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Patient involvement in general practice care: a pragmatic framework

Michel Wensing, Richard Baker

This paper presents a pragmatic framework to guide decisions on involving people in general practice care. Patient involvement may be defined as: enabling patients to take an active role in deciding about and planning their healthcare. It can be located at different levels of care, including the patient-clinician contact or episode of care, and the patient population served by a care provider, or the regional or national population. The involvement of patients depends on considerations that include the aim of patient involvement, the type of health decision, and the type of patient. With respect to the aims, the fundamental question is whether involvement is seen as desirable in itself, or whether it is expected to result in favourable consequences. We suggest that patients' ability and willingness to be involved should determine the level of involvement. The concept of involving patients is relatively new, and new approaches are required to overcome obstacles for its implementation in healthcare.

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Introduction

It is increasingly accepted that people should be involved in decisions about their healthcare, and about the design and delivery of their healthcare services.¹ The case for patient involvement is based on evidence

that lack of involvement can have adverse consequences such as non-adherence to treatment,² increased involvement and information can improve the process and outcomes of medical care,³ recognition of the fundamental importance of patient dignity and autonomy,⁴ and a growing expectation among patients that they should be involved.⁵ However, general practitioners can find that responding to patient requests for investigations generates negative feelings.⁶ A study from the United States showed that informed decision-making was often incomplete.⁷ When faced with conflict between the patient's right to self-determination and the need to promote health, they tended to give health promotion higher priority.⁸ This paper aims to present a pragmatic framework to guide decisions on involving people in general practice care.

What is patient involvement?

In attempts to define patient involvement, different terms have been used to describe similar concepts, such as patient participation, patient involvement, patient partnership, patient centredness, patient responsiveness and shared decision-making. The concept of patient-centred medicine is characterised by a biopsychosocial perspective, a focus on the patient as a person, shared power and responsibility, a therapeutic alliance and acknowledgement of the doctor as a person.⁹ Shared decision-making implies a two-way exchange of information, expression of preferences by both doctor and patient, and mutual agreement on the decisions to implement.^{10,11} The concept of informed choice implies a flow of information, mainly from the clinician to the patient, while all deliberations and decisions are the responsibility of the patient.^{10,11} Its outcomes can be considered equivalent to the perfect agency relationship described in the economics literature.¹²

These different concepts share the fundamental idea that patients' needs and preferences influence the process of healthcare provision and its organisation. They all depart from the paternalistic model in which the doctor takes the decisions in, as judged by the doctor determining them, the best interests of the patient.^{10,11} Informed choice and shared decision-making

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differ with respect to the extent that decision-making is the responsibility of the patient. Also, exploration of patients' needs (a key feature of patient-centredness) and involving patients in clinical decisions are different concepts.¹³ In this paper we use the global term 'patient involvement' to refer to concepts of 'enabling patients to take an active role in deciding about and planning their healthcare'.

How can these theoretical concepts be translated into observable activities? Patient involvement can be located at different levels, including the patient-clinician contact or episode of care, and the patient population served by a care provider, or the regional or national population.

Within the *patient-clinician contact*, patient involvement refers to activities of the doctor to enable the patient to be more actively involved in the consultation, and to activities of the patient to increase his or her involvement in the consultation. Such activities include the identification of patients' views on his or her health problem and treatment options, the provision of additional information or changed delivery of information according to the patient's expectations, and more active participation in the decision-making.¹⁴ An example is shared decision-making on surgery, medication or watchful waiting with an older male patient with lower urinary tract symptoms. Active involvement in the consultation may be regarded as the prerequisite to the creation of concordance between patient and doctor on the diagnosis and the most suitable treatment.¹⁵ Within the *episode of care*, patient involvement implies that the patient has a high level of self-management of the health problem. For instance, asthma patients or diabetes patients can be instructed to monitor their symptoms on a daily basis. Approaches include training programmes which enhance self-management and patient-held records.¹⁶

