Ethics of the Health Systems

Report of the Third Futures Forum for High-level Decision-makers

Stockholm, Sweden
27–28 June 2002
ABSTRACT

The Third Futures Forum brought together decision-makers from 15 western European countries to share views on and experience with five aspects of the ethics of health care systems: patient information and consent, the limits of health care, health system development, intersectoral action for health and ways to strengthen the ethics of health systems in general. Invited contributions and group discussion showed that countries shared similar problems but varied widely in responses to ethical issues, owing partly to differences in size, culture (including religion) and the nature of health care systems. The participants agreed, however, that debates on health systems should take account of ethical considerations and that equality of access to care was an ethically driven principle of any system. The participants received an update on progress on health cooperation in the face of terrorism, which had been the topic of the Second Futures Forum six months previously. Six topics were added to the list of subjects that other fora could consider, and the need for these meetings to tread a difficult path between structure and informality was emphasized.

Keywords

ETHICS, MEDICAL DECISION MAKING DELIVERY OF HEALTH CARE – trends HEALTH SERVICES ACCESSIBILITY EUROPE
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* These sessions took place in different order but are reported here as in the original programme.
Introduction

In 1663 two Swedish physicians set up a body, independent of the state, to tackle an ethical issue – namely, the exposure of charlatans, people who falsely claimed to offer cures but who lacked proper qualifications. In June 2002, that same organization, today called the National Board of Health and Welfare, hosted at its Stockholm offices a meeting on ethics in European health systems. This was the WHO Regional Office for Europe’s Third Futures Forum for High-level Decision-makers.

In Europe today health-policy decisions are often made under pressure of time, and the ethical impact of a policy may not get the consideration it deserves. Participants tackled five large topics that had been selected, with some difficulty, on the basis of feedback from decision-makers in the member states and expressions of a willingness to contribute. The focus was health-care systems and sharing experience of the ethical aspects of policy-making; bioethical topics such as gene technology were excluded because these are currently under scrutiny by other European institutions. There was plenty of sharing and the WHO Regional Office will seek to incorporate the participants’ deliberations into the 2005 renewal of WHO “Health for All” policy for the European Region.

Ethics of patient information and consent

This session focused on patient information and consent. The legally enforceable and specific principle of “informed consent” to treatment and to participation in research continues to be developed but there are now increases both in people’s expectations on access to information about themselves (e.g. to medical records) and in public access to medical information more generally (e.g. via the Internet).

In a treatment setting “informed” refers to the choice of useful therapies, usefulness being a professional decision. The informing process needs a good relationship between patient and doctor In a research setting the principles are also generally agreed: The risks must not be disproportionate; and the patient (or guardian in some psychiatric settings) has to give informed consent. The first applies also where consent is not possible but here, determinations of risks and of benefits to self and others have to have the protection of the law.

With a condition such as dementia a good ethical consensus in the health system means good care for the patient and, importantly, for the carers too. This duality can lead to tensions when what is good for the demented person (e.g. being allowed to walk unaccompanied outside the care setting) leaves the carers feeling anxious. The ethics of dementia care have been studied in depth by the European Alzheimer Clearing House.

In times past the medical professions of Europe would have been collectively opposed to the very idea of patients having access to their medical records. That attitude has changed, and the change is often legally enshrined. For instance, in France in 1998–1999 les Etats Generaux de la Santé held a series of forums. One was on information. Legislation introduced in March 2002 has a chapter on information and health systems that includes a provision for direct access to medical records. These records are seen not merely as an issue of professional obligation but also as an obligation to the individual, the patient.
Organizations of informed patients have long been offering help with patient-support groups or by raising funds for research, for example. Perhaps the value of information changes when a healthy citizen becomes a patient. The US-based international organization AIDSETI (Acquired Immunodeficiency Syndrome Empowerment and Treatment International), led by an HIV-positive person, is clearly informed. It has counters to the arguments usually given for not helping financially with the treatment of people with HIV/AIDS, arguments which include concern about HIV resistance or beliefs that money should not be borrowed to pay for treatment and that treatment should not be started unless it can be continued and unless it can be offered to all rather than just a few.

