



NINTH FUTURES FORUM

on health systems governance and public participation



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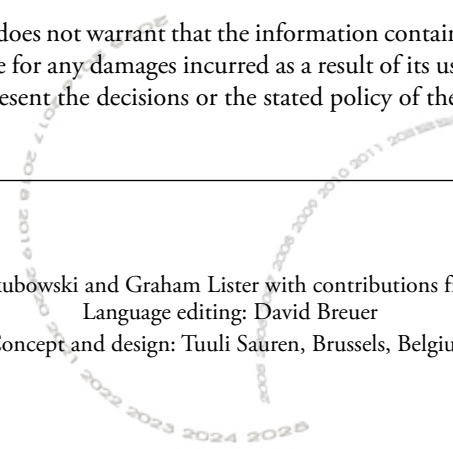
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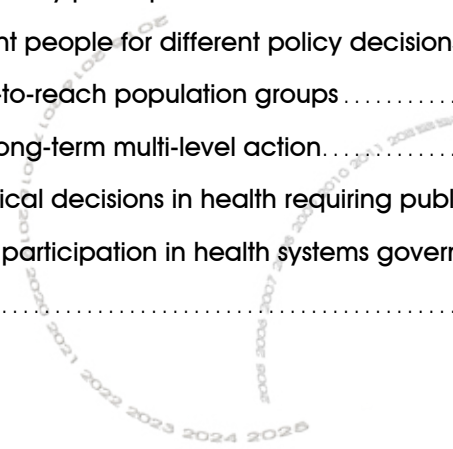
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CONTENTS

Page

1. Why a Futures Forum on health systems governance and public participation?	1
2. Expectations of high-level decision-makers towards this Futures Forum.....	4
3. Understanding public participation in health systems governance	6
3.1 A conceptual framework	6
3.2 Examples from European countries	10
4. Experience of countries in strengthening public participation.....	15
4.1 Public consultation in France	15
4.2 Choice and voice in the Netherlands	17
4.3 Choice and voice in Germany	19
4.4 Public involvement in priority-setting in Sweden	21
4.5 Patients' rights in Belgium	24
4.6 Participation in strategic health planning in Portugal	26
5. Summary and conclusions	29
5.1 Defining what comprises good governance in public participation	29
5.2 Creating the right prerequisites for participation	29
5.3 Deciding on options to enable participation in health systems governance	30
5.4 Participation as a goal in its own right.....	30
5.5 Making participation a main requirement of policy-making	31
5.6 Learning from experience	31
5.7 Developing community participation	32
5.8 Consulting different people for different policy decisions	32
5.9 Focusing on hard-to-reach population groups	33
5.10 Working towards long-term multi-level action.....	33
5.11 Selecting the political decisions in health requiring public participation.....	34
5.12 Monitoring public participation in health systems governance	34
5.13 Next steps.....	34



1. Why a Futures Forum on health systems governance and public participation?

The past two decades of health systems governance in many European countries have been marked by an increasing concern to involve citizens in collective and individual decision-making on health policy. This is based on the perception that involving the public and extending choice will improve decisions, by widening the range of views, experience and expertise available, that it will increase the acceptance of policy decisions among the population and that it will lead people to take more responsibility for individual and community health decisions. An examination of trends in health and health systems suggests several factors that will emphasize even more strongly the need to involve the public in policy-making at the individual and collective levels over the next two decades.

Longevity is increasing across many European countries as a result of improvements in health care and public health. Technical advances are improving the survival rates from cardiovascular disease and cancer, and more effective drugs and treatments will probably address many previously untreatable diseases. In some cases, public health intervention may reduce the onset of disease. However, despite attempts to compress morbidity, the period people spend living with self-reported poor health and with specific health problems is likely to get significantly longer. Many more people are therefore likely to require ongoing treatment and care. The costs of potential technical advances and increased demand for health and social care are likely to outrun the resources available, making it an important policy principle to involve and empower citizens to achieve the highest possible level of health and to help to shape health policies and priorities.

Changing health profiles are likely to result in a higher proportion of lifestyle-related chronic conditions. For example, obesity with its attendant health problem of diabetes will probably continue to rise in western European countries and misuse of alcohol and illicit drug consumption will pose increasing problems. Preventing lifestyle-related diseases not only requires effective policies and programmes but also citizens accepting and engaging with them as societal norms of behaviour. This again indicates the need for public participation in developing and implementing health policies.

A further factor is that family structures are changing, with the three-generation household becoming more rare in most of northern Europe and declining in southern Europe. Many more elderly people will be living alone, and single-parent families are likely to continue to increase. Although immigrant groups often have more tightly knit family structures, these families often suffer from separation from their traditional extended community and lack of access to services in the host country. Informal family care, which represents over 75% of the total care effort, is likely to decline, both due to changes in family structure and as a result of the ageing of carers. With families becoming smaller and more isolated, providing the support and care that will increasingly be needed to help people lead independent lives will be more difficult and more expensive. Voluntary- and community-sector provision will be essential to meet these care needs, requiring that such groups and individuals become more engaged in health and care policy.

Advances in medical technology pose a range of ethical dilemmas requiring political and social debate: for example, in relation to stem cell research, embryology and genetic screening. There are also important ethical questions regarding the cost-effectiveness of medicine: for example, should expensive but more effective personalized medicines be provided? Defining the limits of the health system will also become more important: for example, should such conditions as social anxiety disorder (acute shyness) be treated as medical conditions under solidarity funding? These ethical questions cannot be solved through political and expert views alone but require wider consensus through public involvement in the policy debate.

Last but not least, over the next two decades patients in Europe are likely to become ever more demanding customers for health services, informed by digital interactive television and other mass media about health and health service options. They will increasingly demand highly personalized services responding to their particular requirements and choices.

These developments present a formidable challenge to the governance of health systems in the European Union. Future health scenarios in which people's lives make them ill and they rely on health services to get them better are not sustainable. It is becoming clear that health and care services need a fully engaged public as co-producers of health if they are to be affordable.¹

Nevertheless, despite substantial interest in and recognition of the potential for public participation in health policy-making and other areas of health systems governance, limited insight and evidence are available on how public participation can be ensured and how it actually improves health outcomes in different countries. Some countries have made progress in increasing public participation in public health decision-making; others have emphasized consumer choices of health insurers or providers as a way of influencing the market. Some countries have found it necessary to rethink their approach to this. For example, the United Kingdom abolished its Commission for Patient and Public Involvement in Health and local patient and public involvement forums only three years after creating them.

This Futures Forum was organized to review the progress European countries are making in public participation in health policy and to examine whether any clear lessons emerge. It addressed the logical framework for participatory health policy-making and the limits of the concepts. The Futures Forum focused on practical experiences and examples of best practice and problems in participating European countries related to health systems governance and public participation. The objective was to exchange and learn from experiences, with the aim of identifying the knowledge gaps on improving participation in health systems governance and promoting future planning and cooperation in public participation in the European Region of WHO.

Launched in 2001, the Futures Fora are a series of meetings for high-level policy-makers. They aim to generate insights into real-life decision-making issues that are often not available from academic sources. They provide an impartial environment for directors-general of health, chief medical officers and senior advisers to debate difficulties in policy-making. During the meetings, the participants share their experiences of concrete decision-making issues, describe the solutions employed and draw the lessons. The Fora apply the Chatham House rule

¹ Wanless D. *Securing our future health: taking a long-term view*. London, HM Treasury, 2002 (http://www.hm-treasury.gov.uk/consultations_and_legislation/wanless/consult_wanless_final.cfm, accessed 26 November 2006).

to ensure confidentiality. The Chatham House rule aims to guarantee anonymity to those speaking within it. It allows people to speak as individuals and to express views that may not necessarily reflect those of their organizations, thus encouraging free discussion.

The baseline theme for the Futures Fora in 2003–2005 was tools for decision-making in public health. Several Futures Fora have been organized under this theme, such as one on evidence-based recommendations as tools for decision-making (Brussels, June 2003); one on rapid response decision-making tools (Madrid, December 2003); one on crisis communication (Iceland, May 2004); and one on unpopular decisions in public health (Malta, November 2004). Since 2005, the Futures Fora have been based on policy challenges focusing on governance issues, such as one on governance of patient safety (Erpfendorf, April 2005) and this one on health systems governance and public participation.

Following this introduction, **Chapter 2** presents expectations from Forum participants. **Chapter 3** provides a conceptual framework for understanding different approaches to public participation, some of which are briefly summarized. The chapter also provides some examples of methods of participation applied in countries. **Chapter 4** continues with some specific practical case studies of European countries that have attempted to improve and strengthen public participation in health policy decisions and reports on the discussion of each case study. **Chapter 5** summarizes and draws conclusions from the Forum and provides some possible ways forward for involving the public in health systems governance.



2. Expectations of high-level decision-makers towards this Futures Forum

The Futures Forum brought together high-level decision-makers from different countries, who all brought different system perspectives and interests to the topic of health systems governance and public participation.

In **Germany**, which has a health system highly decentralized to the regional level, it is of interest whether and to what degree public participation takes place in European countries and whether it has made a difference in outcomes. Does it ease or complicate decision-making? Of interest also is whether public participation might move towards a policy tool that enables decision-makers to shift away from the current heavy focus on care to other areas of health policy such as health determinants and risks.

Switzerland traditionally applies a high participatory approach, as popular votes take place on many policy matters on both the cantonal and federal levels. It is felt that this has enabled a better balance of policy focus on clinical and public policy matters as well as a recent trend shift away from care and towards a more public health orientation.

In **Finland**, many policy matters are decided at the local level. It is of interest to learn from other countries how best to engage people in policy-making.

The Ministry of Health in **Slovenia** has been trying to incorporate dialogue and public communication in decision-making since the country's independence. Can current mechanisms in Slovenia be enhanced? How?