While involvement during the patient-clinician contact or the episode of care focuses on individual patients in their actual care, other approaches are directed to involving patient populations in the improvement of the quality of healthcare. A range of approaches aim at involving the *population of patients served by a specific general practice*, which implies that patients can influence the organisation and process of care provided in a specific healthcare organisation so that these better meet their needs and preferences. This may be based on surveys among patients, patient groups or community participation¹⁷ and may extend to the development and monitoring of standards of care by patients.¹⁸ At a *regional or national level*, patient involvement refers to the influence of patients or their representatives on healthcare policy-making. This can be either participation in institutional or regional boards, professional regulation or as external pressure groups. Patient in-

volvement in the development of clinical guidelines is another approach.¹⁹

Considerations on patient involvement

Patient involvement depends on considerations that include its aims, the type of decision, the type of patient, and societal implications of decisions.

The effects of patient involvement in decision-making can be assessed in terms of different measures.²⁰ With respect to the aims, the fundamental question is whether involvement is seen as desirable in itself or whether it is expected to result in favourable consequences. In the first case, the process of involving patients should comply with ethical standards or patients' expectations of involvement, depending on the viewpoint taken. The focus is on the type of involvement rather than its consequences. This focus reflects a needs-based ethical approach.²¹ In the second case, involvement is expected to result in better process or outcomes of care. At the level of populations, equity of access to healthcare can be regarded as a relevant outcome of involving patients. This focus on consequences of involving patients reflects an outcome-based ethical approach.²¹ In both cases, research evidence is needed to justify the claims.

Should the significance of the healthcare decision be taken into account? For example, the consequences of choice of antibiotic for a chest infection are likely to be of less significance than the choice between treatment options for cancer, or the decision about long-term care following a severe stroke. Decisions on opening hours of the surgery may be less significant than decisions on design or continuation of specific services (e.g. programmes for breast cancer screening). Decisions vary in urgency, complexity, and availability of relevant research evidence about the benefits and risks related to options. It can be argued that patient involvement is more likely if the decision is not urgent, if evidence is lacking or conflicting, and if treatment has small benefits and considerable risk for the patient. Although these factors influence the likelihood of patient involvement, they do not indicate whether involvement is desirable. The exception is the urgent health problem when the patient is not able to express his or her preferences and the care provider should treat according to professional standards.

Also, patient characteristics are relevant to the process of involving patients. Crucial are the patient's ability and willingness to be involved in healthcare provision, although these are not black-and-white concepts. Patient involvement requires a range of skills, such as the ability to identify needs for healthcare, to appreciate the likelihood or consequences of adverse outcomes, or evaluate healthcare received. The ability depends on a range of factors, such as the difficulty of

appreciating the risks of different outcomes, personal factors that make different health problems or potential outcomes more or less important to the individual, health status, educational level, health literacy, problems with sight or hearing, or support from a carer with whom to talk through the decisions to be made. If the patient is unable to be involved, positive effects on process or outcomes cannot be expected. The willingness to be involved and preferences about the degree of involvement are related to the ability, and also to past experience of care, cultural factors and attitudes regarding health and healthcare. A problem might be that care providers and patients disagree on the ability and willingness to be involved.

Finally, societal implications of involving patients more actively in healthcare should be considered. In many countries general practice has a crucial role in finding a balance between efficiency and equity of healthcare systems, because decisions in general practice have major impact on the total demand for healthcare services. If individuals have insurance for healthcare expenses, as in most industrialised countries, they may demand more services than they would have done without that insurance.²² This behaviour may result in a loss of societal welfare, rising costs of healthcare and threats to the equity with respect to financing and access of healthcare services.