The concept of the fully informed patient, whether via information provided by carers or via other means such as websites, books and patient-support groups, is still developing, and yet to be explored is the possibility that information might change the traditional roles of provider, recipient and payer and thus alter the ethical context of health-care decision making.

**Ethics of limits to health care**

*This session focused on limits to health care, more specifically limits driven by a patient’s right to refuse treatment or by his or her wish for life to be ended by assisted death (“euthanasia”) or assisted suicide.*

Refusal of treatment is seen as reflecting the patient’s right to autonomy and non-interference, and this principle is not controversial. There was a general acceptance of a competent patient’s right to refuse treatment. However, the status of living wills or advance directives, practices that have been furthest developed in the USA, vary from country to country in Europe, as do the powers of proxies in situations where patients can no longer express their wishes and the age at which such expressions of will should carry force.

No such consensus exists in Europe on whether or not patients have the right to ask for medical help to end their lives. Indeed, as a Council of Europe survey of 44 member countries has shown, less than 10 States recognize advance directives as being legally binding. In countries where medically assisted help in ending one’s own life is prohibited, only two regard assisted suicide as non-criminal in particular circumstances (Estonia and Switzerland). Giving legal expression to a right to seek medical help in ending one’s own life (Belgium, the Netherlands) or merely decriminalizing the action is exceptional in Europe. It is more usual for opposing arguments to prevail, arguments based on the essential benevolence of medicine (doing good, not killing); on the consequences to society (e.g. in the United Kingdom in 1994 a parliamentary committee opposed the legalization of assisted death because it feared that vulnerable people would be insufficiently protected); or on the sanctity of life. In the Netherlands “beneficence” is interpreted as helping a patient to achieve his or her wishes, and in that country assisted death had recently been legalized.

Spain had for the previous five years been working on legislation, known colloquially as the “law on final wishes”, which may become law in 2003. Advance directives would be registered but the registry would have to be consulted before a patient’s wishes could be met. Yet to be decided is what happens when patients/relatives wish treatment to continue when the patient’s physicians judge further therapy to be futile.

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1 The report uses the term “assisted death” as a substitute of the term “euthanasia”.
In Spain the debate on assisted death had effectively ended 2 years previously but elsewhere it continues. In March 2002 Austria decided to maintain its legal prohibition on assisted death but it plans to expand palliative-care provision (from 200 beds to 500). Similar expansion is envisaged elsewhere, including the Netherlands. Indeed there had been a strong interest generally in Europe in palliative and hospice care over the previous 10 years. What remained unclear was whether improvements in care for the terminally ill will lessen the demand for assisted death to be legalised, especially since Belgium, which has gone down that path, already had quite well-developed palliative care both in hospital and at home. Also recognized is the need, not just for palliative-care beds, but also for this form of care to be upgraded in medical-school and postgraduate teaching and training, and not just for doctors. Gaps – gaps with ethical implications for decision-makers – remain between public wishes and provision, not just when about 75% of people want assisted death to be legalised while doctors remain totally opposed (Denmark), but also when 90% of people express a wish to be able to die at home but few do (Germany).

The participants discussed their views of how WHO could help and felt not, clearly, by attempting any sort of consensus because the diversity of opinion and culture in Europe would make that impossible. Participants felt that collecting case studies was one possibility; another a listing of the questions that health systems needed to address. Since the Council of Europe has shown an interest in topics such as palliative care and assisted death (e.g. the survey of 44 members states), it was suggested that the European WHO office should be working with the Council of Europe to avoid duplication.

**Ethics of health-system development**

*Limits to health care that are imposed, not by patients’ wishes at the end of life but by budgetary restraints, were considered in this session. The ethical issues here relate to what goes into a “basket” of health-care services and to the mechanism for deciding this content.*

The ethical principles seem clear: dignity (autonomy), a sound evidence base, equality of access and transparency. These principles should also be applied to special groups not perhaps usually considered in discussion of a common basket of health services, such as asylum seekers and prisoners. However, any basket has to be affordable, so a dominant question is the percentage of a country’s gross domestic product that is allocated to health, which is a political decision. One suggestion was that core services should include emergency care, infection control, prevention and “all clinically efficient services”. All cost-effective medical care is clinically relevant but not all that is clinically relevant is cost-effective, and there may always be a gap between demand (by society) and supply. Another problem is that preventive services, even when they are cost-effective, may receive low priority because they are deemed to be unglamorous (“non-sexy”). In immunization policy, a preventive service par excellence, population targets may need to be set (e.g. the attainment of herd immunity).

