

Informed and empowered individuals, families and communities: a whole systems approach

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Introduction

Health systems throughout 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 healthcare 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, coping with acute episodes of ill-health and managing chronic disease, is often ignored. Substantial evidence exists that this not only improves patients’ experience and satisfaction, but can be clinically and economically effective.

Individuals, families and communities can play a distinct role in promoting health in the following ways:

- by understanding the causes of disease and the factors that influence health
- by self-diagnosing and treating minor self-limiting conditions
- by selecting the most appropriate form of treatment for acute conditions in partnership with health professionals
- by monitoring symptoms and treatment effects
- by being aware of safety issues and reporting them
- by learning to manage the symptoms of chronic disease
- by adopting healthy behaviours to prevent occurrence or recurrence of disease
- by critiquing and feeding back on the quality and appropriateness of healthcare services.

Recognising these roles and seeking to strengthen them is fundamental to securing a more patient-centred approach to healthcare delivery. It also provides the essential underpinning for strategies that aim to reduce health inequalities and improve health for all.

This paper outlines what the research evidence tells us about the effects of engaging individuals, families and communities in their healthcare in relation to the following goals:

- improving self-care
- improving treatment decisions
- improving health literacy
- improving responsiveness.

Literature sources

As part of a wider research initiative to collate and synthesise research on performance, quality, and cost-effectiveness in healthcare, we searched the literature for evidence on patient-focused quality interventions. Electronic databases including Medline, Embase, CINAHL, Cochrane Library, Database of Abstracts of Reviews of Effects, World Health Organization, and Agency for Healthcare Research and Quality were searched systematically. We also searched specialist websites including those of patient organisations, and scanned references for key papers. The search was restricted to English language papers published since 1998. The database can be found at www.health.org.uk/qquip and a full report is available on the Picker Institute website www.pickereurope.org. This report draws on these and other published summaries of the material (1;2).

Improving self-care

Why is it important?

Self-care – actions that we take to recognise, treat and manage our own health problems independently of the medical system – is the most prevalent form of healthcare. Most of us 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 recognise and support people’s self-care efforts encourages unnecessary dependency on professionals. The result is increased demand for expensive healthcare 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. The growing caseload of these conditions is a major future challenge for health services (3). Self-management is what most people with long term conditions do all the time. They manage their daily lives and cope with the effects of their condition as best they can, for the most part without any intervention from professionals.

When people with chronic conditions seek professional advice, they need appropriate help and support to enhance their self-management skills. Unfortunately they do not always receive it (4). Too often, the way in which clinicians and patients interact tends to promote passivity and dependence instead of self-reliance, sapping patients’ self-confidence and undermining their ability to cope (5).

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 long-term chronic problems that affect around 60% of the adult population (6). The Chronic Care Model developed by Ed Wagner and his colleagues in the USA has been highly influential internationally (7). Empowering people to manage their own health and healthcare and providing effective self-management support for long-term conditions is a central component of this model.

The principles of self-care have been developed in a number of theoretical models, mostly from the fields of psychology and behavioural science. Of these, it is Bandura’s self-efficacy theory that is most widely referred to (8). Self-efficacy refers

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 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 this goal. So interventions for improving self-care should focus on confidence-building and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them.

What has been shown to work?

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 (9). Often run by voluntary organisations, participants in the courses learn about relaxation, managing depression, fear and anger, as well as nutrition, problem-solving, managing medication, sharing treatment decisions and making plans for future care. This type of self-help education can bring benefits in terms of improvements in knowledge, coping behaviour, adherence to treatment recommendations and self-efficacy, and modest short-term improvements in pain, disability, fatigue and depression, but there is little evidence of a reduction in the number of doctor visits or hospital admissions (10;11).

Self-management education seems to work best when it is integrated into primary and secondary healthcare systems and the learning is reinforced by professionals. Many *professionally-led self-management education programmes* are aimed at specific patient groups. These can be very effective. Diabetes patients have been seen to gain health benefits from self-management education and some studies have shown that these can lead to a reduction in health service costs (12;13). A review of professionally-led self-management education programmes for patients with chronic obstructive pulmonary disease found that they were associated with a reduction in the rate of hospital admissions (14).

