This permitted the exploration of various possibilities for the adoption and observance of patients' rights in WHO Member States both in formal sessions and in informal discussion.

^a Leenen, H. et al. *The rights of patients in Europe*. Deventer, Kluwer Law and Taxation Publishers, 1993.

DISCUSSION

The focal point of discussion was the document on the principles of the rights of patients, which had been prepared by an expert group convened by the Regional Office, and finalized after consultation with Member States. Short presentations focused on:

- the key issues in the document (information and consent, confidentiality and privacy, and rights to care and treatment);
- how the principles might be applied in practice and the resulting implications; and
- the wider political, social and ethical significance for health policy and for health care reform.

A special presentation on developments in the Netherlands showed how patients' rights could be promoted and the complementary views of physicians and patients/consumers. Then the participants formed three working groups. Their task was to identify the implications of the principles for policy, and the next steps to be taken in countries, depending on their individual circumstances, and by international organizations, to sustain momentum.

The groups' reports showed a notable consistency of the views expressed. There was general endorsement of the document *Principles of the rights of patients: a common framework*. It offered essential guidance to be applied as appropriate by and within countries at various levels. It provided the basis for a continuing commitment to action. Its approach could foster a spirit of partnership and mutual support among all parties concerned: governments and other public or other legally sanctioned bodies, patients' organizations and other nongovernmental organizations, members of the health and legal professions and relevant academic faculties.

In addition, the participants made a number of conclusions and recommendations. The principal recommendations were incorporated in a summary Declaration on the Promotion of

Patients' Rights in Europe,^a which the participants adopted. The Declaration endorsed the principles of the rights of patients, commended the strategies for action identified below, welcomed closer cooperation between international bodies and proposed the monitoring of developments.

CONCLUSIONS AND RECOMMENDATIONS

Importance and timeliness of promoting patients' rights

1. Action taken now to promote patients' rights in the European Region would be a most timely contribution to the process of change in health care systems. Political, economic and social pressures were raising crucial choices in the organization, financing and management of the health sector, as well as fundamental issues of professional ethics and the need for new health legislative frameworks. Citizens' and patients' rights needed to be addressed within the context of these debates. For all countries of the Region, the primacy of patients' rights and health professionals' duties should not be lost under the pressure of economic and other forces.
2. As countries moved into closer relationships through their membership of international and integrational organizations, the need grew for a common spirit, a shared philosophy and culture of care throughout the Region. Nevertheless, differences between countries in the interpretation and realization of that common spirit would be respected, in accordance with their traditions and legal and other frameworks. Countries in political and economic transition had a special need for technical and other support, as they developed their own structures and strategies to promote patients' rights.

^a Copenhagen, WHO Regional Office for Europe, 1994 (document ICP/HLE 121/A).

Principles of patients' rights

3. The participants took particular note of the WHO expert group's comprehensive understanding of health care: the full range of services for health promotion and protection, disease prevention, diagnosis, treatment, care and rehabilitation. This had particular significance for the concept of the patient and of patients' rights. According to the expert group, the patient encountered a wide variety of health care providers and fulfilled a range of roles, from sick and dependent person through client receiving advice to consumer or customer obtaining health products for his or her own use. This implied a continuum of health states, from a high level of wellness to permanent disability and terminal illness. The scope of patients' rights and, as appropriate, reciprocal responsibilities must therefore reflect this continuum.

4. Properly informed and educated patients, in partnership with their professional health care providers, were essential contributors to enhancing and maintaining the quality of the process and outcome of care. This partnership could only be truly effective, however, if it were matched by the development of mechanisms to give feedback to physicians and other care providers on the outcomes of their technical interventions, their efficiency in using resources and, not least, patients' perceptions of their behaviour in the care process.

5. Legal formulations of the rights and obligations of both providers and patients must have the clarification of roles and expectations as a primary objective. They should not be used to constrain the patient-provider relationship, or lead to defensive behaviour from either. They must always have an educational purpose, in addition to their use as a sanction in the event of the exceptional case of failure to fulfil a professional responsibility.

