

ENGAGING CITIZENS IN THE DANISH HEALTH CARE SECTOR

by Daniel Blume

Executive Summary

The report examines how Denmark approaches “government-citizen connections” – provision of information, consultation and active engagement of citizens – in the public debate over the provision of health care. The study includes a special focus on the role of patient groups, because of their growing number and impact on the policy debate.

The report begins by providing a review of the structure of the Danish health care sector and of recent developments. The Danish health care sector is characterised by substantial consensus around certain basic values, namely that all citizens should have free and equal access to public health care services and free choice of a primary care doctor and of hospitals. Debate tends to focus on issues around the margins of these basic agreed values, such as the extent to which private insurance and private hospitals may play a role in the system; who takes on responsibility for what services; and where resources should be focused.

The report goes on to outline the evolving roles of doctors, patients, administrators and political representatives. Alongside the traditional reliance on medical expertise for decision-making in health care, the influence of patients – at both the point of service and policy-making levels – is increasing. Among the most important vehicles are “patient groups” formed around concerns about particular diseases or health problems (e.g. heart disease). Initially restricted to education and awareness-raising, many of these patient groups have now explicitly taken on policy advocacy as an important role, and the largest ones are routinely invited to participate in parliamentary committee hearings and to comment on draft proposals by the Ministry of Health.

Denmark has introduced a range of practices aimed at promoting stronger citizen involvement and balanced public input into health care policy decisions:

- *Consensus conferences* in which “lay-persons” (non-experts) meet to hear experts’ and policy officials’ views on a selected issue, to deliberate among themselves and deliver a consensus view.
- *User surveys* conducted by the national and regional governments whose results are used in the management of the services as well as in the development of medium-term plans for health care.
- *User boards* for obtaining input on the quality of services, monitoring complaints and highlighting user concerns for particular institutions (e.g. hospitals) or services (e.g. psychiatric care).
- *Patients’ choice* which provides important feedback on the overall quality of the public health care system and reflects user preferences.
- *Specially designed mailings, written comments and public hearings* have also been used in the development of four-year county plans for health care.

The challenge for Danish policy-makers today is to make effective use of the range of tools available for obtaining input into their decisions while ensuring that they are both responsive to the range of public interests, and that these decisions also make good public policy. This entails obtaining advice from policy analysts and medical experts, feedback from users, the view of stakeholders with much to lose and gain from decisions, and the opinion of the average citizen. At the same time, safeguards are needed to ensure that during decision-making the inputs received by these various groups are balanced against the broader public interest, which may call for a different allocation of resources either within the health care sector or between sectors (e.g. education or social services). **The case study was submitted to the Secretariat in 1999 and covers events up to that date.**

Introduction

This study examines how Denmark approaches “government-citizen connections” – provision of information, consultation and active engagement of citizens – in the public debate over the provision of health care. The study includes a special focus on the role of patient groups, because of their growing number and impact on the policy debate. It seeks to highlight key challenges of democratic decision-making in the Danish policy development process, promising practices for informing and involving citizens, and issues for further debate.

A country of 5.3 million people, Denmark is known in public management circles for having remarkable support for its public institutions. Voter turnout for parliamentary elections has exceeded 80 per cent for each of the last six elections and rose to 88 per cent in 1998; participation in county council elections hovers around 70 per cent; and turnout for municipal elections has ranged between 75 per cent and 87 per cent over the last 15 years. Comparative surveys of 13 countries conducted by the World Values Institute and supplemented by Danish Government-sponsored surveys show average confidence in Danish public institutions in the range of 65-70 per cent over the last two decades, ranking along with Iceland and Norway at the top of the list. Only 8 per cent indicate dissatisfaction overall with the public sector.

Denmark in 1998 had the second highest public expenditure across all levels of government within the OECD, behind Sweden (55.1 per cent of GDP, according to the *OECD Economic Outlook*). Even so, citizens indicate a willingness in some cases to raise taxes even further in exchange for additional services, as well as support for current levels of taxation.²⁹ Among a range of public sector responsibilities, the health care system is one of the best supported of all: a 1997 Eurobarometer poll comparing all EU countries indicated that 90 per cent of Danes were very satisfied or reasonably satisfied with their health care services, higher than in any other country in Europe.³⁰ Moreover, actual users of the system report higher average levels of satisfaction than non-users, whether for emergency care, primary care or hospital treatment.

Yet, not everything is going as well as such surveys might imply. There has been a growing focus in the media on problems in the health care sector, according to those interviewed for this study. Patient groups in particular have highlighted areas where waiting times for treatment and mortality rates in relation to certain diseases compare unfavourably to other European countries, and the Danish average life expectancy, while growing, has fallen behind most OECD countries in recent years. As expensive new technologies and treatments become available, new demands for increased expenditure are also emerging. Yet health care expenditure decreased in real terms in the late 1980s and early 1990s, but more recently (through 1997) was growing by 1 per cent to 3 per cent per year in real terms, slightly behind Danish GDP growth. All of these developments appear to have taken a toll on the public debate over what many indicated is the number one or number two issue of concern in Danish politics. Thus, debate over Danish health care policy is taking place within a seemingly contradictory environment of high overall levels of satisfaction while at the same time experiencing critical examination of how further improvements could be made.

Purpose and Limitations

The factors cited above make the Danish case – and the health care sector in particular – a rich and promising subject for comparison with other country experience as part of a series of case studies being undertaken within the PUMA activity on “Strengthening Government-Citizen Connections.” The aim of this report is to highlight issues where further consideration and debate could be beneficial, and to provide information and analysis on practices and approaches from which other OECD countries can learn.

