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HEALTH SYSTEMS AND POLICY ANALYSIS

POLICY BRIEF

Where are the patients in decision-making about their own care?

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methods

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This policy brief, written for the WHO European Ministerial Conference on Health Systems, 25–27 June 2008, Tallinn, Estonia, is one of the first in what will be a new series to meet the needs of policy-makers and health system managers.

The aim is to develop key messages to support evidence-informed policy-making, and the editors will continue to strengthen the series by working with authors to improve the consideration given to policy options and implementation.

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Key messages

The policy issue: patient engagement

Occasionally, all citizens have to make important health decisions that affect health outcomes. Strategies to support patient education and engagement should therefore be a fundamental plank of health policy. Also, patients can play an important role in understanding the causes of illness, protecting their health and taking appropriate action, choosing appropriate treatments for acute episodes of ill health, and managing chronic illness. These roles must be recognized and supported.

Policy options

Strategies for promoting an active role for patients should pay attention to health literacy, shared decision-making and self-management.

A number of interventions have been shown to be effective in building health literacy, promoting patient involvement in treatment decisions and educating patients to play an active role in self-management of chronic conditions. These interventions include:

- written information that supplements clinical consultations
- web sites and other electronic information sources
- personalized computer-based information and virtual support
- training for health professionals in communication skills
- coaching and question prompts for patients
- decision aids for patients
- self-management education programmes.

Implementation

Governments, health authorities or payers looking for ways to inform and empower patients need to agree about clear goals and a coherent strategy, with actions targeted at the national, regional and organizational levels.

Executive summary

The policy issue: patient engagement

Patients can play a distinct role in protecting their health, choosing appropriate treatments for episodes of ill health and managing chronic disease. Considerable evidence suggests that patient engagement can improve their experience and satisfaction and also can be effective clinically and economically.

This policy brief outlines what the research evidence tells us about the effects of engaging patients in their clinical care, and it reviews policy interventions that have been (or could be) implemented in different health care systems across Europe. In particular, it focuses on strategies to improve:

- health literacy
- treatment decision-making
- self-management of chronic conditions.

Policy interventions

Improving health literacy

Health literacy involves the ability to read, understand, evaluate and use health information to make appropriate decisions about health and health care. Low health literacy is associated with health inequalities, and people with low health literacy tend to have poorer health and a greater risk of hospitalization. Health literacy interventions have three key objectives: to provide information and education, to encourage appropriate and effective use of health care resources and to tackle health inequalities.

Health literacy interventions take a number of forms that have different merits. Written health information tailored to an individual's needs can be helpful in reinforcing professionals' explanations of health problems. Computer-based information may be more effective than paper-based information, as it can be more easily tailored to needs. Interactive television, audio tapes and web-based interventions have mixed results for improving knowledge, but can have beneficial effects on patients' confidence and ability to be involved in decisions. They may also improve clinical outcomes and health behaviour.

Information and education addressed specifically to people with low levels of health literacy can be helpful. Well-designed education programmes can make a difference, and some evidence shows that people from disadvantaged groups benefit more from computer-based support than do people from affluent groups if access barriers can be overcome.

Improving treatment decision-making

One of the most common sources of patient dissatisfaction is not feeling properly informed about (and involved in) their treatment. Shared decision-making, where patients are involved as active partners with the clinician in treatment decisions, can be recommended as an effective way to tackle this problem. Clinicians and patients work together as active partners to clarify acceptable medical options and choose appropriate treatments. While not all patients want to play an active role in choosing a treatment – because of age-related and cultural differences – most want clinicians to inform them and take their preferences into account.

Well-designed training courses can improve the communication skills of doctors, nurses and pharmacists. As patients become more involved, their knowledge improves, their anxiety lessens and they feel more satisfied.

Patient coaching and question prompts help to empower patients to take a more active role in consultations. These prompts improve knowledge and recall and help patients feel more involved and in control of their care.

Evidence-based patient decision aids facilitate the process of making informed decisions about disease management and treatment. Decision aids can improve a patient's knowledge and their level of involvement in treatment decisions. They also give patients a more accurate perception of risk and encourage appropriate use of elective procedures.

Improving self-management of chronic conditions

Three of ten Europeans suffer from a long-standing illness or health problem. Policy-makers in many countries are now seeking ways to shift resources into the community in an effort to deal more effectively with chronic conditions. In particular, they are looking for ways to empower people to manage their own health and health care, by providing them with effective self-management support.