Information-only education programmes (without participative studying) have little effect on self-care although they can be helpful in building the background knowledge. Written information to reinforce educational messages about self-care and chronic disease self-management given in clinical consultations, for example *self-management guidelines* can also be helpful.

Information on its own does not change people's behaviour or produce better health outcomes (15). Active education, teaching practical skills, is always more effective (16). This type of active approach can be delivered by computer. Two systematic reviews of *computer-based interactive applications* found that patients' knowledge and abilities increased, they felt they had better social support, and their health behaviours and outcomes improved (17;18).

The most effective self-management education programmes are those that are longer and more intensive, are well-integrated into the health system, and where the learning is reinforced by health professionals 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 better than traditional didactic teaching.

Patient-centred *telecare* – providing people with information, health coaching using motivational techniques, advice and support over the phone to their homes – can reduce social isolation, improve people’s confidence and ability to cope, reduce depression and improve quality of life (19). Where it replaces routine personal home visits or clinic visits it can save costs.

Sharing personal medical information and encouraging people to review their records and the advice they have been given can be very empowering. Giving patients *access to personal medical records* has been shown to increase their sense of control, but few other benefits have been proved (20). Providing *audiotape records of consultations* improves patients’ knowledge and recall (21).

There are few systematic studies of the benefits of *self-help groups*, *peer support* and other *community development approaches*. Such evidence as there is shows people welcome this type of social support, gain knowledge, and improve their coping abilities, but there is little evidence of a lasting impact on health outcomes (22;23). Women may gain more than men and people who feel isolated gain the most. However, the few studies that have been done tend to focus on well motivated groups, possibly limiting the chance of demonstrating an effect. There is much interest in using these types of community approaches with disadvantaged groups who perhaps have more to gain.

Self-monitoring and *self-administered treatment* includes things like encouraging patients to monitor their own blood pressure or administer their own anticoagulation therapy. These can lead to positive results (24;25). Health status can be as good as when these tasks are undertaken by health professionals, and some cost savings may be possible.

Given the right tools and support, the evidence shows that people can be empowered to set their own self-management goals and devise appropriate strategies for meeting them. Ironically though, it seems that these initiatives work best when integrated into the health system instead of being separate from it. This means that the role of health professionals in guiding patients through the process is essential. The goal is patient autonomy, but responsibility for achieving this must be shared by patients and health professionals alike.

Improving treatment decisions

Why is it important?

Not being properly informed about their condition and the options for treating it is the most common source of patient dissatisfaction (26;27). Most patients want more information and a greater share in the process of making decisions about how they will be treated.

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” (28). It is closely linked to, but not the same as, the processes of obtaining informed consent and communicating risks.

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 set of outcomes.

Central to sharing is a two-way exchange between the patient and the professional. The health professional acts as the expert on herself and shares information about 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 making the decisions. Older people are more likely to want the doctor to decide. People who are relatively healthy may want to be more involved – in decisions about screening, for instance – than those who are very ill (29). What is important is that the health professional should not make assumptions, based on their observation of the patient, about the degree of involvement they desire. The professional should always try to find out those preferences through communication.

What has been shown to work?

Well-designed *training courses* can improve the communication skills of doctors, nurses and pharmacists (30;31). Patients get greater involvement, their knowledge improves, their anxiety lessens and they feel more satisfied. This does not seem to increase costs and it may bring them down by reducing the number of prescriptions issued (32;33). 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 to the way professionals communicate with their patients.

Patient empowerment techniques help patients take a more active role. They include coaching to increase people's confidence to take a more proactive role in consultations; cards that prompt them on questions to ask; diaries or topic lists for discussion; and summaries of consultations for later review. Patients' knowledge and recall is improved; they feel more involved and in control (34;35). There is no evidence that this active role prolongs consultations – so it does not increase costs. Evidence about whether it improves physical health is mixed.