However, this study does *not* seek to conclude how well the health care system and policy development processes are working overall. The OECD has not developed an agreed framework for such an evaluation, and the number of interviews conducted for this study was necessarily limited in scope due to resource constraints. The study is based on interviews with representatives of some

20 organisations cutting across Danish national government (members of parliament and civil service), county government (Aarhus County), stakeholder groups representing patients, the elderly, pharmaceutical companies, doctors, the media and academic research, along with related written material.³¹ Resource constraints also precluded comprehensive treatment of the issues across the national, county, and municipal levels. While focusing mainly on the national level, the study partially addresses health care at the county level, where most services are provided, through a look at several practices within Aarhus County that appear to be innovative and promising. The municipal level is not addressed because it plays a relatively minor role in health care provision (responsible for home health care, nursing homes, dental care and some preventive services).

The Danish Context

As noted above, Denmark has a history of strong support for, and confidence in, the public sector and open government, and a view that its democratic institutions function relatively well. Any citizen can request and have a meeting with Parliament or a minister, though in practice most consultation with parliamentary committees is by invitation. Danes are said to be “joiners” of organisations, and benefit from a well-educated population and active civil society, though membership in groups and political parties, as in most countries, is declining. Policy-making tends to be based on the building of consensus; several people interviewed made reference to waiting until an issue is “ripe” before acting on it.

Local government plays a strong role in the Danish approach to democracy. Denmark experienced continuing waves of devolutionary public sector reform in the 1970s and 1980s, as services in a variety of areas were decentralised to the county and municipal levels of government. Regional planning, primary health care services, care for the disabled, secondary schools, environmental quality, and public transport moved from the national level to the counties, while social security became a municipal responsibility. These changes were part of a wider OECD trend toward devolution, supported by a view that placing decision-making responsibilities closer to the level where services are delivered can facilitate democratic participation, responsiveness to citizens’ wishes, and strengthen the link between those at the management and decision-making levels. The 14 county and 275 municipal governments in Denmark have the authority to set their own tax rates, and their activities represent approximately half of public spending. While the national level maintains responsibilities for setting overall spending targets and negotiating overall expenditure and revenue agreements with the county and municipal level in the pursuit of a national macroeconomic policy, the counties and municipalities have significant independence.

At the national level, 179 members of parliament are elected on a proportional basis to serve in the unicameral parliamentary system. A coalition of two “centrist” political parties, the Social Democrats and Social-Liberals, currently form a minority government. The majority opposition is split between groups to the left and to the right of the governing coalition, providing the government with flexibility to move toward the left or toward the right to obtain a majority on legislation.

Within the government, the Ministry of Finance plays a strong guiding role in determining national fiscal and economic policy, including expenditure levels for each policy sector. It co-ordinates development of the budget, which requires parliamentary approval. The ministry also plays an important role in managing relations with the county and municipal levels, serving as the lead negotiator with the association of counties and association of municipalities in annual budget target agreements. These agreements not only establish overall spending targets in the various policy sectors at both national and sub-national levels, but also include a range of performance targets for achieving other national policy objectives. Other ministries, including health, also participate in these negotiations. In negotiating on behalf of the counties, the Danish Association of County Councils must reach consensus among all 14 counties. The National Association of Local Authorities in Denmark is also involved in consensus agreements on economic and service objectives at the local level. These annual agreements are not formally binding, but do indicate the broad lines of government policy for the short term (one year) and medium term (four years). Parliament also has a role in their implementation: some initiatives agreed upon between the parties in the negotiations require parliament to pass new laws or to change

existing laws in order to take effect. Parliament also decides on block grants amounting to approximately 10 per cent of total local government expenditures.

Danish laws regarding provision of information to the citizen are quite open, though subject to some important exceptions. Under the Danish Access to Public Administration Files Act, any person may demand access to documents received or issued by an administration authority in the course of its activity. This applies, for example, to all letters received from private citizens and businesses and replies sent by governments. Furthermore, subject to specific exceptions, any person whose personal circumstances are referred to in a document may demand access to such references. Notable exceptions include documents used in internal decision-making processes, documents prepared in connection with consideration of European Union proposals, and information on the private circumstances of individuals or businesses, including where protection of private or public interests are needed because of the special nature of the matter. The Law on Organisation in the Municipalities requires municipal councils to account to the public on all important municipal benefits that are provided or planned.

The Public Administration Act also imposes important restrictions on transmission of personal data from one public authority to another, including information on race, religious belief, membership in political or other societies, sexual behaviour, criminal offences, health, and severe social problems such as drug abuse.

Legislation tends to be less specific and prescriptive regarding public consultation, allowing public authorities some flexibility on how they consult.

Interest groups are considered to be having an increasing influence on policy, not only through direct participation in policy debates, but also through a growing sophistication in working with the media to promote the appearance of articles that support their causes. While no data were available on the overall number of non-profit groups existing in Denmark, it was noted that there are some 180-200 non-profit groups representing different interests within the health care sector alone.

While there are many signs of a strong democracy in Denmark, Danes also maintain a critical outlook, focusing on ways to further improve its functioning. One indication of this is the Danish Parliament's decision in 1997 to establish an independent steering committee to oversee a six-year study of the state of Danish democracy, costing DKK 50 million (6.7 million Euro). The purpose of the study, according to the 1997 report of the Parliamentary Committee for an Analysis of Democracy and Power in Denmark, is "to illuminate the function of democracy in broad terms, including the influence of organisations, movements, and economic power structures in society, as well as the consequences of internationalisation as far as transparency of decisions, influence and power in society is concerned." The study builds upon research traditions and frameworks established through a Norwegian study of power in the 1970s, and by a 1980s Swedish study on these issues. The study is motivated, among other things, by a sense that democracy no longer works as it did in the classical descriptions of Danish democracy, due to such factors as advances in information technology and communications, internationalisation of policy-making, and other changing social conditions.³²

Background on the Danish Health Care Sector

The Danish health care sector is characterised by the existence of consensus around certain basic values:

- That all citizens should have *free and equal access* to health care services.
- That this service should be furnished *primarily by public health-care services* and financed almost entirely through tax revenues.
- That users of the system should have *free choice* of a primary care doctor (within 10 kilometres of their residence with exceptions granted in certain other instances), and of hospitals.