In deciding exactly how an agreed percentage of GDP is to be spent there are inevitable tensions between the perspectives of the politician, the health policy maker, the health professionals and the public. Reliance on expert advice alone (e.g. specialists in evidence-based medicine) can produce a basket of services that exceeds the budget. Alternative methods are commissions, with
representation of doctors, insurers and hospital managers, and more public input via patient representatives or, as in Oregon, USA, via public opinion.

Perhaps “basket” is not the right analogy. We could also think of fruit, with a central kernel of essential services and an optional layer outside; or of onions, with an obligatory and an optional layer and an outside skin of services specifically excluded from the general provision. A question that seemed highly relevant in view of the forthcoming probable expansion of the European Union – namely, could there be a common core block of services agreed for different countries? – remained unanswered.

**Intersectoral health action**

*Appreciation that there is a wide range of social and other determinants of disease has only slowly been translated into intersectoral health action. These actions can be at a national or at a global level.*

A June 2002 meeting on health impact assessment had noted that, just as health claims “rights” in other sectors such as trade, so other sectors have rights in the health sector. Market forces (the commercial sector) seek to keep labour costs low but if workers’ safety is compromised by economies the consequences are borne by the health sector. However, the main focus in this session was on the effects on health of market and taxation pressures (drug prices and government revenue from taxes on tobacco products and alcohol).

At the national level, the Republic of Ireland has in the past year introduced proposals and initiatives on intersectoral action. These include:

- Health-impact assessments on all government policies;
- Business plans for relevant government departments (“health proofing”);
- A National Action Plan for the environment;
- Broader ministerial remits (e.g. a Department of Health and Children, with junior ministers for children, the elderly and food);
- Cross-departmental agencies such as a Food Safety Authority and an Environmental Protection Agency.

Globally, the topical health focus is drug pricing and the implications of the TRIPS agreements (Trade Related Aspects of Intellectual Property Rights), a subject that Medecins sans Frontières has been monitoring. Tough negotiation can bring down market-driven prices, and the November 2001 Dohar Declaration now allows TRIPS to be implemented with a sensitivity to public health. So there has been some movement. Unfortunately, at the level of research and development, intersectoral actions could be inhibited by the fact that universities usually come under ministries of education or science, not health.

In a market-driven pharmaceutical industry research into new drugs for tropical diseases has almost come to a halt, and it is not clear where developments will come from. As AIDSETI had found, even with negotiated price reductions, the economic burden of treating those with AIDS or HIV infection is too great for regions such as Africa. In an age of globalization there seemed to be no global agreement on the value of a life.
Between the national and the global can sometimes lie the continental and the bilateral. In the European Union one directorate is subsidizing tobacco growers while another is trying to highlight the dangers of smoking. Norway has lost a public-health tool because in geographically accessible Sweden alcohol and tobacco prices are much lower. However, when Sweden did raise the tax on tobacco, smuggling increased and government revenues went down.

An intersectoral (health and employment) issue that the Stockholm forum was aware of but did not discuss was the recruitment by richer countries with staff shortages of health personnel from countries that can ill afford to lose doctors and nurses. Already an issue at the global level, this is likely to become a concern with the accession to the European Union of countries in which doctors and nurses are relatively low-paid.

**Strengthening ethics of the health system**

*During this session participants discussed ways in which WHO could help strengthen ethics in systems of health-care provision.*

The Swiss National Advisory Council on Biomedical Ethics is a body newly formed to strengthen health policy. Such bodies need the acceptance of the public, and the council had tried to do this by achieving a balance in the 21 members, a balance achieved after inviting suggestions from stakeholders; by emphasising the role as an advisory and not a decision-taking one; and by allowing, as in its first report on embryo stem cells, publication of both majority and minority opinion.