In **Israel**, one of the most topical questions currently is which interventions to cover as health benefits under the compulsory health insurance system. As this affects the health benefits of the people in Israel, this would be a particularly important policy decision process to open up for more public participation. There are already attempts to form citizens' parliaments at district levels, but a difficult question is *which* people to involve. It is hoped that the Forum can provide some insights from other countries to these questions.

From **Norway**, there are particular concerns to reach out to engage marginal groups in more participatory decision-making. What are the experiences of other countries in focusing on marginalized groups in public health decision-making?

For **Malta**, it is of interest to learn about how other countries approach citizens' participation in health policy decisions. The concept of citizens' participation is relatively new.

Belgium has developed its approach to patients' rights in recent years. Other sectors and especially industry have been more successful in working towards a client-oriented approach. How does the health sector differ, and can other sectors learn from the methods deployed for health policy decisions? Increasing the participation of the public in decision-making also presents very practical questions. For example, for a multilingual country, language by itself already imposes a barrier to effective participation. This has, for example, necessitated the employment of Flemish- and French-speaking ombudspersons in hospitals.

The Ministry of Health, Welfare and Sport in the **Netherlands** tends to regard patients and citizens more and more as partners for health policy-making. The recent health insurance reform has already increased choice on insurers and benefit packages at the individual level. At the collective level, difficult questions are *which* governance decisions require public participation, which will benefit from public participation and which not? How do policy-makers select?

In the **United Kingdom**, a recent health policy paper focused on the concept of “choosing health”. The government aims to increase the choice among health care providers and give people a stronger voice in health policy. One remaining concern, however, is the impact on social inequality in health, as healthy and well-off people are more likely to exercise both choice and voice. What are other countries’ experiences in this respect?

In **Iceland**, public participation has increased during the past 10 to 15 years, and the patient movement has strengthened a participatory approach to health systems governance. For example, boards of hospitals and health centres included representatives of staff as well as representatives from the local communities. However, these boards were abolished recently, and how this will influence participation remains to be seen.

Portugal has advanced public participation by developing its national health strategy through a set of public consultations. This may provide some relevant experience to other countries wishing to use public consultation on policies. Patients’ rights legislation, however, requires more attention in future.

3. Understanding public participation in health systems governance

3.1 A conceptual framework

“The public participates in health governance through voice, choice and representation.”

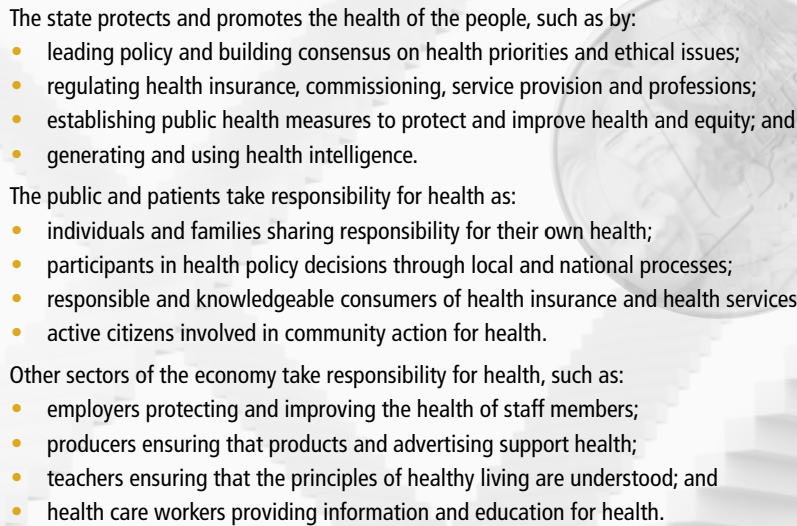
Governance is the exercise of political, economic and administrative authority in the management of a country's affairs at all levels. This definition by the United Nations Development Programme² encompasses the complex mechanisms, processes, relationships and institutions through which citizens and groups articulate their interests, exercise their rights and obligations and mediate their differences. Stewardship is the “very essence” of good health governance, defined by *The world health report 2000*³ as “the careful and responsible management of the well-being of the population”. This entails: formulating health policy, defining the vision and strategic direction, exerting influence, including approaches to regulation and generating and using intelligence. One may argue that, in democratic systems, ultimately elected representatives of the citizens make all policy decisions concerning health and health systems, and these decisions are therefore implicitly participatory. But elected representatives cannot always reflect the preferences of their citizens for specific health policy decisions and may require additional measures to obtain the views of their citizens or of those particularly affected by a specific health policy. Equally, every detail of health policy decisions and their application cannot be expected to be subject to popular vote or individual choice. In the end, national politicians still make major policy decisions and health professionals take detailed clinical decisions, but public participation may help them in taking public and patient views and preferences into account in major decisions, and some decisions may be delegated as community or individual choices.

The concept of public participation in health systems governance may be better understood by examining the roles in health decision-making attributable to the different stakeholders. **Box 1** provides some examples of how different responsibilities can contribute to health decision-making.

Public participation then means that citizens have the possibility to share with the decision makers their views and preferences on health policies, thereby becoming an active partner in the decision making process. Public participation therefore implies responsibility resting on the policy decision makers to introduce mechanisms enabling and participation of consumers in the decision making process on the one hand. This will include empowerment through providing access to better information about health, health interventions, the health system, and health system governance. On the other hand, it also means responsibilities for the consumers to take on opportunities to participate in policy decision-making. One of the principle problems countries will encounter is that it is often the well educated and informed consumers that will participate in decision making, whereby disadvantaged groups may be underrepresented.

² Glossary of key terms. In: *Governance for sustainable human development. A UNDP policy document*. New York, United Nations Development Programme, 2006 (<http://magnet.undp.org/policy/glossary.htm>, accessed 26 November 2006).

³ *The world health report 2000 – Health systems: improving performance*. Geneva, World Health Organization, 2000 (<http://www.who.int/whr/2000/en>, accessed 26 November 2006).

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- The state protects and promotes the health of the people, such as by:
- leading policy and building consensus on health priorities and ethical issues;
 - regulating health insurance, commissioning, service provision and professions;
 - establishing public health measures to protect and improve health and equity; and
 - generating and using health intelligence.
- The public and patients take responsibility for health as:
- individuals and families sharing responsibility for their own health;
 - participants in health policy decisions through local and national processes;
 - responsible and knowledgeable consumers of health insurance and health services; and
 - active citizens involved in community action for health.
- Other sectors of the economy take responsibility for health, such as:
- employers protecting and improving the health of staff members;
 - producers ensuring that products and advertising support health;
 - teachers ensuring that the principles of healthy living are understood; and
 - health care workers providing information and education for health.

Box 1. Examples of different roles in health decision-making

Public participation means that citizens have the possibility to share in decision-making by expressing their views and preferences on health policies and by taking individual or collective choices, thereby becoming an active partner in the decision-making process. This, in turn, depends on a governance responsibility to introduce and support mechanisms enabling the public and patients to participate in the decision-making process. This includes empowerment through providing access to information about health policy choices and mechanisms for developing and expressing opinions and making choices. It also implies a responsibility of citizens to take on opportunities to participate in policy decision-making and to make responsible choices. One problem countries encounter is that well-educated, better-off consumers often participate in decision-making, whereas disadvantaged groups may be underrepresented; thus, considering how such measures affect health equity is important.

European health systems deploy many different measures to support public participation in health policy-making. The measures fall under three main headings of “voice”, “representation” or “choice”. The voice mechanism can be at the collective or the group level: for example, revealing general public views or the views of particular types of service users, such as patient groups or ethnic minorities. Representation is usually at the system-wide level of decision-making, which means that representation applies either in health management bodies at the local, regional or national level or for institutions such as social insurance boards or community-owned hospitals. Choice is most often exercised at the individual level: for example, choosing among health insurers, health care providers or specific treatment and care options. Although individual choices may not seem to be directly related to system-wide governance decisions, the collective effect of individual choices may change health policy by making some options unsustainable. A strategy for public and patient engagement needs to consider all three types of mechanism. The participation of the public in health governance may be protected by a statement of “patients’ rights”, setting out basic principles for voice, representation and choice plus the rights and obligations in related areas such as provision of appropriate information.

Voice

Voice mechanisms articulate collective patient and public views on health policy concerns. Although this ensures the expression of such views, it does not necessarily mean that health policy decision-makers have to follow them in taking decisions. European health systems take patient and public views on health policy into account in many different ways. Regulatory agencies, health insurers and health service providers use focus groups and surveys of public and patient experience and opinions to sample the views of consumers – these provide information to policy-makers on current attitudes. They may initiate consultations on particular issues by publishing consultation documents proposing health policy options and asking for feedback. This usually produces responses from well-organized interest groups such as patient organizations and professional associations, although increasingly such consultations invite individual citizens to send in letters and e-mail responses. Consumer or patient panels or juries are voice mechanisms that seek to engage with consumers by providing information and education to a group of citizens on health policy issues and enabling them to reach an informed judgement. In some cases, special arrangements are made to elicit the views of hard-to-reach groups or specific patient groups. This may be done by undertaking specific surveys or by selecting members of such groups to participate in surveys or panels.

Consumer and patient advocacy groups may also express their views through national and regional structures: for example, France and the Netherlands may also have local networks of patient and consumer groups similar to those now being established in England. Such links and networks have some of the characteristics of representation in that they may gain a recognized and continuing role in decision-making and can follow up and monitor the outcome of policy decisions. However, organizations based on networks of different patient and consumer groups often have difficulty in producing a single consensus on health policy decisions since the various member groups from which they are drawn may have different viewpoints. For this reason, some networks limit themselves to expressing the views of different member organizations without necessarily arriving at a policy position.