The national level establishes the overall budget framework and national goals, as well as legal requirements for provision of health care. Counties run most of the services (through public hospitals and contracts with primary care doctors), and have flexibility to set priorities and allocate resources to be responsive to local demands within the overall national framework. Municipalities are responsible for

home health assistance, nursing home care, dental care and some preventive services. Finally, two private hospitals and a number of private clinics provide an alternative to the public system, generally paid for through private hospital insurance. Only about one-fourth of 1 per cent of the population have opted for fully private health insurance, but some 10 per cent are covered by a “critical illness” insurance that pays a specific amount for such critical illnesses. This sum is not linked to private hospitals and can be used freely.

Total public health expenditure, which was DKK 56.9 billion (7.6 billion Euro) in 1997, has grown relatively slowly in Denmark, by an average of 1.3 per cent between 1980 and 1997, including spending decreases in the late 1980s and early 1990s. Government health spending as a percentage of total government spending also dropped between 1980 and 1997, from 10.7 per cent to 8.9 per cent. Public and private health spending as a share of the total economy dropped during this same period from 7.3 per cent to 6.3 per cent. When some care for the elderly is added to make spending figures comparable on an OECD-wide basis, Danish health spending as a percentage of GNP in 1996 ranked eighth out of 19 countries at 8 per cent. Countries with slightly higher spending included Iceland, Portugal, Sweden, and the Netherlands, while Germany and France spent significantly more at close to 10 per cent of GNP, and the United States was at 14 per cent (Danish Ministry of Health, 1998, pp. 32-35).

Aside from some patient co-payments on medicines, dental care, glasses, hearing aids, and supplemental health and casualty insurance, the vast majority of health care services – 82 per cent – are entirely paid for through public funds. There are no patient co-payments required for doctor or hospital visits. Primary care doctors provide an important restraint on spending, however, by serving as the gatekeeper for referrals to specialists and hospitals. Approximately 98 per cent of citizens subscribe to the basic service for doctors, while 2 per cent subscribe to a reimbursement plan that provides greater flexibility in choosing primary care doctors and private specialists, subject to additional supplementary fees.

Democratic debate tends to focus on issues around the margins of these basic, agreed values and elements, such as the extent to which private insurance and private hospitals may play a role in the system; who takes on responsibility for what services; and where resources should be focused to address perceived problems in treatment.

Policy Development in the Danish Health Care Sector

Key recent issues on the political agenda

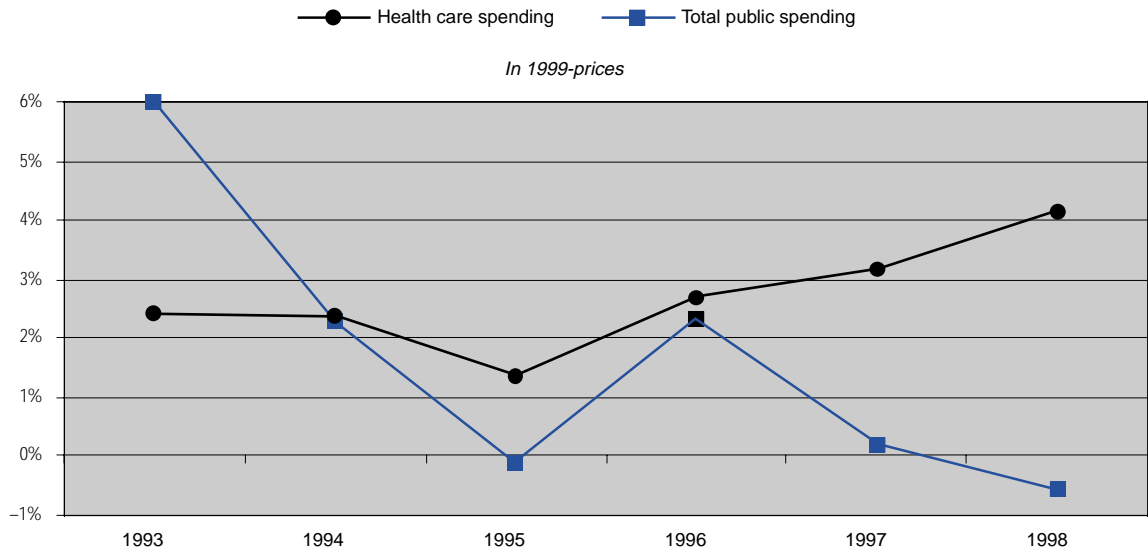
Following a period of relatively slow spending growth in the late 1980s and early 1990s, pressures to increase the rate of spending have increased in recent years. From 1993 to 1996, health spending grew in the range of 1.3 per cent to 2.7 per cent per year in real terms, fairly similar to the overall growth in public spending. More recently, Denmark has adopted larger health spending increases of 3.1 per cent in 1997 and 4.1 per cent in 1998, far exceeding the growth in overall public spending (see Figure 6 below).

Those within the health care system state that recent spending increases and calls at the national level to reduce waiting lists for various treatments have started to pay off: waiting lists have started to diminish over the last few years (see Figure 7 below).

However, many observers of the political debate in Denmark suggest that it remains largely critical and focused on problems, such as lack of coverage for certain new medical treatments or medicines, ongoing problems with waiting lists, and statistics that show certain areas of treatment lagging behind those of “comparable” countries such as Sweden and Norway.

