The future of gastroenterology: patient choice, patient voice

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Abstract

The policy context for patient choice and public and patient involvement (PPI) in the NHS is set out. Both have become increasingly prominent since 2000. A series of NHS systems and policies have been put in place to enable greater patient choice in the belief that the exercise of choice by patients will influence providers to improve quality. This has had some success in elective surgery. One focus has been the publication of outcome data and this may have led to quality improvement through the inherent competitiveness of professionals and institutions. PPI has suffered from a series of unsuccessful reorganisations of patient involvement organisations but has ensured that most health bodies include patient representatives. Capturing patient experience and providing information to enable patient choice have been constantly developed over this time. A particular framework developed by Angela Coulter is used to review current levels of patient engagement in Inflammatory Bowel Disease (IBD), exploring the extent to which patient choice and patient voice are supported and enhanced within current IBD services locally and in national IBD strategy.¹ A 2017 vision of the way in which IBD services might maximise patient choice and patient voice is put forward, based on the adoption of present good practice and current service developments, followed by a few rather more radical thoughts about possibilities for after 2017.

The policy context

Patient choice and public and patient involvement (PPI) have been an explicit part of National Health Service (NHS) policy for almost 40 years, becoming more prominent from 2000 onwards in all governments' policies. Tony Blair raised the subject of choice in his party conference speech in 1999, when he said 'I want to go to the hospital of my choice, on the day I want, at the time I want. And I want it to be on the NHS'.² The following outline of how the policy context developed focuses on England, where there has been greater attention to patient

choice and involvement. However, these themes have been similarly present in the devolved healthcare systems in Scotland, Wales and Northern Ireland.

The NHS Plan published in 2000 voiced the ambition that by 2005 every patient would be able to choose from several hospitals when booking their appointments.³ Payment by results was introduced to equalise costs and allow the funding to follow the patient. Choose and Book went live in 2006 and the following year the NHS Choices website was launched. This aimed to give patients the tools to make better, more informed choices, by enabling them to compare hospitals' profiles and performance without reference to their general practitioner (GP).

NHS Choices also fulfilled another objective in respect to empowering patients. The website provided thousands of pages on different health conditions with video and interactive features to give patients better information on both the conditions and treatments. It thus enabled them to take a more active role in their healthcare. The white paper 'Our Health, Our Care, Our Say' set out details of how people with long-term conditions would be assisted to take a more active role through care plans. The Expert Patients Programme was established and the NHS Constitution in 2009 legislated for the provision of information and patient choice.^{4,5}

PPI was also presented as important, but the policy seems more confused and ambivalent. Community health councils were inexplicably abolished in 2003 and the successor bodies — PPI forums, followed by Local Involvement Networks (LINKS) — failed to establish an effective framework for citizen or public participation.⁶ In general, patient involvement has encompassed a broad commitment to ensuring patient representation of some kind on all health-related bodies.

A different slant to 'patient voice' has been the focus on capturing patient

experience as a means to improve quality or redesign services. One example is the National Inpatient Survey, which since 2002 has measured patient experience across all health trusts in England, enabling comparisons over time and between trusts. Patient experience was one of the three key elements of quality identified by Lord Darzi's next stage review, together with clinical effectiveness and safety.⁷ The Commissioning for Quality and Innovation (CQUIN) payments system was then attached to Payment by Results to provide financial incentives to trusts to improve patient experience.⁸

Underlying these actions is a consistent belief that enabling patients to exercise choice will drive quality improvement in the NHS. The organisational arrangements such as Choose and Book were put in place to enable this. However, the evidence that the exercise of choice acts as a significant influence on providers is scarce and limited to a few areas of care, mainly elective surgery.

One of the key elements related to this belief in patient choice has been the emphasis on publication of data about performance. While this does enable interested patients to research their options, some have argued that the more important effect on quality is the impact of publication on professional staff and their institutions. These often have an inherent competitiveness, which is quite possibly a stronger driver for improvement than choice by patients.⁹

Patient choice and patient voice in IBD: the next 5 years

There is widespread acceptance that involving patients enhances the quality of healthcare at all levels. The effectiveness of national initiatives based on consumerist behaviour, competition and financial incentives can be questioned, but there has undoubtedly been a major change in professional approaches and relationships with patients at the clinical level. Professionals have moved away from paternalistic approaches in which patients were not expected to play an active role in their own care. Patients too have different expectations of how they will be treated—expecting a better experience, more information and more involvement in decisions. These changes of attitude are often expressed in a general way as delivering more 'patient-centred' care.