Educating patients about self-management can improve their knowledge and understanding of their condition, coping behaviour, adherence to treatment recommendations, sense of self-efficacy and symptom levels. Computer-based self-management education and support help to increase a patient's knowledge and self-care ability and help improve social support, leading to better health behaviour and a better outcome.

Self-management initiatives appear to work better when integrated into the health care system, instead of being organized separately. The role of health professionals in guiding patients through the process is critical to successfully implementing these initiatives.

Implementation: it requires a whole-system approach

Governments, health authorities or payers looking for ways to inform and empower patients need to agree on clear goals and a coherent strategy, with actions targeted at macro (national), meso (regional) and micro (organizational) levels. This coherent strategy requires a whole-system approach, in which support for patient involvement is built into the following types of initiatives:

- patients' rights or charters;
- regulatory requirements for provider organizations, including financial incentives and contracts;
- procedures for professional regulation, including patient feedback on interpersonal skills and quality of care;
- provision of health information materials, web sites and portals;
- training health professionals in communication skills;
- self-care education and support integrated into all levels of health delivery; and
- specific aids and techniques to help patients play a more active role.

Despite several important gaps in the evidence, there is a sufficiently robust body of knowledge on which to build strategies for strengthening patient engagement. Differences in morbidity patterns, cultural barriers and social inequalities must be taken into account when planning strategies to promote greater patient engagement. If these barriers can be overcome, the rewards are potentially great, because people who are more informed and engaged tend to use fewer health care resources and to make more appropriate choices, leading to better health outcomes. In addition to the potential for achieving greater efficiencies in resource use, encouraging patients to take more control when they are ill may also prove to be an effective tool for improving public health.

Policy brief

The policy issue: patient engagement

Health systems throughout Europe and the world are searching for ways to make their services more responsive to patients and the public. Often there is a perceived need to respond to consumer pressure and to make health care more like other consumer experiences. But the need for patient engagement – where the patient is encouraged to take an active role as a key player in protecting their health, choosing appropriate treatments for episodes of ill health and managing chronic disease – is often ignored. Considerable evidence suggests that patient engagement can improve their experience and satisfaction, and also can be effective clinically and economically.

Patients can play a distinct role in their health care by:

- understanding the causes of disease and the factors that influence health;
- self-diagnosing and treating minor self-limiting conditions;
- selecting the most appropriate treatment for acute conditions, in partnership with health professionals;
- managing treatments and taking medications appropriately;
- monitoring symptoms and the effects of treatment;
- being aware of safety issues and reporting them;
- learning to manage the symptoms of chronic disease; and
- adopting healthy behaviour, to prevent the occurrence or recurrence of disease.

Recognizing their role and seeking to strengthen it is fundamental to securing a more patient-centred approach to health care delivery. It also provides the essential underpinning for strategies that aim to reduce health inequalities and improve health for all.

This policy brief outlines what the research evidence tells us about the effects of engaging patients in their clinical care, and it reviews policy interventions that have been (or could be) implemented in different health care systems across Europe. In particular, it focuses on strategies to improve:

- health literacy
- treatment decision-making
- self-management of chronic conditions.

The brief draws on studies of the effectiveness of initiatives designed to achieve these goals. While there is a broader, equally important issue of how to engage citizens in decisions about the development, planning and provision of health services, that is not the focus of this policy brief. Instead, it focuses on the role played by individuals in their own health care. The reasons this topic is considered significant for health policy are outlined below. Also, the brief reviews the evidence on the effect of specific interventions to promote greater involvement and discusses the applicability of this evidence to European health care systems.

Health literacy

Health literacy has been defined as “the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the health care system, the market place and the political arena” (1).

The provision of health information and education is seen as crucial in bringing about improved health literacy. Three distinct levels or purposes of health literacy have been identified (2):

- *functional*: basic skills in reading and writing necessary for effective functioning in a health context;
- *interactive*: more advanced cognitive literacy and social skills that enable active participation in health care; and
- *critical*: the ability to critically analyse and use information to participate in actions that overcome structural barriers to health.