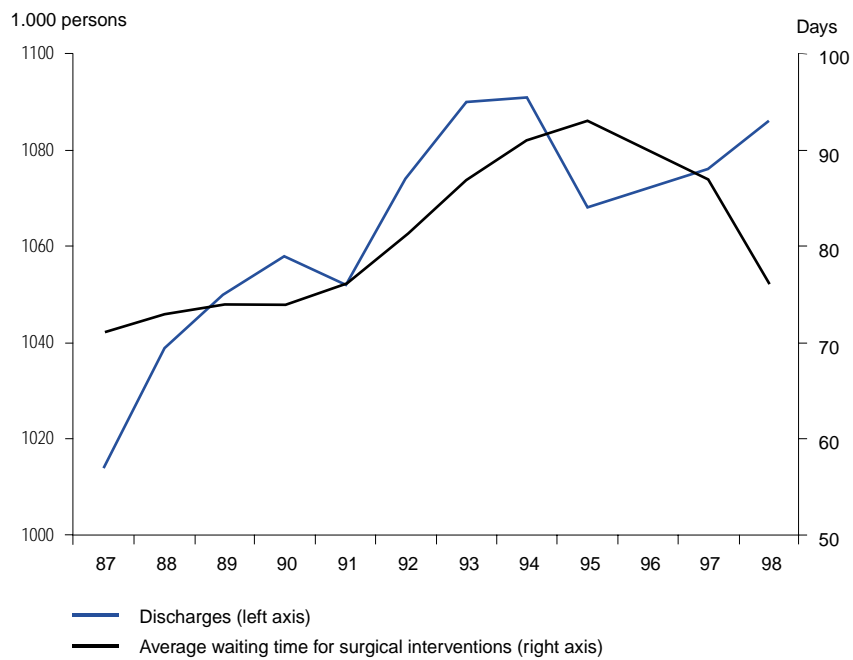
Debates over where to reduce waiting times or improve treatments very often come down to questions of resource allocation. In the early 1990s, the government decided to develop a heart treatment strategy for the entire health sector in response to complaints that Denmark lagged behind other countries. Although data were not available on actual spending on heart disease research during this period, data do indicate that the proportion of deaths in Denmark attributable to heart disease

Figure 6. Changes in Danish health care spending and total public spending



Source: Danish Ministry of Finance.

Figure 7. Number of discharges and average waiting times for surgical interventions



dropped sharply between 1990 and 1996, from 31 per cent to 24 per cent, accelerating a downward trend that had already begun in the 1980s.

However, by raising the priority of heart disease, other groups felt that their concerns had been implicitly reduced in priority. The Danish Cancer Society, noting that deaths from malignant tumours had increased during the same period and had become the leading cause of death in Denmark at 25.6 per cent in 1996, conducted a sustained campaign to develop a similar type of strategic plan to fight against cancer. Parliament ultimately decided last year to require the development of a strategic plan for cancer, and also decided that mammogram screening for women over the age of 50 should be covered on a biannual basis. The focus of public debate has also turned recently toward whether to pay for new medicines, including drugs for treatment of sclerosis and arthritis.

Public involvement in the health sector

Effective public consultation requires the balancing of potentially conflicting inputs and interests. In health care, these inputs and interests include striking the right balance between:

- “Expert” views of medical professionals, independent research findings and policy analysts, versus the non-expert views of users of the system and the citizen at large.
- Those with an immediate stake in strengthening the system (doctors, hospitals, patient groups, and other users), versus the overall public interest to balance spending on health care with other public priorities such as education, welfare and budgetary policies in support of economic growth.
- Investment of the time and resources necessary to ensure that public information is easily accessible and understandable, and that citizens are actively consulted and considered in the policy development process, versus an interest in more efficient and timely decision-making processes.

Additional key challenges include:

- Determining what the public will is among complex and often conflicting preferences (*e.g.* more health spending versus policies in support of economic growth).
- From the national perspective, ensuring accountability for national decisions through effective implementation at the sub-national level.
- From the local perspective, being held accountable to local voters whose priorities may be different from those set at the national level.
- Overcoming the resistance of those who lose out when decision-makers wish to reallocate resources to new priorities.

As Denmark wrestles with achieving the appropriate balance among these sometimes conflicting objectives, its approach to public involvement in the decision-making process has been undergoing a gradual evolution. This section discusses how many of these issues are being addressed at a general level in Denmark, followed by a section describing concrete attempts to deal with them through a range of promising practices.

The evolving roles of doctors and patients

Traditionally, decision-making in health care has relied strongly upon medical expertise. Though basic values and resource levels are determined politically, *i.e.*, health care budgets, laws ensuring universal coverage, patient rights, patient choice and the respective roles of primary care doctors and the public hospital system, medical experts have played an important role in the system’s development. The Board of Health, which reviews emerging health care issues and aims to educate the citizenry on public health concerns, is made up of health care professionals and other medical experts. Other advisory boards within the Ministry of Health also tend to involve health care professionals and academic experts on health care issues. Patient groups such as the Danish Cancer Society and Heart Foundation, as mentioned above, have also found their influence strengthened through the support and involvement of the specialist doctors who work in these fields.

Within the system itself, the individual doctor-patient relationship remains critical to the quality of care and range of choices available to patients. Primary care doctors provide the initial point of contact for the citizen (and full treatment in up to 90 per cent of the cases). Doctors establish priorities through decisions they make on referrals for treatment, according to the premise that they are in a better position than elected officials to make such judgements based on the medical expertise and the case-by-case review required for such decisions. Such decisions nevertheless are not democratically accountable (though the patients' right to choose their doctors provides incentives beyond professional ethics and medical training for keeping the patients' interests at heart).

However, the patient's influence on this system – at both the point of service and policy-making levels – is beginning to increase. On the most direct level, patients are demanding a greater say in the kinds of treatments they receive, and where they go for it. The new patient is better informed, wealthier, and less respectful of authority than in the past, according to one media observer. Recent government initiatives have attempted to strengthen the power of the patient in this regard, by facilitating access to information for patients and their families. This is achieved through a website that provides information on waiting lists (average wait times) for different procedures or treatments, available for each hospital; and by hiring of information resource people at the county level who can help patients and their families get the information that they may need. A private website called the “Web Doctor” provides on-line medical advice, giving patients an alternative source of information to direct contact with their doctor. Recent legislation further consolidated patient rights. Counties also have implemented a national law requiring that each hospital have a board of users with an input into the decision-making process.