In voice mechanisms, the influence patients or the public exert on health policy depends on contextual factors such as the transparency of the policy-making process, the breadth and depth of the available information, the skills of participants and the listening culture of decision-makers. One may argue that voice mechanisms have a limited influence on decision-making, especially when decision-makers are not required to take the consumer voices into account. Nevertheless, when the mass media support voice, it can become a forceful influence on decision-makers.

Representation

Representation implies a formal, regulated and often-obligatory ongoing role in the process of health systems governance. Members of the public and patients often have a formal representative role as members of boards of health regulators and insurers or purchasers and, in some cases, organizations of health service providers. The public sometimes directly elects members, but another public body such as a local council or patient or consumer organizations often appoint members. Direct election and appointment by representative institutions are important means of ensuring legitimacy in representation.

In most European countries, regional elected bodies, county or local municipal councils play a role in health governance. This may range from a relatively weak oversight role – as in the case of local authorities in England – to the direct responsibility of the county and municipal councils for commissioning and managing services in Finland. This example suggests that effective representation mechanisms are linked to the degree of community involvement in local policy decision-making and the degree of decentralization of power. In smaller governing units such as those in Finland, decision-makers may know many citizens personally, which enables citizens to exercise more immediate influence on health policy-making within their community and perhaps makes policy-makers more responsive to the needs, demands and wishes of their electorate. Representation can also be enacted through the boards of publicly owned health institutions. In most European Union countries, health insurers and providers are a mix of publicly owned, private-sector and community- and voluntary-sector organizations. Public ownership is usually vested in regional or county-level authorities, but models of community ownership are now emerging with board members including public and patient representatives.

Representation mechanisms enable local health policy to be shaped to meet local needs, but there is often tension between local decisions and the need for consistent national policy. Thus, although social health insurers or regional health boards may choose to adopt some differences in health policy, this difference is limited by regulation so that, even in the Netherlands, where competition and choice has been encouraged in recent years, policy differences between insurers and between providers are small. All social health insurers are obliged to offer the same basic package of entitlements, with some small scope for variation, and all health providers have to meet the same standards but with scope for some innovation and improved services.

Choice

Choice mostly applies to individual decisions to select health insurance or health and care providers but may also apply to the extent and nature of services chosen. The obvious requirement is that health governance should allow alternative providers and encourage different service options. This is most often achieved through some sort of internal market, often with tight controls on the standard of services provided and costs.

Exercising choice requires that people have the capability and information to select from alternative options. This requires well-informed consumers and providing reliable and relevant information on service options. For this reason, the development of choice has been accompanied by great expansion in consumer information and social marketing on health issues. Consumer magazines and advertising have increased, and detailed information on health service quality, waiting times and outcomes is most often provided through the Internet. However, in most systems patients seek the guidance of their primary care physician (although in some countries patients may choose to consult several). As the range of choices for patients increases, the workload generated by support for patient choice may lead to the need for trained patient advisers with skills in empowering patients and supporting their health choices.

Patients' decisions on the management of their treatment or care also provide examples of choice in personal care. The participation of patients in deciding on their care has been systematized and formalized in models of shared decision-making in the United States and elsewhere or in the concept of patients as co-producers of care and expert patients. These models require training and support for patients to develop the expertise and confidence required to take such choices and participate in care decisions.

In the Czech Republic, Germany, the Netherlands and Switzerland, consumers can select a social health insurer; other European countries only offer one scheme of social insurance or tax-funded benefits. Many European health systems permit a free choice of hospital, although in some Scandinavian countries this has depended on waiting times, and in France some providers are able to command a premium paid by the patient. Most health systems within the European Union provide a choice of primary care physician. In Germany, the Netherlands and, to a more limited extent, the United Kingdom, people receiving long-term care can choose the care package that best suits them within a personal care budget. In some countries people may choose not to participate in social insurance schemes but to opt for private health insurance; this may be termed “exit”. Another example that falls into this category is consumers choosing to purchase over-the-counter drugs: for example, to control elevated cholesterol levels with an associated programme of cholesterol monitoring.

Consumer and patient choice can be a powerful influence on health governance, since patients effectively “vote with their feet”. Nevertheless, not all consumers are able to make a choice, and not all may be willing to do so. Another limitation, as already mentioned above, comes from the requirement to offer alternative options. For example, when there is only one health insurer, consumers cannot choose their insurance package. Likewise, where there is a shortage of providers of certain health services, patients’ choice may be dominated by waiting times.

Patients’ rights

Implementing patients’ rights is one of the cross-cutting ways of formalizing the rights of consumers and patients to enact voice, representation or choice. Such rights often set out the standards of service and information that consumers should expect from health insurers and providers. In some systems, patients’ rights are set in health legislation, as in the Netherlands. In other systems, such as the United Kingdom, patients’ rights are set out in a charter, which is a statement of intent without legal backing. Patients’ rights by themselves are designed to protect patients but are probably insufficient to empower people for participation in health systems governance. Advocacy and representation are required at both the local and national levels to help patients address specific complaints and to take collective action on system failures where complaints reveal them. Local and national patient or consumer advice organizations and/or an independent ombudsperson may support this. This is also a source of empowerment and participation, ensuring that health governance responds to consumers.

3.2 Examples from European countries

Most countries employ a mix of voice, representation and choice measures to enable public participation in health policy decisions. One measure often predominates, depending on the traditional organizational and financial design of the system. In the Netherlands and the United Kingdom, voice mechanisms have been widely used, supported by surveys and consultation exercises. In the Scandinavian countries, the election of municipal and county councillors has been a traditional method of enabling citizens to participate in decision-making through representation, whereas voice and choice have more recently started to play a more important role. Such countries as France or Germany have traditionally more strongly emphasized choice as a means of involving citizens. However, in many countries traditional orientations have evolved to more mixed forms in recent years.

United Kingdom

In the United Kingdom up to 1997, patient and public involvement in health policy was limited to various forms of consultation and representation, through membership of the governing boards of health purchasers and health providers and community health councils, which expressed local views on services. Members of these bodies were selected rather than elected and had limited influence on health policy. Since then a great deal has changed. Health policy responsibility has largely been delegated to the assemblies and parliaments of Scotland, Wales and Northern Ireland. In England, voice mechanisms include: focus groups and citizen juries to determine patient views, used by local health purchasers and national bodies such as the National Institute for Health and Clinical Excellence, which advises on health policy. The Healthcare Commission, which regulates health agency performance, undertakes an annual survey of patient and carer experience of the National Health Service. Most recently, the Department of Health carried out a national consultation exercise called Your Health, Your Care, Your Choice that enabled 40 000 people to express their views.

Representation mechanisms have also been extended with selected patient members of the boards of purchasers and providers. The new foundation trust hospitals take a further step in electing board members from among the people using the services of the hospital alongside elected staff representatives. In 2003, patient and public involvement forums were introduced for every health purchaser and provider, with selected members asked to monitor services from a patient perspective. These were supported by a national Commission for Patient and Public Involvement in Health. After only three years these measures are to be superseded; this time local engagement will be achieved through a linked network of local patient and community groups supported by a national coalition of such bodies with a local focus provided by a committee of the democratically elected local councils.

These developments have been accompanied by the extension of patient choice of hospital care providers. Referrals from primary care must now offer a choice of at least four providers including, where possible, a private-sector provider. A national choose-and-book computer system and processes for providing trained support for patients in making choice decisions support choice. Chronic long-term patients are also being supported to take decisions about their treatment and care through an expert patient programme that trains experienced patients to act as trainers to support others in taking charge of their lives.

Finland

Finland's health system involves the public in health policy through locally elected municipal councils and the Parliament. At both levels coalitions between parties often determine policy, which has encouraged a cross-party approach to health policy. Perhaps for this reason, surveys of attitudes to Finland's health system have shown high levels of satisfaction compared with other European countries, although waiting times are relatively long.

Health policy is determined at the national level, but many local decisions are delegated to elected municipal councils. As the 448 municipalities are rather small, with a median size of 11 000 inhabitants, they have formed consortia to operate hospital and other secondary services through 20 health districts. Municipal health committees (often merged with the social services committee) directly manage primary and community health services through local health centres and small community hospitals and commission secondary care from district hospitals and national hospitals. This structure means that the public and patients have very direct

contact with the local people responsible for health care: both the local politicians and the doctors who provide and commission services for them. In practice, however, the balance of power is more complex, with the five administrative provinces providing national and regional supervision of health policy and hospital districts often able to exert considerable power independently of small municipalities.

Finland is known for its focus on health promotion and the engagement of individuals and communities in self-care. The North Karelia experiment of the late 1970s and 1980s showed how a whole community can be mobilized to combat health threats; more than 20% of people were directly engaged in changing their health and lifestyles. The result was a massive reduction in heart disease and, although it is now thought that other factors contributed to this, the lesson of the importance of community and personal engagement in health is clear. Public health nurses working with national and local patient and community organizations lead self-care.

At the national level, the Finnish Centre for Health Promotion is a nongovernmental organization funded by government, participating organizations and funds from the Slot Machine Association. It is a network organization bringing together 120 patient and other organizations concerned with health promotion and self-care. It has 25 staff members and a budget of about €2 million per year. The Centre provides access to patients' opinions on public health and health policy issues by consulting with member organizations. It also produces an annual report called the Health Barometer, based on a survey of health managers and patient organizations. The Centre provides quality assurance for health promotion programmes and information and develops new initiative in these fields; it is currently developing the use of digital television for health promotion.

Patients' rights in Finland are expressed in a law enacted in 1993, one of the earliest examples of such laws in Europe. This established patients' rights to information and an ombudsperson.

The Netherlands

The Netherlands has a mixed system enabling participation through voice, representation and choice. Patients' rights are supported in three very important ways. First, a declaration of patients' rights is enshrined in civil law. Second, participation is high; some 17% of the population of 16 million belong to one or more of a wide range of patient and health consumer organizations. Third, the Ministry of Health, Welfare and Sport supports the patient and consumer movement as a partner in health governance, representing patient and consumer interests and dealing with complaints, taking up both local and national issues.