Health literacy is fundamental to patient engagement. If people cannot obtain, process and understand basic health information, they will be unable to look after themselves well or make good decisions. Improving health literacy is critically important in tackling health inequalities. People with low health literacy have poorer health status and higher rates of hospital admission, are less likely to adhere to prescribed treatments and care plans, experience more drug and treatment errors, and make less use of preventive services (3). A study of the relationship between education and health in 22 European countries found that people with low educational levels were more likely to be in poor health, particularly in countries such as Hungary, Poland and Portugal (4).

People's information needs are very diverse and vary according to their age, class, gender, beliefs, preferences and coping strategies, and according to their general literacy, first language, skills and abilities. Information needs often change during the course of an illness. When patients first receive a diagnosis, for example, they often need practical information to support care decisions, as well as reassurance to reduce anxiety. Later, when they focus on the long-term

prognosis and self-care, they may need more specific and in-depth information.

Health literacy interventions around the world thus have three key objectives: to provide information and education, to encourage appropriate and effective use of health resources and to tackle health inequalities.

Shared decision-making

The most common source of patient dissatisfaction is not being properly informed about their condition and the options for treating it. Most patients want more information than they are routinely given by health professionals, and many would like a greater share in the process of making decisions about how they will be treated (5).

Shared decision-making is “a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care” (6). Shared decision-making is appropriate in any situation where there is more than one reasonable course of action and where no single option is self-evidently best for everyone. This situation is very common, since there are often many different ways to treat a health problem, each of which may lead to a different outcome. Such cases are known as preference-sensitive decisions – that is, the choice of treatment needs to take into account the patient’s valuation of the outcomes.

Central to sharing is a two-way exchange between the patient and the professional. The health professional acts as the expert and shares information about his or her social circumstances, attitudes to illness and risk, values and preferences. These factors may have a strong influence on weighing the appropriateness of any treatment and should be accepted as legitimate in the decision-making. Also accepted is the patient’s shared responsibility for the decision and for any risks taken.

Not all patients want to share in making the decisions. For example, older people or those with life-threatening conditions tend to be more likely to want the doctor to decide (7). Some people, however, want to participate in all decisions about their care and expect their doctor to provide them with the necessary information to enable them to do so, while others sometimes prefer to delegate decision-making to the doctor.

Views on involvement may vary between cultures or settings. A population survey in Germany, Italy, Poland, Slovenia, Spain, Sweden, Switzerland and the United Kingdom found that a more paternalistic view of the doctor–patient relationship prevailed in Poland and Spain than in the six other countries: 91% of Swiss and 87% of German respondents felt that the patient should have a key role in treatment decisions, either by sharing responsibility with the doctor

or by being the primary decision-maker, but the proportion of Polish patients who felt the same way was only 59%, and in Spain it was only 44% (8).

People who are relatively healthy may want to be more involved – for example, in decisions about screening – than those who are very ill. What is important is that the health professional should not make assumptions, based on their observation of the patient, about the degree of involvement the patient desires. Clinicians should always try to find patient preferences through effective communication.

Self-management

Self-care – actions that people take to recognize, treat and manage their own health problems, independently of the medical system – is the most prevalent form of health care. Most people cope with minor illnesses without recourse to professional help, and people with long-term conditions spend far more time looking after themselves than being under the care of health professionals, yet health service planning tends to ignore this important fact. Failure to recognize and support people's self-care efforts encourages unnecessary dependency on professionals. The result is increased demand for expensive health care resources, which threatens to undermine the long-term sustainability of many health systems.

Much self-care consists of the day-to-day management of long-term and chronic illnesses, such as asthma, diabetes and arthritis. Three of ten Europeans suffer from a long-standing illness or health problem, making the management of such health problems a major European health priority, which is also acknowledged by the European Commission (9). Self-management is what most people with long-term health problems do all the time. They manage their daily lives and cope with the effect of their health problem as best they can, and for the most part without any intervention from health professionals. But when people with chronic health problems do seek professional advice, they need appropriate help and support to enhance their self-management skills. Unfortunately they do not always receive it (8). Too often, the way in which clinicians and patients interact tends to promote passivity and dependence, instead of self-reliance, thus sapping patients' self-confidence and undermining their ability to cope.

Policy-makers in many countries are now seeking ways to shift resources into the community – and away from dependence on the expensive hospital sector – in an effort to deal more effectively with chronic problems. The Chronic Care Model developed by Ed Wagner and his colleagues in the United States has been highly influential internationally (10). Empowering people to manage their

own health and health care and providing them with effective self-management support for long-term health problems are central components of this model.