The growing role of patient groups

Perhaps the greatest influence of patients has come through “patient groups” formed around concerns about particular diseases or health problems such as heart disease, cancer, arthritis, diabetes, or sclerosis, to mention a few of the largest groups. These groups were initially preoccupied mainly with promotion of medical research and education of the public about good health practices. In the past decade or so, many of these groups have explicitly taken on policy advocacy as an important role, and there was consensus among those interviewed that their influence in the policy-making process has increased considerably. By one estimate (Monday Morning weekly magazine), there are currently 137 patient groups with about 750 000 – 800 000 members. Many of these groups are quite young and quite small, with 37 starting up since 1990. A few groups advocate a wider range of interests, such as the DaneAge Society, which represents the elderly, but among those interviewed, none indicated the existence of any interest group seeking to represent the broad range of citizen interests in the health care system. As one parliamentarian put it, “That’s our job.”

The influence of patient groups is both direct and indirect. The largest patient groups are routinely invited to participate in parliamentary committee hearings. The Ministry of Health, after developing a draft proposal in the health sector, generally sends it around to a list of stakeholders, including patient groups, for their comments. On an indirect level, patient organisations interviewed noted the importance of obtaining media coverage for their findings and viewpoints. While direct lobbying may be focused on the decision-makers and policy elite, one NGO representative was told by a Parliamentarian that what mattered most in terms of motivating action was the view of the other “90 per cent” of the public who were not among the policy elite. For this, media coverage is a crucial factor in influencing the policy debate.

While media coverage is one channel for influencing policy, patient groups also considered large membership numbers as a factor influencing political decisions. The DaneAge Society, for example, considered one of the more influential groups in health care politics, has 410 000 members, or 8 per cent of the Danish population. Other large groups include the Heart Foundation, with 70 000 members (and claims of indirectly representing 450 000 Danes with heart and circulatory problems); and the Cancer Society, with 260 000 members, the largest budget of any non-profit group in Denmark, and claims to represent “every Dane” through their work to support cancer prevention. Each of these groups cited the

presence of elected boards and local chapters that help to ensure that their policy positions are responsive to membership opinion.

But questions have also been raised about the representativity of patient groups. No laws oblige these groups to disclose where their funding comes from, and a number of recent articles and commentaries have noted links between funding from private interests (doctors, pharmaceutical companies), and patient group positions in support of increased funding for coverage of medicines and treatments which these funders could benefit from. The 50-member Danish Pharmaceutical Association noted that its position is that any funding from its individual members for research or patient groups should be announced publicly and be transparent in nature. From their point of view, alliances between groups with common interests are a natural part of the political process, but it is important for such processes to be transparent so that the public can make its own judgements as to the credibility of the research findings or positions taken by particular groups.

Greatest influence is achieved by the largest, best-known and most well-funded groups. This is often achieved through the formation of coalitions with doctors or across patient groups. Those entirely at the grassroots level, working independently of the health care professional sector, tend to be much smaller, with non-paid volunteer staff, and it therefore is a far greater challenge for them to navigate the different decision-making structures at the national, county and municipal level, and to have an influence. The larger groups, backed by larger memberships and operating budgets that enable them to maintain a professional staff, are generally invited to participate in Parliamentary hearings of relevance to their concerns, while this is quite rare for the smaller ones.

A key question is, should such influence by interest groups be considered a problem or flaw in the functioning of democracy in Denmark? In one sense, the involvement of patient groups represents a progression toward broader public involvement, beyond that of health policy experts and professional organisations involved in providing care, to more strongly include client or customer viewpoints. On the other hand, some critics suggest that further steps are needed to prevent patient organisations from obtaining too much influence in the health care prioritisation process. Each patient group represents a specific interest, and their political force may not necessarily be correlated to societal priorities as a whole for different medical care or public health initiatives. There is a growing view that prioritisation should be based on better decision support and more balanced input.

Denmark has established other institutions and decision-making processes and structures to promote a balance between stakeholder priorities and overall economic and social objectives. One media representative asserted that devolution reduces the influence of special interests, which are often centralised at the national level. It often is easier for the average citizen to have an impact at the local level through both informal and formal contacts (for example, running into one of the 31 county council representatives at the supermarket or attending a local public hearing). Most decisions on health continue to be taken at the county level.

Denmark's annual negotiations to set expenditure limits and policy targets

Denmark's process for setting its overall economic policy, including spending and output targets within the health care sector, appears to make it easier for decision-makers to balance various interests. These annual negotiations between the national government and association of counties, and – separately – between the national government and association of municipalities, allow representatives at all levels of government to take into account the broad (and sometimes conflicting) range of interests. Public spending limits are sought to encourage overall economic growth and avoid raising taxes, while targets are set for outputs in the various sectors that are responsive to a range of political demands for improvements in public service. The negotiation process is in a sense shielded from special interests, as well as direct participation from any interested citizen. On the other hand, those involved in the negotiations are doing so on behalf of elected county representatives and ministers from the democratically elected government. They may consult freely with their constituents, as they may do in other law development processes. The results of these negotiations, though not formally ratified by parliament, are addressed by parliament through law changes that may be necessary to enable their

implementation, and by parliamentary decisions on block grant funding. Citizens also have the ability to hold the governments accountable for these policies through their votes at election time in support of or against the officials that developed the policies.

However, there are additional challenges involved in ensuring that such decisions remain democratically accountable. The targets are not legally binding, and so counties are not legally obligated to follow them. The national parliament decides how to allocate the block grants and could – in principle – attach certain conditions to the specific allocation of the block grant. Getting counties to meet non-budget targets, such as reductions in waiting list times, can be more problematic, because national funding is largely given through block grants, and counties have the flexibility to allocate funds to their preferred priorities.