Patient decision aids are evidence-based tools to supplement the exchanges between patients and professionals. There are more than 400 available internationally (see www.ohri.ca/decisionaid). They use various media (leaflets, computer programmes, audiotapes, compact discs etc.) to 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 harms of the different options.

Decision aids can be very effective if they are well designed and a set of standards has been developed by an international group to guide the development and evaluation of patient decision aids (36). Patients' knowledge improves; they get greater

involvement and a better match between their values and the treatment chosen (37). Decision aids do not either increase or decrease anxiety, but they do give patients a more accurate perception of risk. The more individualised the risk information, the more likely to affect the treatment choice.

There is also evidence that decision aids can be cost-effective, especially if coupled with face-to-face counselling. For example, a large randomised trial of decision support for patients with menorrhagia, which included a video of the treatment options and outcomes, an accompanying booklet, and a structured interview with a nurse to help patients express their preferences, resulted in reduced hysterectomy rates and lower mean overall service costs (38). Estimates of the effect of using patient decision aids suggest they can lead to reductions of around 25% in elective surgery rates, although this is obviously dependent on the underlying rates which are known to vary considerably both between and within countries.

Decision aids should be based on up-to-date reviews of the research evidence, so a national organisation, such as a research institute, may be required to host, develop and update the materials.

Despite evidence of benefit, widespread implementation of innovations to improve decision-making and promote greater patient involvement has been slow to occur. However, following policy initiatives in a number of countries, including Australia, Canada, France, Germany, Italy, the Netherlands, the UK and the USA, the pace appears to be quickening (39-46). Policy-makers and clinicians are now beginning to realise that involving patients as partners with decision-making responsibility makes more sense than treating them as passive recipients of care.

Improving health literacy

Why is it important?

Health literacy is fundamental to patient engagement. If people cannot obtain, process and understand basic health information, they will not be able to look after themselves well or make good decisions. Health literacy is about empowering people to find, understand and use health information to make sound decisions about their own, their family's or their community's health.

Improving health literacy is critically important in tackling health inequalities. People with low health literacy have poorer health status, 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 (47).

People's health information needs are very diverse and vary according to their age, class, gender, beliefs, preferences and coping strategies; and 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 need practical information to support care decisions. Later, when they focus on long term prognosis and self-care, they may have more specific and in-depth information needs.

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

What has been shown to work?

Well designed *written information* (such as leaflets) can be helpful to reinforce professionals' explanations of health problems and treatments. Information works best if it is personalised to the individual, so computer-based materials can be more effective than paper-based information. For example, a trial of *electronic information* linked to cancer patients' medical records found that these were much more highly valued by the patients than booklets or generic computer-based materials (48).

Low literacy interventions that target health information at people lacking in health literacy have usually involved designing or revising health information for their specific needs. Evaluations have shown mixed results, with some leading to improved knowledge and comprehension (49). Pictograms and other visual aids are popular with some people, but there is not enough evidence to show whether these initiatives have had any effect on health inequalities. People who use computers often like getting 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 (50).

Information in other *electronic formats* – interactive digital television, mobile phone texts, audiotape, web-based – has shown mixed results for 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 (18). Information in electronic formats may be particularly useful for targeting hard-to-reach groups, for example young people with diabetes, where mobile phone text messages have been used with some success to reinforce self-management goals (51).

Mass media campaigns to spread health information can be effective in raising awareness, but evidence of direct effects on behaviour is limited, in part because of the measurement difficulties inherent in population approaches to health promotion. Some successes have been reported, for example in reducing smoking among teenagers and encouraging activity among back pain sufferers. Mass media campaigns may work best as a 'background' against which other actions to change behaviour can take place (52;53).