The Federation of Patients and Consumer Organizations in the Netherlands was founded in the early 1980s. The Federation draws together 23 umbrella organizations representing patients' interests and has about 2 million associated members. The Federation has an annual budget of about €30 million and employs approximately 35 staff members. It offers facilities, training, financial support and a national platform, acting as an effective mouthpiece for a host of organizations and interest groups that represent some of those least fortunate and able to articulate their needs at the highest political level. Since one of its aims is to promote freedom of choice, a key task is to provide a range of information in the form of books, leaflets and newsletters through a national network of information centres on health and care options. Another aim is to define the needs of patients and carers from *their* viewpoints.

This national structure is mirrored by 30 provincial patient councils, which draw together patients' and consumers' interests. Each council runs its own complaints and information desk. Legislation ensures that these regional patient councils are involved in provincial health governance. Insurers and local health providers also have formal patient or user councils, which legislation requires. Patient representatives are also involved in complaints committees, again as a legal requirement. In addition, hospitals and insurers offer patient representatives places on boards and committees.

The Federation, the Royal College of Physicians and the National Hospital Association meet on a joint board that supports and operates a national network of patient and consumer advice centres in the community and complaints bureaux in hospitals (required by law). Patients register complaints and are advised how to take their complaints forward: if necessary, support and/or mediation are provided. If the patient is not satisfied, the patient or consumer bureau will follow up the issue on their behalf. The Federation publishes a powerful annual report that receives widespread mass-media coverage, and there are also plans to produce ratings of hospitals' performance against patient-defined standards. The Federation works as a partner with the Royal Colleges and the National Hospital Association in developing guidelines for medical practice.

Social insurance agencies in the Netherlands include patient representatives on boards. The Netherlands Council of Insured People regulates the appointment of board members. The Council also advises the boards on major governance issues, such as the merger of insurance funds, and in reviewing new ideas. The Council serves as a voice or sounding board for new ideas and occasionally plays a role in major health policy decisions.

Provincial and local government councils are also engaged in developing public health planning for environmental health and in addressing wider health improvement issues, but in practice this tends to be less influential than central government planning.

At the individual level, the health system in the Netherlands offers choice of insurance fund, doctor and hospital. People with long-term conditions may choose between a personal budget to control their own care and predefined packages of care. Only about 10% of those eligible choose a personal budget, but this strongly affects the governance of service providers.

Switzerland

Switzerland provides another example of a health system that combines voice, representation and choice in public participation in health policy-making. The main driver of public involvement is individuals choosing a health insurer and health providers.

Switzerland is a federation of 26 cantons ranging in population from less than 15 000 to more than 1 million. At this level citizens participate in government decisions by a show of hands at a local meeting or in cantonal referendums. Canton councils participate in health governance: planning and accrediting hospital services, often subsidizing local services that they own and on occasions considering and voting on health policy issues.

Switzerland has many cantonal patients' organizations as well as national disease-specific organizations. These are divided between local and disease-specific patient-based organizations and *liga*, which are disease-specific

organizations with medical leadership that raise money for research and development for specific diseases, often with pharmaceutical company support.

Switzerland also has a strong consumer movement, which has developed rapidly in the health sector. This is often based on a magazine, such as *Ktip* (K = *Konsumer*) or in one case a long-running popular television programme, but these are now backed by web sites and other media offering evaluations of medical treatments, products and services. These organizations provide consumer advice both on health providers and on the social and private health insurers.

The Swiss Patient Organisation supports patient and consumer organizations at the national level and patient offices support these organizations at the local level. The government funds this at the federal level and cantons at the local level, but they are independent watchdogs for patients. They produce a range of patient information and represent general patient views alongside the major patient organizations and also provide counselling and advocacy services. Patient and carer experiences of health services are surveyed using an approach developed in the United States and applied in Germany, Sweden and the United Kingdom.

Procedures for supporting patient complaints at the local level depend on the good practice of the hospital or doctor. There is, however, a strong ombudsperson system to pick up complaints that are not dealt with satisfactorily. Patients' rights are an important issue for the patient movement; the web site of the Swiss Patient Organisation currently states "Als Patient haben Sie Recht" (as a patient you are always right).

Switzerland's system provides support for patient and consumer representation as a matter of course. In recent years the population has greatly increased awareness of the cost of health insurance, which is covered by compulsory social insurance payments. A survey in 1997 showed that most Swiss people say they would be prepared to accept some limitations on their health coverage if they could reduce the health insurance premium.

People are free to choose between the basic health insurance schemes, health maintenance organization-type insurance options that limit choice of referral options but offer lower premiums and extended personal health insurance schemes. Individuals select and pay for these schemes, so the Swiss demand value for money not only from their health providers but also from their health insurance organizations. Consumer organizations have developed services to rate the quality of both insurers and health providers. Nevertheless, Switzerland's health system remains the most expensive in Europe, and although there has been some growth in lower-cost health maintenance organization insurance, in practice most people have not chosen this option.



4. Experience of countries in strengthening public participation

4.1 Public consultation in France

“A nationwide consultation involved 200 000 members of the public in a concrete policy decision. It was not clear how it would end up or what would be done with the information, but it showed that individuals as well as organizations could be involved in health policy.”

Case report

The role of the individual citizen in health-related decision-making has recently become a subject of discussion in France, inspired by the commitment from Lionel Jospin before he became Prime Minister at the end of the 1990s.

Jospin’s commitment resulted in the establishment of a national consultation on the future organization of France’s health system. The core idea of the 1998 consultation exercise was to involve the public in the decision-making process and to use public opinion to generate policy options for excluding certain medicines from the package of benefits under solidarity funding. The consultation was an opportunity for France’s population to express their wider views on health policy. The consultation was organized with the help of public health centres, and mass-media reports triggered attendance. Each consultation meeting involved professional expert panels to answer questions. About 200 000 people attended the consultation with a lively, constructive discussion in more than 1000 consultation events in about 180 cities throughout France. Nevertheless, the decision to remove 221 products from the list of reimbursable medicines was not made until six years later.

The consultation might merely have provided an opportunity for people to express their views on this issue but instead turned out to be a forum for dialogue and lively and constructive discussion between health professionals, patients, associations and elected officials.

The consultation also supported the adoption of legislation on patients’ rights and the quality of the health system enacted on 4 March 2002. The act included a provision for patient associations to participate in the process of accrediting health institutions in France.

The health insurance reform act of 13 August 2004 further confirms and illustrates the stronger role of patient associations in decision-making by stipulating that patient associations have to be represented on the boards of the national health insurance funds.

There are concrete examples of how the 2002 and 2004 acts affected health decision-making in France. One example concerns the disclosure of information on the procedure for the accreditation of health establishments. The accreditation is based on a prior self-assessment of the institution, the quality of which depends on the

sincerity of the respondent. French law states that any administrative document is intended to be made public, and thus it was claimed that the institutional self-evaluation should be made public. Yet, it was feared that this might affect the results of the self-evaluation. The government, anxious to avoid being suspected of withholding information, was unable to reach a decision as to whether or not to publish the results from the self-evaluation. It was only after various hospital federations and a group of health associations took a non-institutional initiative that a solution was found. Notably, patients' associations and hospitals suggested to the government a legal modification to allow the self-evaluation not to be made public.

Discussion

France's experience illustrates a move towards a new role for citizens. In the past the system had a rather paternalistic relationship between health care providers and insurers and the purchasers of care and the public. On an issue as fundamental as the place of the patient in health decision-making, the demand came from individuals but was not a priority for patient associations. The approach still commonly adopted in France today is to consult the associations only when there is a problem to be solved; others involved in the health sector still do not generally consider them as partners.

The core idea of the 1998 public consultation process was to inform and involve the public and to use the creativity of public opinion for making difficult health policy decisions. In the end it was the politicians who took the decision to exclude 221 medicines from reimbursement through the health insurance system – but the final decision took about six years. Perhaps not surprisingly in a decision to cut benefits from solidarity funding, there were major differences between public opinion and the political decisions. However, although the consultation may not directly have led to this decision, it probably helped to prepare the public for a difficult decision.

This case shows how dialogue and public consultation can be useful for policy-makers in preparing consensus on difficult decisions. Public participation may help in explaining official policy matters by translating the policy language into public language. But people will focus on their own interests. Thus, public consultation will probably fail to support a political decision when the volume or quality of benefits of care for consumers is at stake. The participation process may nevertheless be helpful in exposing different views and explaining difficult decisions if not reconciling people to them.

The nationwide consultation involving the public in a concrete policy decision was a bold initiative arising from political leadership. It was not clear how it would end up or what would be done with the information. Although this created some difficulty, it did provide useful lessons for health governance on the importance of engaging with the public and showed that individuals as well as patient and consumer groups could participate in decision-making.

4.2 Choice and voice in the Netherlands

“Voice and representation have helped to determine the extent of choice.”

Case report

Until 2006, choice in the compulsory social health insurance system of the Netherlands consisted of consumers' free choice of sickness fund and of the providers who held a contract with the sickness fund. The content of the insurance scheme benefit package offered by sickness funds was set by law and not subject to consumer choice. Citizens with earnings above a certain threshold were not entitled to participate and thus could not choose to take out insurance with a sickness fund. However, they could choose to purchase private health insurance voluntarily. In practice the system left little choice for older and chronically sick people.

The system underwent a substantial reform in 2006. An important driver of the reform was to increase the focus of the system on consumer demand by allowing people more equal opportunities for choice in their health insurance arrangements. The reform also aimed to diminish the bureaucratic barriers between public and private health insurance schemes, leading to more competition among health insurers by creating a level playing field.