In one sense, this budget negotiation process enables public officials to more easily make difficult decisions involving resource reduction or reallocation, because the process attempts to balance competing interests within a single decision-making process, and because many of the most difficult prioritisation decisions are deferred to the local level. This has been particularly evident in earlier moves to cut health spending as part of overall budget deficit reduction measures, when many of the difficult details of managing budget cuts were left to counties to implement.³³ The flip side of this is that when national governments wish to increase spending for new priorities, counties have some leeway to shift funds to their own, sometimes differing priorities.

Parliamentarians may express frustration when county priorities differ from the national priorities that they have established, but from the county perspective, this ensures a higher quality of democratic responsiveness to local demands. The problem in terms of democratic accountability arises when it is not clear who is responsible for an action – the national or local level. With health care near the top of the political agenda in Denmark, all levels of government would like to take credit for success, and no one is eager to accept the blame for failures. Several patient organisations suggested that Denmark sometimes suffers from a lack of clear accountability regarding allocation of health care resources, because budget decision-making is split between three levels of government. Under these circumstances, only the most sophisticated of groups can determine where it may be most effective to apply pressure.

While the annual expenditure negotiations do not provide for direct democratic participation, no one interviewed suggested that such negotiations reflect a democratic deficit in Denmark. The public is considered to be supportive of overall macroeconomic policy goals that include constraints on public spending. Their support (albeit largely tacit) for this process indicates an environment in which there is trust and confidence in public officials to represent the public interest. In addition, these negotiations, though not subject to direct public input, are ultimately subject to democratic accountability because the ministers who negotiate them for the government are directly accountable to the voters, and because counties and municipalities must act separately to implement them.

Promising Practices

Danish political leaders and public officials have established and experimented with a range of practices aimed at promoting stronger citizen involvement and balanced public input into health care policy decisions. These examples, though they do not reflect a comprehensive review, were cited by government officials as potentially promising approaches, and can provide some indication of innovations that could be of interest for other OECD countries.

Accessibility of ministers and parliamentary committees

Based upon a long tradition of open access to the political level, several Danish ministers schedule open meetings on most Thursdays, to which any citizen may come to voice their concerns. Most of these are held in the capital, but at least one minister, the Minister of Culture, frequently goes on tour to conduct these consultations. Some exceptions are made to the weekly meeting policy, but notices of the meetings or lack of meetings are published in the newspaper to keep citizens informed.

Parliamentary committees also have a policy that any citizen may request and be granted an audience to raise an issue of concern to them. Citizens do make use of this right to raise issues of concern, but these meetings tend to occur more frequently at the invitation of the committees. The only exception to the open meeting policy is the Budget Committee, which has determined that the multitude of stakeholders concerned with annual budget decisions affecting the full spectrum of public policy issues would make open invitations to all unmanageable. Such consultation is considered easier to manage around single-issue concerns of other parliamentary standing committees.

These consultations at Parliamentary level are supplemented by earlier consultations conducted by the responsible ministries during bill preparations. In health care, the Ministry of Health consults with the National Association of Local Authorities, the Association of County Councils, patient organisations and other interested stakeholders during the policy formulation process, before bills are submitted to Parliament.

Danish Board of Technology (Teknologirådet) consensus conferences

The Danish Board of Technology, which advises parliament and seeks to inform public debate on science and technology issues, has adapted a technique known as a “consensus conference” for more closely involving citizens on specific questions on the political agenda. About 16 randomly-selected “lay-persons” (non-experts) are invited to meet over a four-day period around a pre-selected issue, first to hear experts’ and policy officials’ views, and then to deliberate among themselves. On the final day of the conference, they present their agreed upon, or “consensus”, views. However, unlike a jury, which must agree on a single position of “guilty” or “not guilty,” the consensus conference framework allows for nuanced viewpoints and citizen-defined framing of the issues that can indicate how a position may shift, depending upon different conditions or situations. According to programme officials, this supports an understanding of the thought process of a broadly diversified group of citizens, rather than merely public opinion poll statements of viewpoints, or the sometimes more extreme viewpoints portrayed in the media. It also provides a way for citizens to be able to provide informed input into technically complex subjects without having to defer solely to the judgements of technical experts.

The approach originated within the medical profession for assessment of new medical technologies, relying upon a group of experts who would convene to review evidence and work toward a consensus on their evaluation of the technology. The Council adapted the technique for democratic purposes in the mid-1980s and has organised at least 20 such conferences since then, addressing such subjects as fertility treatment, human genome research, gene therapy, and risk assessment thresholds. The Danish Board of Technology approach, using randomly selected, non-expert citizens, has shown enough promise to be picked up in a number of other countries: Australia, Canada, France, Japan, the Netherlands, New Zealand, Norway, the Republic of Korea, Switzerland, the United Kingdom, and the United States (city of Boston).

Among the challenges associated with expanding the use of such conferences are funding [(each conference costs DKK 500 000 to 1 million (about 65 000 to 130 000 Euro) to organise]; integrating them into the decision-making process (some members of parliament attend parts of the conferences to hear citizens’ views, while others interviewed for this study were not familiar with the conferences); and dealing with heightened expectations of citizens who become heavily involved in an issue for several days, but who then have little opportunity for involvement in the issue thereafter.