When should (and should not) patients be involved? If we focus on non-urgent decisions which constitute by far the majority of clinical decisions in general practice, we suggest that the aims of patient involvement should guide decisions to involve patients in decisions (table 1). These aims may be grouped into five broad categories. First, if patient involvement is seen as valuable in itself, patients should be involved as much as possible. Second, in contrast, if involvement is intended to meet patients' preferences to be involved, then involvement is only recommended if patients indeed wish to be involved. Third, if involvement is intended to promote clinical decisions on the basis of evidence, all patients capable of employing information about evidence in making decisions should be involved. Fourth, if patients are involved in order to improve process or outcomes of medical care, involvement would depend

on ability to be involved. Fifth, if the aim is to attract customers in a competitive healthcare market, we think patients should only be involved if they are willing and able to.

In practice, patient involvement has a variety of aims. It can be difficult to assess whether patients are able and willing to be involved in decisions, and patients and doctors may sometimes disagree about the desirability of involvement. A problem may arise when a patient wishes to receive treatments or services, which are unlikely to be effective or which conflict with the professional's viewpoint. In such cases, involvement should not be taken as implying that the preference of the patient should prevail, but that the health professional provides full and detailed information to ensure the patient fully understands the professional's viewpoint. Thus, involvement does not automatically mean agreement. The professional and patient can agree to disagree. Involvement does not require the abrogation of the professional's responsibilities.

Involving patients may not always be the preferred choice, particularly if involvement is sought to improve processes or outcomes of medical care. There is a case, however, for promoting the involvement of those who do not wish to be involved if the consequent impact on outcomes is beneficial. If involvement has proven effects on the health status of individuals or populations, but patients do not want to be involved, it may be appropriate to challenge patients' preferences. For example, if there is convincing evidence that the involvement of the patient in the management of a chronic condition such as diabetes or ischaemic heart disease improves disease control and survival, the professional should make every effort to involve the patient.

A problem might be that patients' preferences have undesired societal implications. In particular, patients' desires may have significant consequences for the use of resources, particularly in systems with full health insurance. The choice of some patients may eliminate options for other patients, because the resources that had been available have been consumed. For instance, a large-scale use of statins to reduce risks for cardiovascular diseases may result in too few resources for competing health needs.²³ There is no simple solution or blueprint for dealing with such difficulties. At the

Table 1. Patient characteristics in relation to involvement: should patients be involved?

Patient is able to be involved Patient is willing to be involved	Able	Able	Unable	Unable
	Willing	Not willing	Willing	Not willing
Aims of involvement	Whether patients should be involved			
1 Involvement is valuable in itself	Yes	Yes	Yes	Yes
2 To meet patients' desire to be involved	Yes	No	Yes	No
3 To improve adherence of doctor and patient to evidence about best clinical practice	Yes	Yes	No	No
4 To improve health status, coping and satisfaction	Yes	Yes	No	No
5 To attract customers in competition with other care providers	Yes	No	No	No

level of the patient-clinician contact, the general practitioner should negotiate such desires with the patient, balancing between patients' trust, societal needs and professional opinion.²⁴

At the regional or national level, the problem may be addressed by increasing patient involvement rather than overruling it. Thus, involvement of a wider group of representatives of the public in allocating priorities for the use of scarce healthcare resources may lead to decisions that are more acceptable to the population. The role of the National Institute for Clinical Excellence (NICE) in England and Wales presents one example of an attempt to share difficult choices about healthcare funding with the public.²⁵ In taking cost impact into account in making recommendations, and involving representatives of patients and public in its deliberations, NICE represents an approach to patient involvement at the national level. It is too early to judge whether this approach is successful, but it does signify another step towards greater patient involvement in healthcare.

Conclusion

Involving people more actively in general practice care is an important challenge to general practitioners. General practitioners and policy makers should consider why they want to involve patients in specific decisions on their treatment and primary care services. The aims of patient involvement should guide decisions on whether or not to involve patients, and tailoring the level of involvement to the preferences and abilities of the patients is desirable. If patient involvement is sought, more effective interventions to enhance patient involvement in primary care need to be developed.¹⁴ At present, the level of involvement is less than some patients would like, and growing numbers of people will expect involvement in the future. The framework presented in this paper helps to guide decisions on how to respond to such expectations. ■

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