The reform contained the following main measures: for curative care the compulsory social scheme was virtually abolished in 2006, and all insurance for curative care is open to the private sector with the creation of a universal scheme. All citizens are now required to purchase private health insurance for curative care and insurers have a contractual obligation to insure all citizens who apply to them. Premiums are fixed, currently at a nominal premium of €1100 per year, and a fixed employer contribution, to avoid risk-adjusted premiums. Low-income households receive state subsidies to pay for their insurance. A new legal scheme was introduced that is intended to adjust for differences in risk exposure between health insurers. Every citizen is now free to choose a health insurer and can cancel an insurance contract with an existing insurer and change to a different insurer once a year. Opting out from the mandatory scheme is no longer possible, but consumers are now free to choose between different variants of standard packages and between cash benefits, benefits in kind or a combination. Thus, overall consumer choice of insurance arrangements was intended to be increased with respect to health insurers and the volume of schemes and benefits (in cash, in kind or combined). Beyond enhancing choice, the reform is expected to stimulate more competition among insurers and among health service providers.

The Federation of Patients and Consumer Organizations in the Netherlands represents an important element of voice in the system (see Chapter 3). The Federation has participated in the dialogue on designing the reform by providing opinions and organizing consultations. The Federation is now entrusted with contributing to the monitoring of the new legislation with respect to its impact on consumers. Consultation with the Federation of Patients and Consumer Organizations in the Netherlands and other organizations provided the basis for a decision by political representatives on the reform measures and was not a substitute for the democratic process.

Discussion

The reform of the health insurance component of the health system in 2006 has been driven by the objective of introducing more competition. This required the system to be opened to more consumer choice of health

insurers and benefit packages. It is expected that individual consumer choice of insurer and benefit packages will lead to a stronger role of consumers in determining their health insurance arrangements. Although consumer choice has been increased, health insurers will have to respond to a greater competitive stimulus, and thus consumers are expected to play a stronger role as clients of their insurers and as partners in governing the system – shifting the power balance from health insurers to consumers. Although consumer choice at the individual level is expected to have a stronger impact on the behaviour of insurance companies, choice is also expected to lead to a stronger voice at the collective level. Voice still plays a role, for example, through the Federation of Patients and Consumer Organizations in the Netherlands representing several patient organizations that have played an advisory role in the reform process and will now monitor its impact on patients. The reform reflected two of the objectives of the Federation of Patients and Consumer Organizations in the Netherlands: to create a demand-centred system that is based on patients' perspectives and to follow the principles of freedom of choice and personal autonomy. However, during the consultation one of the challenges for the Federation of Patients and Consumer Organizations in the Netherlands was that it was not able to present a consensus view on all aspects of the reform. This may have weakened its influence but reflected the diverse opinions of its member organizations.

The direction of the health insurance reform presented several potential pitfalls. An issue of concern was the basis on which consumers would make choices on their health insurers and insurance scheme benefits package. Choices may be made on current individual preferences but may not necessarily reflect health risks for the future or evidence about the cost-effectiveness of interventions. For example, if consumers were free to decide whether or not to include screening programmes in their selected health insurance scheme, they might opt to reduce screening entitlement without being able to take their personal risk of developing future diseases into account. This may be because their knowledge of their health risks is limited, because they choose to ignore future risks or because the future options for treatment and care are simply not known. For these reasons, voice and representation mechanisms were important in determining the appropriate extent of choice in the system.

The experience in the Netherlands has shown that one challenge is to balance reform objectives related to increasing citizen choice with other objectives of the system. For example, although choice may result in a balance of health benefits better matched to demand, well-educated people will probably be better able to make informed decisions about their insurance than disadvantaged people, thus reducing health equity. Choice may also negatively influence evidence-based decision-making, since in deciding on their insurance package, consumers may be guided by short-term personal perceptions, lacking information about health risks and the cost-effectiveness of interventions. Thus, ensuring that the population of the Netherlands becomes health literate, understanding their personal health risks and the implications of different health insurance schemes, will be important. Getting this understanding and information to all groups in society will be challenging.

With respect to consumer representation in decision-making, this case has shown that consumer or patient interests may differ between groups, posing difficulty in achieving consensus on all issues. A coalition of consumer and patient organizations cannot guarantee consensus. Their legitimacy is not based on representing the opinions of the general public but on presenting the views of patients and consumers based on their specific experiences of health and health care. It is important to understand the points on which consumer or patient groups agree and to understand how and why they differ.

Voice mechanisms are different from representation mechanisms, as the former articulate a range of opinions from specific viewpoints: that is, patients with a specific health problem or consumers of particular services, whereas the latter involve democratically accountable decision-makers who must take a broad view of the overall impact of such decisions. Choice mechanisms can be powerful drivers of the system, but determining what limits to place on the choices offered and how education and information can enable choices are important.

In the Netherlands, voice and representation mechanisms have helped to define the extent to which choice will be allowed within the health system. But the process of participation has also clearly further refined and strengthened voice and representation processes. The three elements of participation are therefore interlinked components of health governance.

4.3 Choice and voice in Germany⁴

“The combination of strengthened voice, representation and choice coupled with the development of the ombuds system is changing the culture of health governance with respect to setting the policy agenda, transparency and justifications of decisions in Germany.”

Case report

In Germany’s health system, decision-making is shared between the federal government, the governments of the federal states (*Länder*) and the self-governing bodies of health insurance funds and health care providers. The compulsory system is based on social health insurance for salaried workers. Self-employed people and people with earnings above a certain threshold are able to opt for the purchase of full-coverage private insurance, where they can choose their benefit package from a restricted catalogue of benefit combinations. German citizens have been able to choose their health insurance fund or private insurer for compulsory social and private health insurance since 1996. Choice of providers is nearly unrestricted. In compulsory social health insurance there is no choice of the package of care as the benefit package is set by law and is uniform. However, funds can offer deductibles, bonus reimbursements and special insurance services on a voluntary basis.

Only 2–5% of all insured citizens in the compulsory system make use of their right to change health insurer each year. Those changing to a different insurer are mainly healthy people, and most choose a fund offering a lower contribution rate than their former insurer.

The key problems of health systems governance and public participation include the following. 1) Opting out into private insurance is restricted to high-income employees, self-employed people and civil servants. Beyond the equity aspects, this also significantly undermines solidarity in the system as mainly people with good health risks choose private health insurance and private health insurers do not contribute to risk-sharing with compulsory social health insurance funds. 2) Consumers are not represented in the traditional self-governance bodies. 3) The role of the federal government has been too weak to lead the system.

⁴ This contribution was provided in written form.

Germany's system provides nearly unrestricted choice of all providers. Although Germany's system has recently tried to promote a family doctor gatekeeper system, a minority of insured people have a family doctor. Patients often consult specialists directly without referral, and hospitals become the centres of emergency medicine outside the doctors' working times. The unrestricted choice of providers has led to a high prevalence of misuse and overuse of health services.

Choice is more limited among the insurance schemes. First, law regulates the benefits package and the contribution rates in the public system. Funds can, however, offer deductibles, bonus payments and special services on a voluntary basis. Privately insured people also have limited choice, as the combinations of benefits are restricted, premiums depend on health risks and the calculation is standardized.

There are some voice mechanism in place. By social votes, insured people are represented by elected members on the board of health insurers. They typically represent members of labour unions and are not necessarily representative of all insured. Further, a legacy of the past has been that patient representatives, consumer organizations and self-help groups were not included as partners in the health insurance system. They were nearly entirely excluded from the decision-making process, so that sick and disabled people had no organized, collective voice in the system.

Several measures introduced in 2004 address some of these shortcomings. The governance framework is being rearranged. The traditional strong focus on self-administration of the system by providers and health insurers is being revised with the introduction of more competition between health insurers and providers and the empowerment of patients, who are anticipated to play a larger role in decision-making in the future. Co-payments were introduced to increase the leverage of the end user, maintaining a social balance by policies exempting chronically ill and marginalized patients. People consulting a specialist or a hospital doctor have higher co-payments if their general practitioner does not refer them. Financial incentives were introduced to improve the compliance of patients with the management of their diseases, such as by granting bonus payments if they enrol in certain disease management programmes. Financial incentives, such as rebates or deductibles, are also granted for patients enrolling in disease prevention programmes. The government has also enhanced mechanisms for patients' collective participation in decision-making processes. The most prominent example is the decision to invite patients' representatives (nongovernmental organizations, consumer agencies and self-help groups) to participate in the Federal Joint Committee of Sickness Funds, Physicians and Hospitals, which decides on coverage – albeit they do not yet have voting rights. To strengthen voice, an ombudsperson was established at the national level to facilitate the expression of individual concerns and complaints.

Discussion

Germany's experience suggests that a small proportion of the insured people choose a health insurer. This is also the experience in Israel, where people may choose between four sickness funds but do not usually make use of their right to change insurer when they fall ill. It is mainly healthy people that choose an insurer, and choices are mostly made on the basis of contribution rates. Germany's case shows the tradeoffs between objectives for choice and other system objectives, such as solidarity and fairness in funding.

A special feature of the recent developments in public participation is that not only are the voices of patient interest groups listened to but they are increasingly represented in decision-making bodies and as partners in care by, for example, engaging self-help groups. The Federal Standing Committee of Physicians and Sickness Funds, responsible for coverage decisions in ambulatory care, currently incorporates the views of consumer and patient groups. They have not had any voting rights so far. This is being considered, although it is feared that this may blur and complicate decision-making, leading to collective “non-responsibility” or failure to ensure accountability for decisions.

The necessary reforms to the health system will not be possible without the support of citizens, whether they are directly concerned or not. It is therefore anticipated that the individual and collective rights to participation will have to be extended to create a more equal partnership between health insurers, health providers and citizens. Participation has been enhanced at the federal level in Germany, but more needs to be done at the regional and local levels of decision-making in Germany, in particular with respect to the decisions at the level of the joint decision-making of providers and insurers. Further regulation in this respect might be expected.