The goal of self-management support is to enable patients to perform three sets of tasks (11):

1. managing their illness medically – for example, taking medication or adhering to a special diet;
2. carrying out normal roles and activities; and
3. managing the emotional effect of their illness.

The principles of self-management have been developed in a number of theoretical models, mostly from the fields of psychology and behavioural science. Of these models, Bandura's self-efficacy theory is the one referred to most widely (12). Self-efficacy pertains to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control and to the willingness to take on (and persist with) new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident about their ability to achieve their goal. Interventions for improving self-care should therefore focus on building confidence and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them.

Policy initiatives to foster patient involvement

A great number of methods for encouraging patients to play a more active role in their health care have been developed and evaluated. The executive summary draws on a review of studies designed to assess the effectiveness of relevant initiatives which was updated for this policy brief (13, 14). Electronic databases – including Medline, Embase, CINAHL, the Cochrane Library, the Database of Abstracts of Reviews of Effects, the World Health Organization and the Agency for Healthcare Research and Quality – were searched systematically. The search, which was restricted to English language articles published since 1998, identified a total of 120 systematic reviews. The findings from these reviews are summarized here. More detailed summaries of the methods and findings and the full list of references are in a separate document (available on request from the authors). There are significant gaps in the evidence – in particular, the evidence on cost-effectiveness and long-term outcomes is weak – but the initiatives outlined below are those supported by a reasonably strong evidence base.

Initiatives to build health literacy

There is considerable interest within Europe in providing health information to patients and the public. Most of the recent developments focus on computer-based information and the development of web sites and health portals, including virtual support groups (15). Well-designed written information can be helpful in reinforcing professionals' explanations of health problems and treatments. Information works best if it is personalized to the individual, so computer-based materials can be more effective than paper-based information (16).

Interventions that specifically target people with low levels of health literacy have focused on training courses, community-based initiatives, and designing or revising health information for this group's specific needs. Evaluations of these interventions have shown mixed results, with some leading to improved knowledge and comprehension, but not all (17, 18). The use of pictographs and other visual aids has been tried, but there is not enough evidence to show whether these initiatives have had any effect on health inequalities. People who use computers often like obtaining their health information on the Internet, but reliance on this can reinforce health inequalities by excluding elderly or disabled people, people with low incomes, and people from ethnic minorities. However, if access barriers can be overcome, there is reason to believe that people from disadvantaged communities can benefit more than those from affluent groups (19).

Information in other electronic formats – such as interactive digital television, mobile-phone texts, audio tapes and web-based interventions – has shown mixed results in improving knowledge, but it can have beneficial effects on patients' confidence and ability to be involved in decisions. There is also evidence that it can help to improve clinical outcomes and health behaviour, especially when used to complement health education provided in a clinical setting (20). Information in electronic formats may be particularly useful for reaching hard-to-access groups – for example, young people with diabetes, where mobile-phone text messages have been used with some success to reinforce self-management goals (21).

What people want most of all is health information that is available at specific decision milestones. It needs to be appropriate, timely, relevant and reliable. The quality of Internet information is very variable and often problematic, so tools for assessing quality and reliability can be useful (22). Clinicians and policy-makers usually think it is important to provide mainstream medical information, such as the facts about a disease, but patients may be more interested in treatment options, their probability of success (prognosis), or how to obtain support to manage their condition (23). A number of quality

checklists have been developed to address concerns about the reliability of health information materials, such as the Health on the Net Foundation Code of Conduct (24) and the DISCERN quality criteria (25).

Initiatives to promote shared decision-making for treatment choices

Patients need encouragement from well-trained clinicians, if they are to play an active role in decisions about their care. The evidence suggests that well-designed training courses can improve the communication skills of doctors, nurses and pharmacists (26, 27). As a result of this encouragement, patients become more involved, their knowledge improves, their anxiety lessens and they feel more satisfied. This does not seem to increase costs, and it may bring them down – for example, by reducing the number of prescriptions issued (28, 29). Also, people stick to their course of medicine better (adherence), thus increasing the chance that treatment will be effective. It is clear that it is possible to make a significant difference in the way professionals communicate with their patients.