What people want most of all is health information that is available at specific decision points. 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 (54;55). Clinicians and policy makers usually think it's important to provide mainstream medical information, such as the facts about a disease, but patients may be more interested in treatment options and their probabilities of success, or prognosis, or how to get support to manage their condition (56;57). A number of quality checklists have been developed to address concerns

about the reliability of health information materials, e.g. the Health on the Net Foundation Code of Conduct www.hon.ch and the DISCERN quality criteria www.discern.org.uk.

Improving responsiveness through public involvement

Why is it important?

There is increasing recognition that a high quality health service is one which is both organised around, and responsive to, the needs of the people who use it. To this end, lay people should have genuine opportunities for involvement in decisions about the development, planning and provision of health services.

There is a wide range of methods for involving members of the public, from information-giving, through consultation, to full user control. These methods can be distinguished in various ways, but most importantly in the extent to which they seek to empower people and democratise the decision-making process.

A distinction can be made between ‘consumerist’ and ‘democratic’ approaches to public participation. The first of these focuses on individuals as the users of products or services and emphasises *choice* as a driver for quality improvement. The second situates participation within a broader political context, emphasising democratic accountability or *voice*.

Several factors have been identified that can inhibit efforts to engage members of the public and ensure that services are truly responsive to their needs and preferences. These include lack of clarity about aims and objectives, financial and resource limitations, resistance from health professionals or managers and concerns about whether people who get involved represent all sections of the community.

If it is not clear what an initiative is intended to achieve, it may be difficult to secure public interest and commitment, gather momentum, produce a coherent strategy of action or maintain momentum. Without adequate resources – including funding, staff time and training – public involvement initiatives are likely to fail or have limited impact on service development. Health professionals may feel threatened by public involvement, undermining the potential for open and trusting relationships. Managers and health professionals often try to retain control of agendas and resources, with lay participants feeling that their role is merely to rubber stamp decisions that have already been made. Where lay participants are felt to represent only a select group or to be pursuing strong personal agendas, the legitimacy of the initiative may be called into question, particularly if disadvantaged groups are excluded.

What has been shown to work?

There is ample evidence that people generally like having the opportunity to express their views and get involved, at least in theory - in practice it can be more difficult to secure people's active participation. However, the evidence base on the impact of public involvement is weak. There are many published accounts of public involvement initiatives, but few report on benefits or costs, and hardly any have attempted a formal assessment of outcomes. In part, this is a reflection of the

difficulty of evaluating public involvement projects and the lack of an agreed framework for such evaluation.

Patient participation groups, lay membership of policy-making bodies and public meetings can help to initiate changes in services. Examples include making services more accessible through simplification of appointment procedures, longer opening hours, improvements in transport facilities and support for people with disabilities (58). User involvement can also help to broaden understanding of the patient perspective and generate ideas for new services. A number of initiatives to involve service users and their family carers in the planning, delivery and evaluation of mental health services have been evaluated, with mixed results (59-62).

A variety of methods have been devised for securing public views on policy priorities. These work best when those organising them are genuine in their wish to know what local people think. When there are specific trade-offs to be made, deliberative methods, for example *citizen's juries*, can be effective. The issues must be pertinent to the participants and the process must be carefully facilitated to avoid dominance by a small number of people with strong views.

Deliberative methods such as citizen's juries can overcome the shortcomings of other public consultation methods, for example public meetings, by giving participants a clearer role, giving them time and support to make considered decisions, and allowing those decisions to have a clear impact on services. But they are expensive, making cost-effectiveness an unresolved issue (63).

Public views on priorities can be obtained more cheaply using *surveys* and *focus groups*. Various methods have been devised to enable people to express their views on priorities. These include electronic voting systems, ranking, scoring and rating, Delphi methods and economic techniques such as 'willingness to pay', 'time trade-off' and 'standard gamble' (64).

Surveys, focus groups and other market research techniques can also be used to monitor the quality of patients' experience or to determine population needs and preferences. Measurement of patients' experience is a useful component of a broader quality improvement strategy and publication of survey results has been shown to stimulate quality improvements (65). Regular *feedback from service users* is a good way to monitor performance and stimulate quality improvement. Coordinated patient survey programmes have been initiated in a number of countries to measure adherence to standards and to enable healthcare facilities to benchmark their performance against others. Surveys and other market research techniques can also be used to assess the needs and preferences of specific population groups and to seek out the views of disadvantaged or 'hard to reach' groups.