The combination of strengthened voice, representation and choice coupled with the development of the ombuds system is changing the culture of health governance with respect to setting the policy agenda, transparency and justifications of decisions.

4.4 Public involvement in priority-setting in Sweden

“Public participation is achieved mainly through information and consultation, but priorities are based on expert analysis and political leadership.”

Case report

Sweden has a compulsory health care system providing coverage for the entire resident population. Sweden’s system is mainly publicly financed by means of general taxation. It has specific power balances between the national, regional and local levels, a strong focus on equity in access to care and intersectoral health work. The system also features regional planning of specialist medical care. Regional-level planning is intended to incorporate public and personal health perspectives. Regional- and local-level participation is ensured via voice and representation mechanisms through general elections of county councillors. In addition, many health committee meetings at the county level are open to the public. Other mechanisms are user councils, citizen dialogues, study groups and health barometer surveys – public and patient surveys are frequent. The boards of hospitals are currently implementing pilot projects on patient participation. Sweden has no patients’ rights legislation.

One of the most important experiences in Sweden of participation in policy decision-making has been a process of discussing priorities for health care in public. Long waiting times for medical interventions, especially elective medical care, triggered the priority-setting process, which aimed at guiding decisions on resource allocation.

Observations of substantial differences between counties on outcome indicators from medical interventions also stimulated the process. The work of the Swedish Parliamentary Commission on Priorities in Health Care from 1992 to 1995 prepared the consultation on medical priorities. The basis for the process was a document issued in November 1993 discussed with experts and citizens in numerous public consultations. The Commission published a final report in May 1995. The Commission based its work on three key ethical principles: human dignity, recognition of needs and solidarity and cost-efficiency. Public participation was not one of the principles.

The expected outcomes were two sets of guidelines: guidelines for the political and administrative level and guidelines for the clinical level. The clinical guidelines were organized around five priority groups (*Box 2*).

Priority group	Content of care
IA	Care of life-threatening acute diseases and diseases that, if left untreated, will lead to permanent disability or premature death
IB	Care of severe chronic diseases. Palliative terminal care. Care of people with reduced autonomy
II	Individualized disease prevention in contacts with medical services. Rehabilitation as defined in the Health and Medical Services Act
III	Care of less severe acute and chronic diseases
IV	Borderline cases
V	Care for reasons other than disease or injury

Box 2. Priority groups in clinical activity in Sweden

The priority-setting explicitly excluded several factors, including age, birth weight, self-induced diseases and the economic and social conditions of a patient. The government established a committee in 1998 to promote implementation, follow developments among county councils and take into account international developments in priority-setting.

The Western Health Services Region, which employs 48 000 people in 17 hospitals and 160 health centres, often serves as model for the implementation of the recommendations from the Parliamentary Commission. One of the major implementation tools is the resource allocation model, which was developed following the work of the Parliamentary Commission. The purpose of developing a new resource allocation process was to implement the national requirements regarding priority-setting, work towards a more equitable health system, develop better tools for managing the system at both the clinical and regional levels, develop a more balanced contract between clinicians, managers and politicians and break the traditional habits and accept priority-setting as a joint task.

The Western Health Services Region allocates resources based on a basic formula by geographical region to local health boards. The regional health councils determine resource allocation between different fields of medicine.

Allocation decisions between medical specialities are called horizontal priorities. Within disease groups, decisions are based on vertical allocations grading different interventions. Twenty-two medical expert groups were formed, representing hospital and primary care perspectives and all major medical fields in order to advise health service managers and politicians on implementing the recommendations of the committee on priorities. They have worked on a systematic priority exercise for the past three years. Each medical speciality has listed their activities according to a common framework. Distinct groups of patients are categorized according to their need for care in the above-mentioned four broader national priority-level groupings based on the disease (I–IV) and a more detailed list of 10 scores for medical interventions (1–10). Interventions are graded according to the preferred method of intervention for the patient, the medically indicated acceptable waiting time, an estimation of effectiveness by doctors, scientific evidence of effectiveness, and cost-effectiveness of the intervention.

Table 1 reflects some elements of this priority-setting process.

Indication	Treatment	Priority I-IV	Priority 1-10	Acceptable waiting time for ambulatory care (weeks)	Acceptable waiting time for an operation (weeks)
Gallbladder cancer	Operation	I	2	2	2
Gallstone	Laparoscopic/open operation	III	5	12	12
– without symptoms		IV	8	26	26
Obesity, BMI>40	Operation	I	5	26	26
Soft tissue overflow	Operation Operation	III	5	26	52
– disabling – cosmetic		IV	9	No limit	No limit
Menopausal dysfunction	Pharmaceutical treatment	III	3	2	NA
– severe		III	6	6	NA
– medium – light		IV	8	12	NA

Table 1. Selected criteria for and examples of medical intervention priorities in Sweden

The priority-setting exercise built on the motivation of physicians to create a better platform for allocating resources between specialities. It resulted in a detailed priority listing for practically all frequent medical interventions, a rank order in all medical specialities, judgements or statements according to a common framework and a validation procedure between specialities. An internal evaluation procedure has started whereby one medical speciality rates another.

There are now plans to use the vertical priority lists within the horizontal resource allocation, adding volumes of interventions and resources. There are also plans to enhance the utilization of scientific evidence. An expert management function will be established to manage the priority-setting exercise. Political activities will reassure and support the process but not interfere in the medical ranking. The public health care system is expected to have to address specific sensitive issues to exclude interventions from coverage in the public system.

Discussion

Public participation was ensured by considerable coverage of the process and the proposals in the mass media. Specific information campaigns were organized to describe particularly difficult issues of valuation and choice. There were several consultations with the public at an early stage on the principles to be adopted. Discussions were also organized with patient and consumer interest organizations. However, although there were numerous information campaigns and public consultations, overall public opinion did not contribute much to the priority-setting process in Sweden, which is still very much driven by politicians, managers and clinicians.

Canada is taking a more proactive approach towards public participation in setting priorities for care. First a survey is undertaken to recruit citizens who are interested in contributing to policy-making to create a pool of interested citizens. The group of people first obtain a briefing from experts on the subject. They are then isolated and continue to collect information on the subject. After a few months, they meet with the same experts again and initiate a debate.

A similar experiment was undertaken in Israel, where the health minister nominated a number of citizens representing different professional groups to let them decide about a set of health care interventions. In the experiment, the group was to allocate an imaginary US\$ 1 million among health care interventions. They were equipped with an intersectoral list of medical interventions and were supposed to weight the different interventions by certain monetary amounts. Unfortunately, the experiment was not finished as it turned out to be too lengthy and thus too costly for the committee to come to consensus.

In Sweden's case, public participation is achieved mainly through information and consultation, but detailed priorities are based on expert analysis and political leadership on the principles to be applied. Although public participation may not appear to have been particularly strong in this case, the fact that the process was open and transparent and led by clear political direction to which the public could contribute has added to its acceptance. This aspect of health governance in Sweden may reflect high levels of trust in society.

4.5 Patients' rights in Belgium

“The ombuds function can be a powerful support for patients' rights and patient influence on health policy; it needs to be linked to other mechanisms for patient involvement including patient voice organizations and political representation.”

Case report

Belgium's health care system is based on principles of patient orientation and an integrated approach to health promotion, disease prevention and treatment. There is a trend towards a whole-person approach to health, seeing more in the patient than the disease and its treatment. This trend is reflected in a progressive movement to achieve a more balanced relationship between patients, health care providers and managers.

The preparation of patients' rights legislation is a good example of how consumers are consulted in a legislative procedure. The Patients' Rights Act of 22 August 2002 enshrine the rights of patients and aims at strengthening the legal status of patients within the health care system and improving the quality of patient relations with health care providers and the authorities. The Act stipulates the following rights: the right to high-quality care; the right to choose the health care provider freely; the right to information on health status; the right to informed consent; the right of access to medical records and to a copy of these records; the right to the protection of privacy; the right to lodge a complaint with the ombuds function; and the right to receive the most appropriate care to relieve their pain.

Taking into account the views of all involved parties before adopting the Patients' Rights Act was important. Several parliamentary hearings consulted patients about the draft act and also consulted other stakeholders such as health care providers, hospital managers, legal experts and others.

The following concrete measures were added to the Patients' Rights Act as a consequence of the consultation with patients: adopting separate legislation on patients' rights, rather than embedding it in other legislation; the right for patients to consult their medical records directly; and arrangements for patients unable to exercise their rights.

The Patients' Rights Act also led to the foundation of the federal Patients' Rights Commission. The Commission comprises four ordinary members and four alternates, representing patients, health care providers, hospitals and health insurance institutions. They have the following responsibilities: to gather and process information about patients' rights; to advise the Minister for Social Affairs and Public Health, on request or on its own initiative, about the rights and duties of both patients and health care providers; to evaluate the implementation of the rights of patients; to evaluate the functioning of the ombuds office; and to handle any complaints about the functioning of the ombuds office.

All patients can complain about a health care provider in a local mediation office. If there is no local mediation office, the federal mediation service for patients' rights is responsible. Every hospital has two ombudspersons representing the French and the Flemish communities, respectively.

The federal Patients' Rights Commission exercises considerable influence on policy decisions. The Commission issues an annual report on the discharge of its duties to the Minister for Social Affairs and Public Health, including a discussion of the problems in implementing the rights of patients, the functioning of the ombuds office and proposals for improvement. It also issues reports and opinions on an ad hoc basis: for example, protection measures for people with mental disorders.

The patient ombuds offices work in hospitals and in psychiatric group practices. There is also a federal ombuds office. The policy influence of ombuds offices is expressed through annual reports, which largely originate from patients' complaints and comments. The reports include surveys of complaints, information on the subject and outcomes of complaints, difficulties encountered when dealing with the complaints and recommendations. The offices submit the reports to the Minister for Social Affairs and Public Health and the federal Patients' Rights Commission.