In Denmark they are trying to strengthen health-system ethics by greater transparency, to be achieved by “declarations of quality”. These self-declarations, available on websites, will be overseen by the National Board of Health and by a consumer panel but it was not clear how the accuracy of claims made will be independently verified. Press coverage is a powerful tool here, provided it itself is accurate. For example, Iceland, with its population of only one-quarter of a million, has been seen as an excellent resource for gene studies. However, press reporting worldwide has left the impression that a single company somehow “owns” the genes of Icelanders. This is incorrect, and an example of misinterpretation that can deter important development in the area. In reality the centralised database will include coded information from patient records only. At the present genetic information is not allowed in the centralised database. If genetic information will be used for diagnostic purpose in the future, such information can only be included after obtaining informed consent.

Transparency does have its critics. Monitoring quality, with its huge demands for documentation, can be expensive. Also transparency may be abused when it becomes the trigger for compensation claims. Transparency can be exploited.

There are no monopolies on explorations of health-system ethics. Other international organizations (Council of Europe, CIOMS, OECD) are involved, as are European health ministers generally with the 2003 conference on Health, Human Dignity and Human Rights, but that did not mean that WHO could let the subject go. It was felt that WHO needs to find a niche and to identify and fill in gaps. For example, WHO might take data as its starting-point; it could provide a network for sharing experiences; it was probably well placed to respond to non-acute situations; and it could provide, in debates on intersectoral matters, a health-ethics balance to the
more technical or trade arguments; and, as with the health implications for subsistence farmers in Slovenia of that country’s hoped-for accession to the European Union, WHO can be responsive to requests for help from individual states. WHO’s Regional Office for Europe is now pledged to come up with specific proposals.

Progress on health cooperation in the face of terrorism

The Second Futures Forum (Copenhagen, December 2001) had been arranged at relatively short notice after the terror attacks on the United States on 11 September 2001. The report is now available in print and as a CD-ROM. The Stockholm forum received an update on various cooperative initiatives taken in Europe between September 2001 and the World Health Assembly resolution of May 2002. These included discussions on water services, chemical incidents and epidemic alerts.

The Nordic countries had in June 2002 signed an agreement on the sharing of health services in the event of a terrorist attack. Two weeks after the Stockholm forum a European Union task force was due to meet in Luxembourg to discuss stocks of drugs and vaccines in the context of future terrorist threats. The threat of smallpox is now a major focus of attention in Europe.

Suggestions for future topics and services

Since the first meeting, in London, United Kingdom, there had been 13 topics on the table for Futures Forums. The Stockholm meeting added six more:

- Quality indicators;
- Credibility of government health information;
- Health impact assessments of non-health policies;
- Mobility of health personnel in the European region;
- Sustainability of health-care provision;
- Intersectoral influences on health.

The Futures Forum programme had had a difficult start, in part due to the effects of the 11 September attacks and to staff changes in the Copenhagen office. One criticism was that the Stockholm agenda had been too broad so that no one topic could be debated in depth. The informality of the meeting, including an absence of precirculated documents, was clearly appreciated by participants. Striking the right balance between informality and some sort of preparation, such as the circulation of case studies collected by WHO’s European Office, would be a challenge for Futures Forum organizers from now on. During that preparatory phase there could be feedback from decision makers, to ensure that the draft programme was addressing their interests.
Annex 1

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Annex 2

PROGRAMME

Thursday, 27 June

09.00 – 09.30  Welcome and introduction

**Focus on Ethics of the Health System**

09.30 – 11.00  Ethics of patient information
Information patients should have regarding diagnosis and treatment

11.00 – 11.30  Break

11.30 – 13.00  Ethics of limits to health care
Patient’s rights to say no to health care
Dilemmas in people’s right to ask for health care to end their lives

14.00 – 15.30  Ethics of health system development
A “common basket” of services: Implications for access to appropriate care
Developing reforms that may not be sustainable

15.30 – 16.00  Break

16:00 – 17:30  Ethics of intersectoral health action
Trade of health services, health personnel, health goods and health aid: the health gap

Friday, 28 June

09.00 – 10.30  Strengthening ethics of the health system: sharing knowledge and cooperation

10.30 – 11.00  Break
The Futures Fora series

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| 11.00 – 12.00 | Progress on health cooperation in the face of terrorism  
|             | (Second Futures Forum)                                               |
| 12.00 – 13.00 | Suggestions for future topics and services                           |
| 13.00 – 13.15 | Closing session and farewell                                         |
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