Responding to patient demands: user surveys, user boards and patient choice

Because nearly every citizen is a user of the health care system at one time or another, Danish efforts to obtain user perspectives are relevant not only in terms of managing service delivery, but also as a democratic input into the policy process. As noted in the preamble, the Danish Government has conducted extensive surveys of Danish citizen attitudes towards the full range of public services, and tracked views in relation to both users and non-users of the services. In the health sector, as in other sectors, actual users of the system have expressed more positive views than non-users. For example, in a Spring 1998 Gallup survey commissioned by the Ministry of Finance:

- Sixty-three per cent of users said they were satisfied or very satisfied with emergency services, while only 38 per cent of non-users reported being satisfied or very satisfied (with 43 per cent answering “don’t know”).
- For hospitals, 78 per cent of users reported being satisfied or very satisfied, compared to 64 per cent of non-users (17 per cent said “don’t know”).
- Satisfaction was highest of all for users of general practitioners, with 91 per cent of users very satisfied or satisfied. Fewer than 5 per cent of respondents indicated that they were non-users, and of these, 77 per cent said they were satisfied or very satisfied (while 9 per cent answered “don’t know”).

Several government officials hypothesised that the less positive non-user perspective is the result of press coverage focusing on exceptional problems, while more routine medical care that is administered without problems receives no media attention.

Supplementing these national surveys, regional governments such as Aarhus County conduct their own user surveys that provide more detailed feedback regarding different aspects of health care services. Aarhus County, whose population of 650 000 makes it the second most populated region in Denmark after Copenhagen, is now committed to conducting systematic surveys of all of its medical institutions to track user attitudes over time. Results feed both into discussions of the management of the services with health care administrators and professionals, as well as into the development of the next four-year county plan for health care. Aarhus County officials noted the importance of developing indicators not just of user satisfaction, but also of quality of care. One official cited a study that found that users actually reported higher satisfaction levels in cases where errors in treatment had occurred, because doctors spent more time making sure the patient was satisfied in such cases. Thus, over-reliance on user perspectives risks missing out on the full picture.

Aarhus County officials have some aspirations that such indicators of quality and user satisfaction could eventually serve as a national model that other counties could adopt to enable comparisons to be made more easily. Ultimately, such information could be made entirely public through the Internet in order to strengthen incentives for improvement as well as the information available to patients to support them in their health care choices. Already, information on the length of waiting lists for specific procedures is available on the Internet. For those who cannot access it directly, counties have information specialists available to provide this information to anyone who asks for it.

User boards represent another channel for obtaining input on the quality of services, monitoring complaints and highlighting user concerns. In addition to a hospital user board established nine years ago, Aarhus County more recently began regular consultations with two separate groups representing psychiatric patients.

Aarhus County's interaction with users of psychiatric services is of particular interest. One group represents current psychiatric patients and their relatives, while a second organisation formed more recently represents past users of psychiatric services who are now more or less cured. Seeking to change the traditional approach in which doctors provided treatment for psychiatric patients with relatively little input from the patients themselves, the county adopted a policy two years ago to involve users in decisions regarding those services at three levels: the policy level; daily living; and individual treatment. The Director of Psychiatric Services has four meetings a year with these two groups. This approach has been supplemented by an active effort to ensure that patients and their families have access to independent information on psychiatric maladies and their treatments obtainable through a county information unit. Public meetings are also organised on particular subjects related to psychiatric treatment: one public meeting on schizophrenia attracted more than 200 people. Other counties are in frequent contact with Aarhus County as they consider how to develop their own programmes to attain greater public involvement.

Important challenges remain, however, to promote effective interaction: the need to change the culture among doctors who may not be used to sharing larger amounts of information and participating in a more mutual decision-making process. Such decision-making also requires more time than the

traditional approach. In addition, psychiatric patients themselves often are not used to participating in groups and democratic processes, while professional care-givers may not be skilled in encouraging their involvement. Training can help both groups to interact more effectively.

All of the efforts to provide better information to users – whether on quality of care, user satisfaction, or treatment options – are part of a general trend toward greater empowerment of the patient to make effective choices in using the health care system. Underpinned by the patient's right to choose their own doctor, and in turn to choose a hospital through a referral from their doctor, patients' choices provide important feedback on the overall quality of the system. An increasing number of patients have recently begun opting for private hospital insurance and opting out of the public health system (this number has doubled in the last few years, according to the Ministry of Finance, but exact figures were not available). Some officials expressed concern that if this trend continues, it could undermine the public hospital system. Indeed, trends in choices of public and private hospitals can be seen as an important, indirect means of providing information on user preferences and influencing public health policy considerations that will be closely watched in the future.

Policy consultation in the development of health plans (Aarhus County four-year plan)

All Danish counties are required to develop four-year plans that set out priorities for health care provision. The Law on Public Health Insurance requires counties to consult with the municipal councils, health care practitioners and specialists before presenting their health plans to the county council (but consultation with citizens and patients is not required at this stage). Nevertheless, Aarhus County undertook a much more active consultation process in developing its plan for the years 1998 – 2001. Public input was sought through a specially designed mailing to all citizens, intended to make the plan easy to understand for non-experts. The mailing requested written comments and invited citizen participation in a series of six regional public hearings. An average of 100 people attended each of the six hearings, and 250 written comments were received. Citizens expressed overall support for the plan, but also sought and received some changes, including the creation of the county's first hospice, and development of plans for more care of vulnerable families, including those afflicted by alcoholism and psychiatric problems.

In developing its next four-year health plan, Aarhus County intends to repeat this consultative process, while supplementing it with new information obtained through more systematically developed health care user surveys and other indicators being developed on health care quality.

Conclusions

It can be sobering to realise that even in an extensive effort to consult with the public, as Aarhus County did in developing its four-year health plan, little more than 0.1 per cent of the county population actually attended hearings or provided written feedback. Other feedback was available through user satisfaction surveys, informal contact between elected representatives and citizens, and groups who spoke on behalf of larger populations of stakeholders (health care professionals, patient groups, user boards, etc.). Nevertheless, the large majority of citizens do not provide direct feedback on their preferences regarding county health care policies and spending priorities.