Angela Coulter in her book *Engaging Patients in Healthcare* provides a useful framework for separating out different aspects of healthcare in which patient choice and patient voice are relevant.¹⁰ She identifies eight policy areas and uses these as the framework for evaluating the extent of patient engagement. These are:

1. improving care processes;
2. building health literacy;
3. selecting treatments;
4. strengthening self-care;
5. ensuring safer care;
6. participating in research;
7. training professionals;
8. shaping services.

Improving care processes

In IBD in recent years the area of greatest change has been in improving care processes — the development of the IBD Standards, the IBD Audit, IBD Quality Improvement Programme (IBDQIP) and now the IBD registry.^{11–14} The patient voice nationally is strong: Crohn's and Colitis UK has been involved in each of these developments on behalf of patients. Thus there has been a survey of inpatient experience in the most recent audit and an emphasis in the IBDQIP on patient stories at meetings and patient involvement in the self-assessment exercise.

There is much discussion about what the drivers should be for improvement in IBD care. The IBD Standards are not mandatory and there are mixed feelings about whether the audit and IBDQIP should develop into a formal accreditation process. However, data from the audit about individual hospitals is now in the public domain and available to patients. It is therefore possible for them to choose to which hospital IBD service they wish to be referred. Perhaps just as important it is possible for professionals and managers in neighbouring institutions (and potentially commissioners) to compare these results.

The IBDQIP website resource has seen considerable professional interest in how patient feedback can be gathered at the local level. Most have been looking for ready-made patient surveys to gather views about their services. Three hospitals undertook a trial of the Patient Opinion website in a joint scheme with the British Society of Gastroenterology and Crohn's and Colitis UK. This website enables patients to comment on their experience at a hospital with a system for the hospitals to receive the feedback and, if they wish, reply. Analysis of the feedback did lead to change in one of the hospitals.

IBD patient panels, facilitated by Crohn's and Colitis UK, are another means of incorporating the patient voice in improving care processes.¹⁵ There are now 35 panels in the UK and experience has shown that they can be effective in lobbying for better services and, with committed health professional engagement, provide an effective forum for discussing service improvement based on their collective experience.

Perversely, the potential for competition and patient choice as drivers of service change is restricted by the fact that the present tariff system is a barrier to developing innovative models of outpatient management.

Building health literacy

While information provision has undoubtedly improved and a few hospitals have adopted the information prescription approach, there has been little emphasis on health literacy and formal assessment of the understanding of their disease and treatments by patients with IBD. There is a need to move beyond information to providing education with the aim of improving patients' ability to undertake self-care, achieve better adherence and participate with confidence in shared decision-making.

Selecting treatments

Is there information on the extent to which patients are truly given choices in IBD treatments—for example, nutritional treatment for Crohn's disease as opposed to steroids; 5-aminosalicylic acid as opposed to steroids for flare-ups; treatment with infliximab or adalimumab; earlier surgery rather than persevering with medical treatment? This is an important area of patient choice and shared decision-making. Explaining the risks of treatments and investigations is also important, and probabilities need to be presented in an understandable way. There are instances of how this can be done which are beginning to be used — for example, the lymphoma risk of immunosuppressive agents¹⁶ — but more patient decision aids would be helpful.

Strengthening self-care

This is one of the few areas where evidence has been provided by a randomised controlled trial. Kennedy *et al* in 2004 demonstrated that education of health professionals and patients to undertake self-management was clinically safe and cost-effective in saving healthcare resources.¹⁷ We are now 10 years on and such approaches are still a rarity. This has to be a focus for development in the next 5 years if we are to maintain quality of care, improve outcomes and be cost-effective.

Ensuring safer care

There is a strong belief in government that publication of outcome data will help to ensure safer care through patient choice. Publication of mortality data might not be helpful for patients because IBD-related deaths are relatively rare. However, surgery is an important decision for all patients and they might be interested to see well-presented data on surgical outcomes. Even an indication of the number of operations conducted in each hospital might be of value if patients were informed that there is evidence suggesting that higher-volume centres have better outcomes.¹⁸

Participating in research

Participation is mostly limited to individual patient representation in research governance groups or to participation in clinical trials. The IBD audits showed that participation in trials is low, although this is improving, and it is difficult for patients to find out about opportunities to participate in trials unless invited by their doctor/clinician.

Involving patients in defining research goals should be an aim and there is a well-established process developed by the James Lind Alliance which should be adopted in IBD.¹⁹

Training professionals

Usually curricula for training health professionals incorporate communication and interpersonal skills and invite patients to give their perspectives. This needs to be repeated throughout postgraduate education and continuing professional development. There has been an immensely positive response to the inclusion of patient perspectives in the regional meetings held as part of the IBD Audit and IBDQIP.