Other approaches have been tried, including *patients' panels* and *consensus conferences*, but as yet the evidence is not available to conclude which forms of public participation work best, and in what circumstances.

The best methodology for securing public involvement is a seriously under-researched topic. We lack a coherent and agreed upon framework for assessing the effectiveness

of different methods and there is no consensus on what public involvement is aiming to achieve. A number of goals might be considered important:

- to empower local communities
- to devolve decision-making
- to strengthen accountability
- to improve responsiveness
- to improve the quality of care
- to improve health outcomes
- to reduce complaints and litigation
- to build partnerships
- to ensure the legitimacy of policy decisions
- to determine priorities
- to enhance democratic involvement
- to improve public health.

The challenge of developing an evaluation strategy is not only to identify the criteria against which projects will be judged, but also to define them in such a way that they can be reasonably measured. Funding for monitoring and evaluation should be built into the commissioning, planning and implementation of public involvement initiatives to enhance our collective knowledge of how to do it better.

Policy options

Governments, health authorities, or payers looking for ways to inform and empower individuals, families and communities need to agree clear goals and a coherent strategy, with actions targeted at national, regional and organisational levels.

The range and balance of initiatives should be culturally relevant and locally determined and the vision and strategy must be clearly articulated so that everyone knows what is expected of them. Initiatives at different levels in the system should be mutually reinforcing and well coordinated. 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 in the light of the evidence reviewed above:

Action at the macro level (e.g. national, federal or state government)

1. *Patients' rights, charters, health service constitutions*
The right to information and engagement of patients is enshrined in the law in some countries. Consideration should be given to the following mechanisms:
 - Placing a duty on health care providers to protect and promote patients' interests
 - Requiring evidence of public and patient involvement at every level of health care commissioning
 - Requiring clinicians to ensure the maximum possible level of patient engagement in their own care and treatment

- Making patient and public involvement a requirement for all oversight and scrutiny arrangements, quality control and other accountability mechanisms.
2. *Organisational regulation, incentives and contracts*
Regulatory bodies can play a key role by insisting on patient and public involvement in service development and performance monitoring arrangements.
- Explicit standards or targets can require evidence of patient and public involvement in setting priorities and in decision-making.
 - Standards could also require evidence of support for self-care, and 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.
 - Coordinated patient survey programmes have been shown to be a useful way of monitoring performance across the system.
3. *Professional regulation*
Professional regulation also has a key role to play.
- Professional ‘good practice’ standards can require clinicians to involve patients in treatment and management decisions, to provide them with education and support in self-care and to build health literacy.
 - Standards could also require clinicians to help patients navigate through the system and to signpost them to appropriate sources of health information and decision aids.
 - Coordinated patient survey programmes can be used to monitor the performance of clinicians and reward good practice.
 - National bodies responsible for professional education, including development of educational methods, curricula and assessment should ensure that they comply with patient-centred standards.
4. *Health information materials, websites and health portals*
Despite the recent proliferation of consumer health information in written and electronic form, many governments and other official bodies have decided to invest in this field to ensure the availability and accessibility of reliable information.
- Websites or portals can be developed to help people find relevant and reliable information to support their health decisions.
 - As well as responding to the general demand for reliable health information, particular attention should be paid to the needs of people with low health literacy.
 - Other forms of electronic format information – ‘virtual communities’ or networks, interactive digital television, touch-screen kiosks, wireless hand-held computers, videos, DVDs and audiotapes – can be particularly useful for specific patient groups or disadvantaged communities.
 - Coordinated mass media campaigns can be used to broadcast specific health education messages.

Action at the meso level (e.g. regions, health authorities, provider organisations)

5. *Patient participation groups and lay representation*

Despite the existence of patient groups in many countries, reliance on the voluntary sector alone is unlikely to be sufficient to ensure participation throughout the healthcare field.