Discussion

The Commission started work in September 2004 on the nomination of the Commission members. The Commission's work is anticipated to be evaluated. For now the collaboration is considered constructive, and an important achievement is that it has allowed continuous movement away from a system that previously focused on providers and insurers and was driven by budgetary constraints. With the patients' rights legislation, the system is now progressively moving towards being more oriented towards patients.

The ombuds function is an important element of patients' rights legislation in Belgium. Through the ombuds offices, patients can exert influence by providing feedback on provider performance, and they can issue complaints about providers. Complaint procedures are organized at the federal and local levels. The help provided by ombuds offices is wide ranging, such as financial and psychological help.

Some of the discussion on the ombuds function – which originally stems from the Swedish system – focused on the procedure of appointment of ombudspersons in the different countries and whether the ombudspersons are sufficiently independent. In some countries such as Germany, the ombudsperson at the federal level is a politician appointed by the Government. In Slovenia, Parliament appoints the ombudsperson. In the United Kingdom, a health ombudsperson focuses on administrative issues and local, independent services for complaints advocacy, but these play very little role in health policy. In most countries, patient organizations seem to play a minor role in appointing the ombudspersons.

Belgium's case has shown that the ombuds function can be a powerful support for patients' rights and patient influence on health policy, but it needs to be linked to other mechanisms for patient involvement including patient voice organizations and political representation.

4.6 Participation in strategic health planning in Portugal

“The opportunity to engage with health policy in an open and transparent way is helpful even if not all those invited become involved or when popular preferences are overturned.”

Case report

In Portugal voice mechanisms achieve much of the public participation in health policy. The development of the current national health strategy is a good example of how Portugal is engaging people in the policy-making processes.

An earlier national health strategy document is thought to have failed due to the lack of public, political and expert consultation. Plans for the development of the current national health strategy therefore included widespread consultation exercises to involve all stakeholders at every stage in the development and implementation of the strategy. The national health strategy was planned in three phases. Phase I from 2002 to 2004 included a situation analysis, setting of national objectives, definition of specific, measurable, achievable, realistic and time-bound (SMART) targets and issuing strategic guidelines. Phase II from 2004 to 2006 included launching

the strategy, making structures, indicators and resources operational and allowed for reformulating the plan if necessary. Phase III will last from 2006 to 2010 and will entail implementing and monitoring the strategy.

During the first phase, a major consultation process was initiated. A draft strategy was placed on the web and a web site discussion forum initiated in January 2003. From October 2003 to March 2004, several thematic public consultation meetings were organized on topics such as research and health, environmental health, social care, and poverty and health. Specific questions for the public consultation were developed, and representatives of the mass media and political parties were personally invited to all the consultations. A second draft of the strategy was submitted for public discussion for the whole of 2004. The results of the participation exercise showed 108 responses to requests for views and opinions – somewhat disappointing given that 614 requests had been sent (*Fig. 1*). Most contributions were received from civil society (42), academic institutions (32) and staff from the Ministry of Health and the National Health Service.

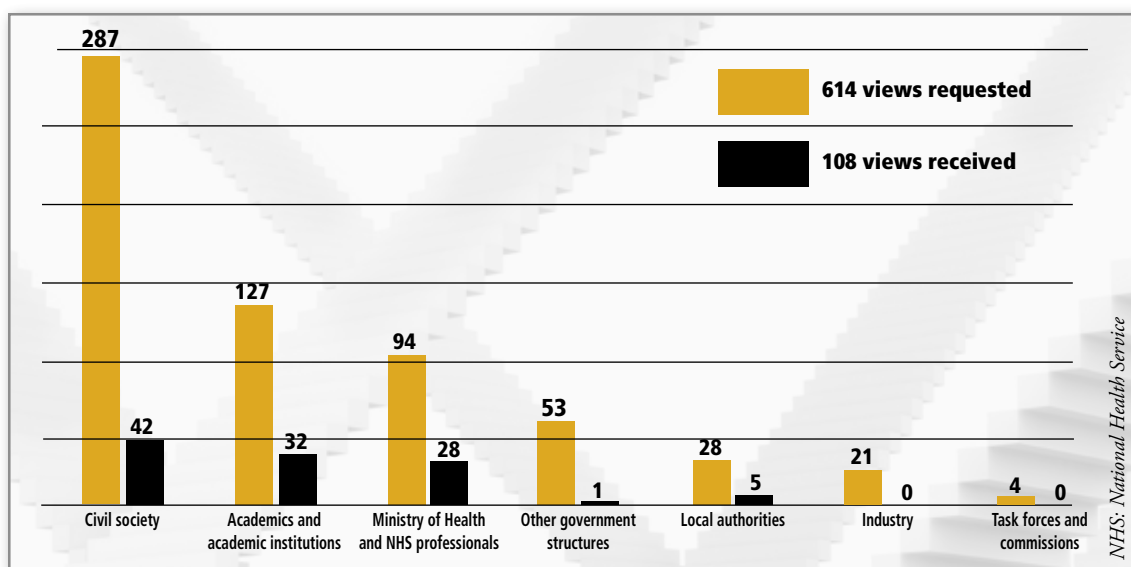


Fig. 1. Requested and received views on the national health plan in Portugal, December 2004

The implementation of the strategy from 2006 to 2010 is another phase of the process that will feature participation. In particular, regional and national forums will be organized – aiming to increase visibility of and awareness for the plan – as well as the strategy to mobilize stakeholders such as people working within the National Health Service. Mobilization strategies are themselves participatory mechanisms. The High Commissariat for Health is coordinating, promoting, reporting and monitoring implementation, and the implementation phase is currently starting.

Discussion

Portugal's case is a good example of public participation through voice, enacted through public consultation. It may have been one of the most transparent consultations of a public policy document in Europe in recent years.

Measuring the success of public consultation is difficult, since not all results of a participatory policy process will be attributable to public participation. One option is to take a stepwise approach, assessing progress regularly, for example, once a year using qualitative measures of progress and commitment. In Portugal, one demonstration of the success for the development of the plan in total has certainly been that commitment to the policy has sustained support to the plan even when the government changed in 2005.

An important concern is to recognize the disappointment of people when a policy decision does not reflect their preferences. Taking a decision differing from the preference of the majority of the population may be necessary: for example, to control costs. In such cases, participation is nevertheless valuable, but ensuring transparency in the decision-making process and explaining the process of consultation and the impact it had on the decision-making process are vital.

Wide-ranging participation seems to be preferable, but the opportunity to engage with health policy in an open and transparent way is helpful even if not all those invited actually become involved and even when other considerations overturn popular preferences.

5. Summary and conclusions

5.1 Defining what comprises good governance in public participation

Good governance and public participation are intertwined. The definition of good governance entails a participatory process, responsiveness of governing institutions to the views and preferences of consumers and a consensus orientation. Accountability and transparency are further essential components of good governance. Public participation is a tool within governance leading to greater system responsiveness.

This does not mean that public opinion can or should be the deciding factor in every health policy decision. Good governance also requires political leadership and evidence-based decision-making. It involves a wide range of stakeholders and interest groups including health professionals, representatives of wider civil society and industry. Ultimately, politicians have to set policy direction on behalf of the people who elected them, and civil servants, managers and health professionals have to exercise their technical expertise in taking specific decisions and guiding patient choice. However, public participation is still important when unpopular decisions are required because understanding and working with public perceptions are essential if decisions are to be respected and upheld in the long term.

5.2 Creating the right prerequisites for participation

The Futures Forum participants agreed that three factors are most important in creating the right preconditions in health systems governance and policy-making for participation. The first is the quality of health education and information, the second is transparency and the third is health system design.

Health education and information are needed since effective participation requires the health literacy of consumers. More progressive social marketing and education on health issues, use of the mass media and other ways of communicating information can support this. There are potential pitfalls in disseminating information: for example, when using methods that exclude people who do not have access to them (for example the Internet or digital television) or even information provided in language or jargon that everyone does not understand. Other risks include information overkill, providing information in the wrong form or at the wrong time and appearing to impose values on the public.

Participation requires transparency since people will not become involved unless they understand the policy-making process, the policy decision at stake and the impact of their voice or choice on the decision and on the different positions of the health policy-makers who are responsible. Nevertheless, making the policy-making processes transparent also requires that decision-makers show courage despite being potentially subject to more criticism from the public, in particular when decisions negatively affect health care benefits.

Some aspects of health system design are clearly directly related to mechanisms for participation: for example, choice of insurers requires competing insurance schemes. The case from the Netherlands suggests that offering the same insurance package through different sickness funds may not be sufficient; they are now seeking to offer options to choose from different benefit packages in a more open market. This will make health insurers more

responsive, but if health consumers are unable to assess their long-term needs this could lead to worse outcomes. Similarly, choice of health provider may lead to different hospitals offering exactly the same service or it could result in hospitals offering quite different styles of treatment and service to attract patients. For example, some women may prefer to be solely treated by female staff.

Thus health education, information, transparency and system design are important factors in creating the right preconditions for public participation. But there is no simple formula for this; it requires that policy-makers be highly sensitive to the populations they serve.

5.3 Deciding on options to enable participation in health systems governance

The cases discussed at the Futures Forum showed that voice, representation and choice supported by patients' rights are complementary elements of an overall approach to participation. The appropriate balance of such elements depends on the current culture of each health system. For example, in some cases people have high levels of trust in political leaders and health managers and professionals, whereas in other cases building this trust from a relatively low level may be important.

Considering other aspects of the health system in which such mechanisms are invoked is also important. For example, health insurers or purchasers and providers are publicly owned organizations accountable to political representatives in some systems but not in others. Similarly, the system may include variable co-payments or other incentives that influence consumer decisions.