Shaping services

The IBD patient panels have provided opportunities for patients and professionals to discuss local services.¹⁵ Service redesign is likely to become more important in the next few years, particularly where commissioners are keen to see changes to current services. Various tools have been developed by the King's Fund, Involve and others for including patients in service redesign and these need to be used more often in IBD and the results shared.²⁰

How should service design and the experience of a patient with IBD reflect increased commitment to patient choice and voice and a collaborative approach to IBD care by 2017?

Service design

- There should be integrated IBD services across primary and secondary care. All diagnosed patients with IBD would be registered with the service and should be able to access both GP and hospital services without further referral. There would be a shared (electronic) record of the current care plan accessible to the patient (if they wish), GP and hospital staff.
- The IBD nurse would train and support patients with IBD in self-managing using web-based or telephone communication to maintain contact. Self-managing patients would monitor their own symptoms and seek help when indicated, but would have a formal annual review either remotely or by attending the GP practice or hospital.
- Patients would have the choice of an outpatient management system depending on their situation and preference, but would generally be encouraged to move towards self-managing if clinically safe.
- The GP would check annually that an IBD review had taken place and would arrange the review if it had not. This review would be a basic well-being and safety check followed by referral to the IBD team if problems were evident.
- IBD staff involved in supporting self-management would have had training in motivational interviewing.
- The IBD clinic would mostly see patients requiring active management. The multidisciplinary team (MDT) would review patients with complex problems or major treatment choices. If the patient's case were to be referred to the MDT the patient's views and preferences would be explored beforehand and reported at the meeting. The MDT should make recommendations, not decisions, which would then be discussed with the patient.
- Clinical information would be recorded on a local IBD database with registry data for national audit being exported automatically.
- The IBD team and a patient would undertake the IBDQIP assessment annually and submit results nationally to be included within the UK IBD Audit report. Audit results would be in the public domain.
- Patient feedback surveys or other systems would be automatically provided after inpatient admissions and at annual review.
- There would be an IBD patient panel with a meeting at least annually to which all patients were invited and which

worked with the professionals to review audit results and feedback on services.

The patient's experience

- The GP and patient would have access to an IBD (or gastrointestinal) service description and public audit data at the time of referral, enabling a choice of provider if IBD seemed at that stage to be a likely diagnosis.
- On diagnosis the patient would have a separate session to discuss the implications of diagnosis and an information prescription would be given, including a leaflet about the IBD service.
- Within the first 3–12 months the patient would be encouraged to take part in a group educational session about IBD, treatments, 'living with' issues and the IBD service. This might include understanding risk and probabilities in relation to treatments to familiarise the patient with any decision aids before they are used as part of the decision-making process.
- Patients would be made aware of the role of the MDT and that there would be opportunities to participate in decision-making.
- Consultations would include a means for patients to define their problems before the consultation so that their concerns would be covered (53% in the EFCCA Impact Study, 2011, said they were not able to tell their doctor something important insert 2011 after study²¹).
- The annual review would take a more holistic approach to living with IBD, including psychological well-being—with a longer time allocated, covering choice of management, treatment adherence, plus the opportunity for the patient to talk about living with IBD and their experience of the service. The review would essentially have a clinical well-being element set within a patient-directed consultation.
- The IBD service leaflet should explain what data about the unit are publicly available and where to find them.

Beyond 2017? Some ideas for the future!

Patient choice

- (1) Given that patients often wish to explore complementary approaches to management of their IBD perhaps an IBD service could offer patients a panel of 'approved' local therapists who are committed to a safe approach which does not undermine the patients' confidence in their medical management.
- (2) A second option might be to provide all patients with an annual service review, including details of their hospital's performance compared with national benchmarks.
- (3) The IBD service might have a managing board that included a number of patients, rather like a school governing body, responsible for reviewing the audit data, service developments and requests to management for service change.

Taking the patient voice closer to actual clinical care, should we hold a trial to see whether it might be beneficial to have the patient present at the MDT discussion of their situation?

Finally, perhaps we should avoid talking about 'giving patients choice or a voice' as a separate focus. This implies something is being offered as an extra rather than being embedded in the overall approach. The

patient–professional relationship should be respectful and collaborative and consider consistent patient engagement as an integral part of a normal way of working.

Disclaimer The opinions expressed in this article reflect the authors' own views and not necessarily those of Crohn's and Colitis UK.

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