- Governments or payers can invest in patients' organisations or establish them from scratch
- Provider organisations can invite patients and lay people to join their organisations as 'members'
- Lay people can become non-executive directors on the boards of provider organisations
- Patients can be invited to work with staff on quality improvement programmes
- Patient groups should be given guarantees of independence if they are to represent patients' interests effectively
- Support, both financial and training, may be necessary to enable patients and lay people to participate in policy-making bodies and committees running hospitals or primary care facilities.

6. *Consultation mechanisms, citizen's juries and deliberative events*

A variety of methods have been devised for securing public views on policy priorities and service quality.

- Public meetings
- Focus groups
- Population and patient surveys (face-to-face, postal, telephone and online)
- Rapid appraisal techniques
- Citizens' juries and other 'deliberative' methods
- Patient/citizen panels
- User-generated online feedback to allow patients to share their views on the quality of care received.

7. *Patients' rights and public involvement*

Health authorities and provider organisations can do much to reinforce and legitimise active patient involvement by:

- Ensuring that local people are kept informed of their rights and responsibilities
- Monitoring patient experience and publishing the results
- Publishing information on performance and facilitating patient choice
- Holding meetings in public
- Ensuring that policy decisions are open and transparent and involve members of the public whenever possible
- Being prepared to explain the reasons for unpopular decisions (e.g. closure of services) and establishing a formal process of appeal
- Working with local voluntary organisations and patient and community groups

- Actively seeking the views of minority groups and people who do not belong to patient or community organisations.

Action at the micro level (e.g. clinical teams, group practices, local communities)

8. *Communication skills training for health professionals*

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:

- How to understand the patient's perspective
- How to guide patients to sources of information on health and healthcare
- How to educate them about protecting their health and preventing occurrence or recurrence of disease
- How to elicit and take account of patients' preferences
- How to communicate information on risk and probability
- How to share treatment decisions
- How to provide support for self-care and self-management
- How to work in multi-disciplinary teams
- How to use new technology to assist patients to become more engaged in their health
- How to manage time effectively to make all this possible.

9. *Self-care education and support*

Self-care education needs to become an integral part of professional-patient interactions. This will require:

- Effective professional leadership
- Development, implementation and evaluation of education programmes for patients
- Availability of telephone and email advice, telephone coaching and counselling
- Text messaging with prompts and reminders
- 'Virtual' support (interactive websites, virtual networks)
- Assistive technologies and self-monitoring equipment
- Personal budgets and/or vouchers to purchase support services where appropriate.

10. *Aids to engagement*

Encouraging patients to play an active role in decisions about their care can be an effective way of ensuring that treatment and disease management is appropriately tailored to the individual. The following methods have been shown to be useful:

- Clinicians 'signposting' their patients to useful information sources
- Question prompt cards giving 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

- Referral letters copied to patients.

11. *Community initiatives*

Local communities can do much to promote health and self-care and support patients and individuals with long-term conditions:

- Community action to reduce health risks
- Advocates and advocacy groups
- Self-help groups and support networks
- Rehabilitation, counselling and therapy groups
- Care coordinators and home help
- Wheelchair and equipment provision
- Advice on social security, employment etc.

Conclusions

There is now a substantial evidence base on which to build effective strategies for informing and empowering individuals, families and communities in relation to their health and healthcare. It is important that health policy takes account of, builds on, and contributes to this evidence. 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 involvement of patients in their care, all strategies to strengthen patient engagement should aim to improve health literacy. Health inequalities could widen if the problem of health literacy is not dealt with.

Patients' knowledge and understanding improve when health professionals engage them actively in their care, leading to better outcomes. Shared decision-making and self-management are mutually supportive approaches which should be given equal importance and implemented consistently.

Strategies for informing and empowering individuals, families and communities and improving the responsiveness of healthcare delivery systems should be high on the policy agenda in all countries. This is important not just 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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