In addition to interventions aimed primarily at clinicians, various patient empowerment techniques have been developed and evaluated. These techniques include: coaching, to increase people's confidence to take a more proactive role in consultations; cards that prompt them with questions to ask; diaries or topic lists for discussion; and summaries of consultations for later review. As a result of using empowerment techniques, patients' knowledge and recall are improved and they feel more involved and in control (30, 31). The evidence suggests that patient empowerment can be done in ways that improve the effectiveness of consultations without increasing costs. The evidence about whether it improves physical health is, however, mixed.

Patient decision aids are evidence-based tools that help supplement the exchanges between patients and professionals. There are more than 500 available internationally (32). They use various media, such as leaflets, computer programs, audio tapes and compact discs. These decision aids help patients review the evidence on the effectiveness of different treatments and work out their preferences, so they can make decisions based on knowledge of the potential benefits and detriments of the different options.

Decision aids can be very effective, if they are well designed. With such an effective aid, patients' knowledge improves, and they become more involved and have a better match between their values and the treatment chosen (33). To guide their development and evaluation, a set of standards has been developed by an international group (34). Decision aids neither increase nor decrease anxiety, but they do give patients a more accurate perception of risk. The more individualized the risk information, the greater the chance that it will

improve patient participation in decision-making and agreement between the patient's preferences and the treatment choice. There is also some evidence that decision aids can be cost effective, especially if coupled with face-to-face counselling. Estimates of the effect of using patient decision aids suggest they can lead to reductions of about 25% in elective surgery rates, although this obviously depends on the underlying rates, which are known to vary considerably, both between and within countries (35).

Decision aids should be based on up-to-date reviews of the research evidence, so a national organization, such as a research institute, may be required to host, develop and update the materials. Despite evidence of their benefit, widespread implementation of innovations to improve decision-making and promote greater patient involvement has evolved slowly. However, following policy initiatives in a number of countries, including Australia, Canada, France, Germany, Italy, the Netherlands, the United Kingdom and the United States, the pace appears to be quickening (36–43). Policy-makers and clinicians are now beginning to realize that involving patients as partners with decision-making responsibility makes more sense than treating them as passive recipients of care.

Initiatives to educate patients in self-management skills

People with chronic conditions – for example, depression, eating disorders, asthma, arthritis and hypertension – have benefited from lay-led self-management education, where they learn from other people with the same chronic condition. Chronic disease self-management programmes, which are often run by voluntary organizations, have been implemented in Austria, Italy, the Netherlands, Norway, Spain, Sweden and the United Kingdom (44). Participants in these programme course offerings learn about relaxation, managing depression and anxiety, fear and anger, as well as nutrition, solving problems, managing medication, sharing treatment decisions and making plans for future care. This type of self-help education can stimulate the benefits of improvements in knowledge, coping behaviour, adherence to treatment recommendations and self-efficacy. It can also stimulate modest short-term improvements in pain, disability, fatigue and depression (45).

Education in self-management may be more effective when it is integrated into primary and secondary health care systems and when what is learned is reinforced by professionals. Many professionally led self-management education programmes are aimed at specific patient groups. For example, diabetes patients have been found to gain health benefits from self-management education, and this can reduce health service costs (46). Also, a review of professionally led self-management education programmes for patients with chronic obstructive pulmonary disease found that these programmes were associated with a reduction in the rate of hospital admissions (47).

While there is a strong case for improving the amount and quality of health information available to patients and the public, written information on its own is seldom effective in changing people's behaviour or producing better health outcomes. Active education and teaching practical skills are always more effective than simply providing leaflets (48). This type of active approach can be delivered by computer. Two systematic reviews of computer-based interactive applications found that patient knowledge and abilities increased. Also, patients felt they had better social support, and their health behaviour and outcome improved (20, 49).

The most effective self-management education programmes are those that are longer and more intensive, are well-integrated into the health system, and have health professionals reinforce what is learned during regular follow-up care. Efforts should be focused on providing opportunities for patients to develop practical skills and the confidence to self-manage their health. Hands-on participative learning styles are usually better than traditional didactic teaching (50).

Policy options to improve patient involvement

Governments, health authorities or payers looking for ways to educate, inform and empower patients need to agree on clear goals and a coherent strategy, with actions targeted at national, regional and organizational levels. The goal is cultural change, and a whole-system approach is therefore needed to strengthen and reinforce interventions in the different settings.