This underscores a great difficulty that all OECD countries face in making their democracies work: most citizens do not become actively involved in individual policy decisions, but rather delegate decision-making through elections to their political representatives. The lack of active participation is not necessarily a problem, if citizens perceive that they have adequate information and opportunities to participate and have their views taken into account, if they wish to do so. Likewise, politicians will not consider a lack of active citizen participation a problem if they continue to have adequate tools to gauge public opinion and the public perceives that their decisions reflect the overall public interest.

Good public information and public consultation processes that provide citizens with the opportunity to become involved if they wish, or alternatively to allow others to act on their behalf, will continue to be a fundamental underpinning to democratic quality. The Internet is having a positive

impact in Denmark in increasing the availability of health care information, particularly for direct users of the health care system, but its use as an interactive tool for policy consultation remains an area for further development.

The challenge for elected representatives is to be able to make effective use of the range of tools available to them for obtaining input into their decisions to ensure that they are both responsive to the range of public interests, and that these decisions also make good public policy. This includes obtaining advice from policy analysts and medical experts, feedback from users, and the views of stakeholders with much to lose and gain from decisions, as well as interactions with the average citizen who may have a less immediate stake in those decisions. The examples cited above – ranging from public hearings to user surveys, user boards, user choice, input from patient groups and other organised stakeholder groups, to more innovative approaches such as the Danish Board of Technology consensus conferences – can all play a role in improving the quality of democratic decision-making.

These are supplemented by independent sources of expertise – benchmarking comparisons across counties and internationally, review of medical research on cost-effectiveness and quality of emerging treatments and technologies, and measurement of performance against both broad-based and specific objectives for efficiency, quality, and responsiveness to users.

As Danish decision-makers continue to wrestle with how to most effectively involve the public and other inputs into their decision-making processes, this study points to a number of conditions and practices that have facilitated achievement of these objectives. Among the factors favouring effective democratic decision-making in Denmark are:

- A relatively small population (5.3 million people) and devolved responsibilities that allow decisions about most public services to be taken at the local level, where informal contact with decision-makers and local democratic participation may be easier to achieve.
- A well-educated public and active civil society. Denmark has strong traditions of participation in groups and the political process, and confidence in its public institutions. This trust re-enforces its traditions of openness, since information obtained is more likely to be used constructively in efforts to reach consensus, rather than to generate conflict and policy stalemate.
- High trust and public satisfaction levels that provide the government with some leeway to develop policies internally before subjecting them to public scrutiny, without unduly raising suspicion that the public interest will suffer. This provides some insulation from excessive influence by stakeholder groups that may not represent the full range of interests in a particular policy.
- Government attention to user attitudes toward public services through customer satisfaction surveys and overall opinion polls provide an additional instrument for considering the overall public interest and countering potential over-representation of stakeholder groups or non-representative media coverage in the policy-making process.
- A strong interest in and openness to learning from international experience in this area. Many of those interviewed for this study – both within and beyond government – cited lessons from international experience as contributing to their own thinking and initiatives. Indeed, the Danish government agreed to participate in this OECD study in part to provide a vehicle for comparing Danish experience to others through the OECD's series of country case studies being conducted on "Strengthening Government-Citizen Connections" in a range of policy sectors (including the Canadian health sector – see previous section).

Despite these favourable factors, the improvement of democratic quality in Denmark will remain a continuing challenge. A number of issues and questions remain an ongoing concern, and there are no easy answers for addressing them. For example:

- Is there a way to clarify sometimes unclear lines of accountability between national, county, and municipal levels of government to increase democratic responsiveness?
- Where is the exact balancing point between too much public consultation and not enough? Is there a need for more direct democracy to improve the quality of democratic decision-making, or

are other measures, such as more transparent, accessible and better-quality information and existing opportunities for public input sufficient?

- How much should the government rely on alternative sources of information on citizen viewpoints such as opinion polls, information on user choice, and media reports rather than on their direct participation?
- Should additional steps be taken to require stakeholder groups who participate in policy debates to disclose information on who they represent (members), and who they are funded by, in order to facilitate public judgements on how to balance their interests versus others?

The OECD is not in a position to resolve such questions, which are best addressed according to consideration of Danish national interests. The fact that Denmark maintains a positive environment for debating such questions is a factor that works in its favour when addressing these challenges in the future.

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BIBLIOGRAPHY

- BLOM-HANSEN, J. and T. PALLESEN (1998),
 “The Fiscal Manipulation of a Decentralized Public Sector: Macroeconomic Policy in Denmark,” Aarhus University Department of Political Science.
- CHRISTIANSEN, T. and J. LAURIDSEN (1996),
 “Progressivity, Horizontal Equity and Reranking in Health Care Finance,” Odense University.
- DANEAGE ASSOCIATION (1998),
 Report 1998.
- DANISH CANCER SOCIETY (1999),
 series of articles.
- DANISH MINISTRY OF FINANCE (1998),
 “The Citizens and the Public Sector,” unpublished summary of results of Gallup Survey conducted for the Ministry of Finance between May and June.
- DANISH MINISTRY OF FINANCE (1999a),
 “Government-Citizen Connections in Denmark: First Draft,” unpublished response to OECD questionnaire.
- DANISH MINISTRY OF FINANCE (1999b),
 “Two Analyses of Digital Communication between Citizens and Public Institutions in Denmark,” unpublished compilation of survey results.
- DANISH MINISTRY OF FOREIGN AFFAIRS (1999),
 “Denmark in a Nutshell”, see: http://www.um.dk/english/danmark/om_danmark/nutshell/nutshell.general.html
- DANISH MINISTRY OF HEALTH (1998),
 “The Danish Health Care Sector”.
- DANISH MINISTRY OF INTERIOR (1996),
 “Parliamentary Elections and Election Administration in Denmark”.
- OECD (1997),
 Managing Across Levels of Government, Public Management Service, Paris.
- OECD (1994),
 The Reform of Health Care Systems: A Review of Seventeen OECD Countries, Paris.
- PEDERSEN, L. D (1994),
 Aarhus University, “Hospitals and Their Institutions”, March.