

# Really putting patients first:

ensuring significant involvement for patients in healthcare decision making

The title for this editorial is partly taken from the successful and ongoing Royal College of General Practitioners' campaign supported by the National Association for Patient Participation (NAPP) — 'Put Patients First: Back General Practice' — to highlight the deficit in funding for general practice.<sup>1</sup> However, this editorial focuses on what measures are required to really put patients first in their dealings with GPs.

### REALLY PUTTING PATIENTS FIRST: THOSE WITH LONG-TERM CONDITIONS

The need for easily accessible and transparent information for patients is essential. A recent study<sup>2</sup> highlights the increasing numbers of people living with more than one and often several lifelong physical and mental chronic conditions. Patients with multiple long-term conditions and their carers face an increasing and time consuming burden as they monitor symptoms at home, collect and input clinical data, adhere to complex drug regimens and deal with uncoordinated health and social care systems.<sup>3</sup> Really putting such patients first means:<sup>4</sup>

- ensuring that such patients have continuity of care with a healthcare professional whom the patient knows and trusts;
- longer appointments as required;
- shared decision making and an agreed care plan; and
- easy access to care.

People with such long-term conditions and disabilities often need help and care that crosses traditional service boundaries including those between primary and secondary care, health and social care, as well as other service areas such as employment, social welfare, and housing.<sup>5</sup> Dealing with different departments and different agencies in different locations is time consuming and can be enormously frustrating for the patient who simply wishes to live as ordinary a life as possible. The more widespread availability of the electronic patient record may help, although there are still many difficulties with interoperability, but sharing of the record should only be with the express permission of the patient when the information is being transferred to different agencies. A notebook with recent test

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results and medication can be helpful with information added by both clinicians and patients who are self-managing. However, perhaps really putting patients first should mean that the ownership of the medical record, as suggested by Sir John Oldham,<sup>5</sup> be transferred from the Secretary of State to the patient to be kept in safe keeping by the GP.

Patients experience not only the burden of the illnesses but also the burden of the treatment. Really putting patients first may mean changing services so that the patient can deal directly with certain services. For example, enabling patients (or their carer) to hand in specimens directly to the lab and subsequently have the results reported both to the patient and the GP so that the patient can take action if required; and ensuring that patients can have a follow-up visit with a specialist who considers this necessary without the patient having to go back to the GP to initiate a new referral, as happens in some cases.

### REALLY PUTTING PATIENTS FIRST: PROVIDING INFORMATION ABOUT TARGETS AND GUIDELINES

The NHS and general practice are generally revered institutions providing treatment free at the point of delivery, but paid for out of general taxation. And yet patients and the public know relatively little about how general practice is organised, the implications of guidelines, protocols, and targets such as QOF (and performance management) on how GPs consult and work, how GP practices are funded, the

price of the different elements of health care, and the standards of care patients can expect. Some of this information is in the public arena but not always readily accessible. It is difficult to think of any other public service that affects so many of us every day and about which we know so little.

Really putting patients first requires information for patients about the effect of targets such as QOF, protocols, and guidelines on the work of GPs and their consultations with patients. Quality indicators such as QOF tend to concentrate on medical processes without adequate recognition of the problems that are important to patients.<sup>6</sup> Putting patients first should ensure that issues important to patients are included in all quality initiatives. Treatment guidelines can be discussed with patients; this is particularly important for patients with long-term conditions. Quality also includes the standard that patients can expect from all practitioners. Patients must be able to expect that the doctor treating them is a good diagnostician, clinically competent, and up to date. While the introduction of revalidation and Care Quality Commission inspections may give some indication of quality, the bar for revalidation is low, with limited meaningful patient input into the process. Copies of the General Medical Council's *Good Medical Practice* should be on view in all practices.

### REALLY PUTTING PATIENTS FIRST: PROVIDING INFORMATION ABOUT FUNDING OF GP PRACTICES

Putting patients first means that patients

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*“Putting patients first means that professionals and policy makers are honest and transparent.”*

should know how GP practices are funded including, for example, how much a GP consultation costs, the price of medicines, X-rays, and other investigations, and the payments for targets reached. Such information could be available in GP surgeries and disseminated through patient participation groups (PPGs) and NAPP. Some of this information is in the public arena but not always readily accessible.

Easy availability of such information will demonstrate that patients and the public are being treated as responsible adults. The availability of this information should also assist patient and public involvement in commissioning and planning of services as well as demonstrating accountability.

### **REALLY PUTTING PATIENTS FIRST: THE NEED FOR HONESTY AND TRANSPARENCY**

Putting patients first means that professionals and policy makers are honest and transparent. Charlotte Williamson discusses how one primary care trust paid GPs to reduce the number of patients referred to hospital specialists and states ‘giving financial incentives — bribing — GPs to do something so potentially harmful to patients, not in their interest and without prior discussion was unacceptable’.<sup>7</sup> Many examples of a lack of transparency can be found, such as not informing patients of the black triangle status of a medication. This is not due to wickedness on the part of practitioners, it is simply that the system has not encouraged or indeed required the sharing of such information with patients and the public. The system must now change. As Mitzi Blennerhasset points out,<sup>8</sup> without honesty there can be little respect and unless patients are respected there can be no compassion.

### **REALLY PUTTING PATIENTS FIRST: SHARING UNCERTAINTY**

I believe that being honest also means sharing uncertainty with patients so that meaningful (as defined by the patient) decisions can be made. In addition we, patients, need to appreciate that the practice of medicine is full of uncertainties and that doctors, however competent and dedicated, are also fallible human beings.<sup>9</sup>

Public and patients want real opportunities for significant involvement in healthcare decision making in the consulting room and at an organisational level. Really putting patients first must make this a reality.

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