The mechanism chosen also depends on the policy question at stake. Voice mechanisms such as citizens' surveys and discussions with patient organizations may be most appropriate when dealing with an issue affecting specific types of patients. Representation may be more appropriate when dealing with system-wide changes at the national or local level. Choice allows the equivalent of market forces to guide the evolution of the system.

Whatever mechanisms are deployed, they require political commitment and training at all levels for behaviour change, a legal basis for patients' rights, a network organization to support local initiatives and technical resources such as training, measures of patient perception and expertise to engage communities across ethnic and social divides as part of a broadly based approach to active citizenship.

The Futures Forum concluded that there can be no standard for how much participation systems should allow or what mechanism to deploy in what combinations. The degree of public participation in a health system will depend on cultural factors and the characteristics of the system. It is a value-based decision in each system how much power citizens or patients exercise in the decision-making process. However, it is clearly important to consider all three types of mechanism for participation and to maintain a balance between them.

5.4 Participation as a goal in its own right

A healthy society is one in which levels of trust in both governance and the community in general are high. Evidence suggests that people with widespread social engagement through different networks improve their opportunities for health and well-being. Involvement in health decisions may both increase public understanding

of and trust in public policy decisions and also create and support other forms of networking. Thus, increased participation can be regarded as a goal in its own right. However, this may also depend on the management of the process of involvement, since if the experience of involvement disappoints or disillusiones the members of the public, this may lead to dissatisfaction and decreased trust in others and specifically in health governance.

5.5 Making participation a main requirement of policy-making

Despite the differences between countries and systems, the Futures Forum shared a clear consensus that increased public and patient participation is a necessary and growing trend in all the systems discussed.

Three main reasons underlie this trend. First, public participation improves the responsiveness of the system to the views and preferences of health consumers. Second, participation is essential for the full engagement of the members of the public in managing their health. Third, public and consumer engagement in community organizations is essential to the health of the community and the provision of care.

In recent years, consumerism has developed in all European countries. People now expect health services to be designed around their personal needs, offered at times and in ways to match their lifestyles and to reflect the level of customer service they find in other industries. But health is not simply another form of consumer product; health is a public good mostly financed by taxation or social insurance and hence effectively free to the consumer. For this reason, health policy decisions require collective decision-making. Health is also a product of personal and community action as well as treatment services. Further, as the number of older people requiring health and care services increases and the number of family carers declines, health care will rapidly become unaffordable unless people can be engaged both in protecting their health and in the care of others in the community.

The participants at the Futures Forum agreed that health systems need cultural change progressively away from seeing patients and citizens only as patients, potential patients, clients or health consumers towards treating them as partners in policy-making. Such a cultural change will require time for health care professionals, health care managers and the public to accept. Although this cultural change may occur naturally in the long term, an essential task of health governance is to facilitate this change in time to ensure that health and care remain affordable.

5.6 Learning from experience

The Futures Forum agreed that, given the importance of this topic and the many difficulties it presents, establishing and maintaining learning networks on patient and public involvement in health would be helpful.

Traditions and culture, system design, political context, socioeconomic situation, and access to care differ substantially across Europe. European countries also differ in health challenges. One cannot therefore simply transfer methods of involving the public and patients from one country to another; no one-size-fits-all models enable greater public participation in health policy-making. Different countries need different approaches to public participation and thus different interventions. However, countries' approaches to participation provide valuable lessons to be learned and opportunities for countries to share experiences.

Another possibility for learning from experience is to look at other sectors within countries. The Futures Forum participants agreed that many industries, including the food, automobile and aviation industries, have been more successful in tailoring products to consumer preferences, and that, although health as a public good is very different, learning from the experience of such industries would be useful.

The Futures Forum therefore agreed that making the subject of public participation better known, collecting and publishing examples of good practice and creating a European network of experts to exchange practical experience with public participation in health systems would be important.

5.7 Developing community participation

Public participation in health policy often engages with groups representing specific local or ethnic communities and specific patient groups. The case studies presented recognized that working with such groups is a way of supporting participation. They may form a local or regional network of patient and consumer groups as in the Netherlands and Switzerland and can be an important source of mutual support for members.

One of the strengths of patient and community groups is their continuity, so that organizations involved in a voice consultation exercise are likely to be able to follow up and monitor the outcome of policy decisions. These groups also build up knowledge and understanding of health issues and specifically the particular diseases and particular local service issues. These strengths are further enhanced if the organization has a national structure so that it can capture a variety of experience and identify the best and worst experience of health services across the country. For this reason, many health governance systems now provide support to patient and consumer organizations at the local, regional and national levels and involve them in health policy.

Although some patient groups already have a presence at the European level, engaging national federations of patient and consumer groups in the proposed European network on public and patient involvement in health would be helpful.

5.8 Consulting different people for different policy decisions

Input to health policy decisions depends on the interests of the group consulted. For example, in choosing an individual health plan, people with cancer will in principle vote for more health and care benefits, whereas healthy consumers may rather opt for lower contribution rates, accepting a more limited package of benefits. Likewise, decisions can differ from one representative patient group to another. Decisions of individual patients and patient groups may also differ depending on whether they will affect health on an individual or collective level. For example, excluding a benefit from a package under solidarity funding will affect some patient groups more strongly than others. Similar considerations may also affect collective decisions such as whether access to specialist care should be subject to referral through a general practitioner. Opinions on policy decisions may also differ depending on the point of care that is affected, whether it is health promotion and disease prevention, treatment or rehabilitation.

As noted in the case in the Netherlands, a single body will always have difficulty in developing a consensus of the views of all consumers and patients on all health decisions. One approach is to develop a loose network or coalition of local and regional bodies that can itself present either a single consensus view or the multiple views

of its member organizations. Even so, it will be important to recognize the specific interests of the organizations consulted. For example, pharmaceutical industries fund many patient organizations, and although they may provide perfectly legitimate input to health policy, any such interests should be transparent.

France's case showed that members of the public can be consulted directly on health policy decisions; this also applied to the consultations on public health policy in the United Kingdom. In developing public participation, considering the issues on which to consult with specific patient organizations, when and how to consult with coalitions of consumer and patient organizations and when to consult members of the public directly are important.

5.9 Focusing on hard-to-reach population groups

One of the core challenges of increasing public participation is that it may lead to greater inequity in policy-making, as people who are well educated, well informed, and well off are very likely to participate, whereas the more hard-to-reach, vulnerable groups – immigrants, older people, people with mental and physical illness and those who lack language skills – will probably not participate as much. This raises equity concerns, as people who are marginalized in society will also probably be excluded from decisions in health systems governance. It can be assumed that involving hard-to-reach groups in collective participation will be especially difficult, since most of the people in this category will understandably have much more concerns about their individual problems and other community concerns – in this context health may be a lower priority for such individuals and community groups.

Policy-makers should consider the impact of different mechanisms for increasing participation on other health goals such as equity. People with more education and time are likely to dominate the opportunities to express voice, representation is likely to represent the political majority to the exclusion of ethnic and other minorities and educated, confident consumers more easily exercise choice. Such biases should be recognized and countered by specific measures to engage minority and disadvantaged groups.

This requires that policy-makers target hard-to-reach groups to invite them to participate in decision-making processes and communicate the benefits of choice – collective or individual – more explicitly. Encouraging the formation of further representative and self-support groups by, for example, providing training in community leadership and social enterprise may also be important. Gathering international examples of best practice in this field would be particularly useful.

5.10 Working towards long-term multi-level action

The Futures Forum clearly showed that public participation in health governance will be an ongoing long-term project requiring multi-level action in all countries. Other governance sectors, such as education, social, employment and families, will also contribute, by educating people as better informed health consumers, by increasing social security and employment and making people more open towards collective participation in health systems governance or by strengthening families to see themselves as co-producers of health. Effective public participation will require cultural change to a more fully engaged society across all sectors.

5.11 Selecting the political decisions in health requiring public participation

Good governance implies that decision-makers are able to select the health policy decisions that either require or will benefit from public participation. Public participation will be neither feasible nor sensible for all policy decisions. What can be achieved by public participation must be clarified. This requires decision-makers to differentiate between the decisions at stake when deciding whether to seek the views of the public or not. It also requires the right timing in seeking people's views. An earlier Futures Forum, for example, presented the rationale for Ireland in seeking public consensus on new rigorous tobacco control legislation.⁵ Explicitly, public opinion surveys were conducted only after disseminating evidence about the harms and risks of passive smoking and after the political decision about the legislation was launched.

The selection of policy decisions to open for public participation is a difficult task, and the process of selection itself must remain open for scrutiny and justification.

5.12 Monitoring public participation in health systems governance

Evaluation will be difficult. As in other fields of health system observation, randomized controlled conditions cannot be created that would allow reliable interpretation of the causality of policy and effects. The development and impact of participatory policy-making needs to be monitored in a gradual step-by-step process. This requires both external academic review and closer observation and reflection by health policy-makers and public and patient representative groups.

5.13 Next steps

The Futures Forum has shown that any final conclusion on public participation in health systems governance is far away. More work needs to be done on defining principles for public participation in health systems governance, and more experience will have to be collected on good practices in involving the public through voice, representation and choice.

It is hoped that this Futures Forum will be a starting-point for a European network for the exchange of experience between those concerned with developing, applying and studying the impact of public participation on health governance. As a first step in supporting this development, a network wiki site has been established for the exchange of contacts and information at <http://www.ukglobalhealth.org/whoeuro>. This allows participants to load their own contacts, news and experience. Please join this European initiative.

⁵ *Seventh Futures Forum on unpopular decisions in public health, St. Julian's, Malta, 11–12 November 2004*. Copenhagen, WHO Regional Office for Europe, 2005 (<http://www.who.dk/document/e86722.pdf>, accessed 28 November 2006).

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