6. It was essential that provisions for patients' rights respond to the needs of everyone with a stake in health care. They must seek:
- to promote and sustain beneficial relationships between patients and health care providers, and in particular to encourage more active patient participation;
 - to reaffirm fundamental human rights in health care, and in particular to protect patients' dignity and integrity, and to promote respect for all patients, particularly the most vulnerable;
 - to help patients obtain the fullest benefit from their use of the health care system, and, when necessary, to mitigate the effects of any problems they may experience with it; and
 - to strengthen the opportunities for dialogue between patients' organizations, health care providers, health administrations and groups representing wider societal interests.

Strategies for patients' rights

7. The development of a policy to promote patients' rights was the necessary first step; as soon as feasible, a carefully prepared strategy needed to be developed to ensure that the political intention was translated into a course of action that commanded the support of all parties involved. Such action would not follow automatically, but would take time to become fully effective. This meant that the people who were responsible for launching and guiding the action had to sustain their effort and sense of commitment.
8. While countries differed in legal frameworks, processes of health care reform, economic conditions and social, cultural and ethical values, certain common approaches could be adapted to the circumstances of each. The most positive

consequence of the Consultation would be for all interested parties in each country to initiate or renew multiple strategies of implementation. These would probably need to include most or all of the following:

- (a) legislation or regulations specifying the rights, entitlements and responsibilities of patients and care providers (both health professionals and health care institutions);
- (b) professional codes, patients' charters and similar formal or quasi-formal statements of rights and obligations, to complement or supplement the relevant legislation or regulations (these should be drawn up in the light of understandings agreed between the representatives of citizens, patients, health care providers and policy-makers, and then periodically revised in response to changing circumstances);
- (c) networking between and among patient and provider groups, recognizing the distinction between citizen and user participation;
- (d) government support for the establishment and effective running of nongovernmental organizations involved in patients' rights;
- (e) national colloquia and conferences to maintain the shared sense of understanding that has been reached between the representatives of citizens, patients, providers and policy-makers;
- (f) sustained involvement of the mass media in informing the public, stimulating constructive debate and promoting awareness of the rights and responsibilities of patients, service users and their representative organizations;
- (g) strengthening of training in communication skills at all levels of the professional education of providers, and introducing training in advocacy skills for patient and other user groups (both types of training implying the

development of a proper understanding of the perspective and role of the other party); and

- (h) commissioning of research of various types to help evaluate and document the effectiveness of legal and other provisions to support patients' rights, complemented by other research on health care providers' performance of technical tasks and aspects of patients' behaviour.
9. The pillars of any health policy that took proper note of the issue of patients' rights were equity and ethics in health and health action, as described in the WHO regional targets for health for all. Inefficient and ineffective practices in health care were unethical in themselves and perpetuated inequities by preventing the use of limited resources on people in need.

International action

10. Support for patients' rights at the international level hinged on good cooperation between international organizations, such as WHO, the Council of Europe, the European Union, and relevant international nongovernmental organizations, such as the World Medical Association. Patients' rights needed to be the subject of continuing discussions between them and their members. Consistent policy positions, coordinated strategies of implementation and an understanding of how their resources and competences could best be used were essential components of a sustained Region-wide movement to promote and protect the rights of patients and professional health care providers.
11. The forthcoming WHO Regional Conference on Health Policy would provide an important opportunity for increasing understanding of and disseminating strategies for the promotion of patients' rights in the European Region, and that the proposed WHO regional conference on health care systems in transition, to be held in Vienna in 1996, would address the rights, roles and responsibilities of both patients and providers. The Regional Office should monitor developments following

from the Consultation and present the findings to the conference in Vienna.

*Annex 1***WORKING PAPERS^a**

ICP/HLE 121/5	Principles of the rights of patients in Europe
ICP/HLE 121/6	Introduction to the study and the principles on patients' rights in Europe, by H.J.J. Leenen
ICP/HLE 121/7	Health professionals and the rights of patients, by M. Bonnel
ICP/HLE 121/8	Consumers' views on health care systems, by M. Calnan
ICP/HLE 121/9	Patient education and health education, by A. Deccache

^a Copies can be obtained from the Training and Research in Public Health unit, WHO Regional Office for Europe, Scherfigsvej 8, DK-2100 Copenhagen Ø, Denmark.

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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.

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