Initiatives at different levels in the system should be mutually reinforcing and well coordinated. The range and balance of initiatives must be culturally relevant and locally determined, and the vision and strategy must be clearly articulated, so that everyone knows what is expected of them. It is not possible to design a universal blueprint for policy that will work in every setting, but the following initiatives are worthy of consideration.

Action at the macrolevel (such as national, federal or state government)

The right to information and patient engagement are enshrined in the laws of some countries. Consideration should be given to the following mechanisms: making protection and promotion of patients' interests a legal obligation for health care providers; requiring clinicians to ensure the maximum possible level of patient engagement in their own care and treatment; and ensuring that people are kept informed of their rights and responsibilities.

Explicit standards or targets can require care providers to demonstrate their competence in patient education and to provide evidence of patient involvement in decision-making. These standards might also require evidence of

support for self-management and of provision of health information and decision aids in a variety of formats. Incentive-based or competitive systems, including choice mechanisms or specific contractual requirements, can be used to motivate change among care providers. Also, coordinated patient survey programmes have been shown to be a useful way of monitoring performance across the system, by requiring care providers to undertake systematic surveys of patients' experiences and to publish the results.

Action at the mesolevel (such as regional health authorities and professional organizations)

Professional regulation can play a key role. Good practice standards developed by professional bodies can require clinicians to: involve patients in treatment and management decisions; provide them with education and support for self-management; and adopt strategies guided by evidence, to build health literacy. Standards could also require clinicians to help patients navigate the system and to guide them to appropriate sources of health information and decision aids. Once again, patient feedback obtained by means of standardized questionnaires can be used to monitor the performance of clinicians and reward good practice. National bodies responsible for professional education, including the development of educational methods, curricula and assessment, should ensure that care providers comply with patient-centred standards.

Despite the recent proliferation of commercially provided consumer health information in written and electronic form, many health authorities have decided to invest in this field, to ensure the availability and accessibility of reliable information. In some countries, health authorities, insurers or care provider organizations have invested in web sites or portals, to help people find relevant and reliable information that can support their health decisions. Aside from responding to the general demand for reliable health information, particular attention should be paid to the needs of people with low health literacy. Also, other forms of electronic-format information – virtual communities or networks, interactive digital television, kiosks with touch-screen computers, wireless handheld computers, videos, DVDs (digital video discs) and audio tapes – may be particularly useful for specific patient groups or disadvantaged communities.

Action at the microlevel (such as clinical teams, group practices and local communities)

Fostering a culture of partnership between health professionals and patients requires professionals to develop a specific set of skills and attributes. Clinicians

will require the following knowledge and skills:

- an understanding of the patient's perspective;
- the ability to guide patients to sources of information on health and health care;
- the ability to educate them about protecting their health and preventing the occurrence or recurrence of disease;
- the ability to elicit and take into account a patient's preferences;
- the ability to communicate information on risk and probability;
- the ability to share treatment decisions;
- the ability to provide support for self-care and self-management;
- the ability to work in multidisciplinary teams;
- the ability to use new technology to assist patients in becoming more engaged in their health; and
- the ability to manage time effectively, to make all this possible.

Patient education needs to become an integral part of professional–patient interactions. This will require effective professional leadership and the development, implementation and evaluation of effective education programmes. Patient confidence and competence in self-management can also be enhanced by providing appropriately targeted telephone and e-mail advice, telephone coaching and counselling, text messaging with prompts and reminders, so-called virtual support (such as interactive web sites and virtual networks), and assistive technologies and self-monitoring equipment. Personal budgets and/or vouchers to purchase support services (where appropriate) are being introduced in some countries, to facilitate personalized care for those with complex needs.

Encouraging patients to play an active role in decisions about their care can be an effective way of ensuring that treatment and disease management are appropriately tailored to the individual. The following methods have been shown to be useful: clinicians guiding their patients to useful information sources; question prompt cards that give patients examples of questions they might want to ask about their treatment and care; evidence-based patient decision aids, to help patients share decisions with clinicians; self-management guidelines, to help patients with chronic conditions to cope with symptoms, disabilities and emotional problems; patient access to paper-based and electronic medical records; and sending copies of referral letters to patients.

Implementation: developing national and local strategies

The studies identified for this brief varied in the way in which they described the initiatives evaluated and the outcomes measured. Some did not provide sufficiently clear descriptions of the interventions or the study context. Some missed or reported poorly on patient demographic and clinical characteristics. Also, the length of the follow-up period was often quite short, so that the longer-term effectiveness of many of the interventions was unknown, and few studies evaluated the cost-effectiveness of interventions or considered their potential opportunity costs. Most of the research was conducted in single countries, much of it in North America, and few studies carried out in eastern or southern Europe were identified. Caution must therefore be exercised when considering implementing these initiatives in different settings.

Nevertheless, we believe we have demonstrated that there is a substantial evidence base, albeit imperfect, on which to build strategies for strengthening patient engagement. The majority of the reviews reported positive results for important outcomes, and the balance of the evidence suggests various promising avenues to pursue.

Differences in the pattern of illness must be taken into account when planning a patient-engagement programme. The vast majority of Europeans believe themselves to be in good health, with just 7% reporting poor health, but one in three has a chronic condition (9). In the 25 countries of the European Union that were Member States before January 2007, self-reported health is worse in the 10 new Member States, where on average 61% describe a positive state of health, compared with 76% in the 15 older Member States. The countries with the highest proportion of people who feel hampered in their daily activities by long-standing illness are in eastern Europe (34% in Slovenia, 30% in the Czech Republic and 28% in Estonia and Hungary), while the lowest proportions are in Luxembourg (15%), Spain (15%), Italy (12%) and Switzerland (8%). Also, 25% of the European Union population is receiving long-term medical treatment for a chronic condition. The highest proportions of people reporting long-term treatment are in Finland (33%) and in Hungary and Sweden (31%), whereas less than 20% of the people in Austria, Italy and the Netherlands fall into this category.

Cultural barriers – for example, patient and health professional beliefs about their roles within the consultation – may be hard to overcome in some countries. These barriers make it difficult to change practice, unless patients are themselves willing to become more involved in their health care, at whatever level is comfortable for them. Professionals must be prepared to support them in this role. For example, people will be unlikely to become involved in self-management education programmes if they disbelieve they have a key part to

play in managing their health. Interventions will also be difficult to implement without further training for health professionals.

Social inequalities may also inhibit changes in patient involvement. Those with lower levels of education and lower incomes may feel less confident about becoming involved in their care and in evaluating health information. They are also less likely to have access to computers and the Internet. The digital divide is more apparent in some European countries than in others. A survey of citizen's use of e-health services found that health-related use of the Internet was most frequent in northern European countries, such as Denmark (62%), Norway (59%) and Germany (49%) (51). The eastern European countries of Poland and Latvia reported a 42% and 35% health-related use of the Internet, respectively, while southern Europe had the lowest proportion of Internet health users, with 30% in Portugal and 23% in Greece.

However, if these barriers can be overcome, the rewards are potentially great. Engaging patients in their health care and encouraging people to take responsibility for protecting their health may be the best way to ensure the sustainability of health systems. The evidence suggests that people who are more informed and engaged tend to use fewer health care resources and make more appropriate choices that lead to better health outcomes.

Besides the potential for achieving greater efficiencies in the use of health care resources, encouraging patients to take more control when they are ill may prove to be an effective tool for improving public health. Traditional paternalistic practice styles undermine people's confidence in their ability to look after themselves, so replacing paternalism with a partnership approach could help enhance a sense of self-efficacy. Helping patients to help themselves when they are ill and boosting their ability to deal with the effects of disease can also encourage them to take more responsibility for reducing risk factors and preventing ill health. Patient engagement is essential to improving health outcomes and population health.

Conclusions

There is now a substantial evidence base on which to build effective strategies for informing and empowering patients and involving them in their health and health care. It is important that health policy takes this evidence into account, builds on it and contributes to it. However, more robust evidence and experiential learning will be required, if health systems are to exploit the many opportunities to build better health.

Because health literacy is central to enhancing the involvement of patients in their care, all strategies to strengthen patient engagement should aim to improve health literacy. If the problem of health literacy is not dealt with, health

inequalities could widen.

Knowledge and understanding improve when health professionals engage patients actively in their care, leading to better outcomes. Also, shared decision-making and self-management are mutually supportive approaches that should be given equal importance and implemented consistently.

Strategies for informing and empowering patients and for improving the responsiveness of health care delivery systems should be high on the policy agenda in all countries. This is important not only because it is the right thing to do, but also because it may be the best way to enhance people's health and ensure the future sustainability of health systems.

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