

Patient perspective

Challenges for primary care in the age of the autonomous patient

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ABSTRACT

Patient expectations of and concerns about health care have changed over recent years and now present new challenges to the primary care clinician. Involving patients and carers more widely in general practice services (and also medical education), and accepting their views is essential to achieving

patient-centred services and is likely to enhance doctors' standing in patients' eyes.

Keywords: attitudes, therapeutic alliance, user expectations, user involvement

How this fits in with quality in primary care

What do we know?

The spontaneous patient 'movement' against paternalism had already sparked a consumerist approach to health care when the scandals of Bristol, Alder Hey and Shipman emerged, threatening to break public trust. Patients have 'grown up', and in 2000 *the NHS Plan* put them firmly at the heart of health services.

What does this paper add?

The new GP contract 2003 had wide implications for patient care. Today's patients may have access to the knowledge base of medicine through the internet, yet have difficulty accessing health services. Their expectations have changed, perhaps more than is realised, with resultant training implications. Trust, and the doctor–patient relationship, is now dependent upon a change in professional attitudes. Openness, the ability to share power and advanced communication skills training are vital to ensure adequate information-giving and an effective GP consultation, while user involvement can lead to mutual respect and patient-centred services.

Change

On the rare occasions I visited a doctor as a child, the family general practitioner (GP) collected patients from the waiting room with a shake of the hand. Now an impersonal, disembodied sing-song voice, roboticised by hidden speakers, broadcasts my name to the throng, and electronic locks reinforce the demarcation line between doctors and patients. This does not hint at 'patient-centred' health care.

It is no longer medical science alone, but the information age along with consumer and patient groups that is driving change.¹ All is indeed 'changed utterly'.² Patients used to be satisfied if they left the surgery with reassurance and a prescription. Now,

they are likely to arrive with potentially challenging computer printouts of possible diagnoses and cutting-edge treatment alternatives, and to check their prescriptions on the internet. Why does this happen? Could it be that doctors do not always give patients all the information they want?

A further problem is highlighted by Jelley and Walker in their view that 'the basic assumption is that our training equips us to make decisions on behalf of our patients. Even when we have been unsure, we have rarely shared this uncertainty with the patient'.³ Today's patients want hard facts, rather than meaningless

reassurance, and respect doctors who admit they ‘do not know, but will try to find out’.

Increasingly, patients want to be involved in their care pathway from the outset: to understand what a diagnostic test is for and what results could mean; to weigh the implications of false negatives and false positives against the advantages of screening.

Some patients, of necessity, become experts in their own illness, and expect their GP to be as up to date as they are. Although the dynamic of the doctor–patient relationship has altered to reduce doctors’ authority over patients, a more meaningful alliance is evolving. Among enlightened clinicians, paternalism has given way to honesty, ‘compliance’ to ‘concordance’.

With GPs taking increased responsibility for minor operations and patient follow-up, plus the advent of point-of-care testing and rule-out screening, patients may want reassurance regarding training, quality assurance and audit of the services being provided.

The consequences of increased patient choice are likely to mean the need for a ‘new approach to professionalism in all the health professions’.¹ Are GPs ready for the challenge?

Communication skills and patient choice

Sometimes patients cannot make informed treatment choices because professional bias puts pressure on them. When a woman ignores an invitation to cervical screening she may receive another letter from the surgery which says her GP is concerned to learn she has not responded and includes details of a smear test appointment. This might seem reasonable – to a doctor. But how does the woman feel? She does not want a smear test, but feels her decision has been disregarded. The fixed appointment puts the onus on her to take action. She does not want to inconvenience the surgery, or to have to justify her decision to her GP, but fears she might compromise their relationship. It feels like coercion. Health professionals need training so that they do not use their power to influence patient choice.³

Patients’ understanding of doctors’ everyday language can be different from their own. What does ‘serious but treatable’ mean to you? To some patients this can mean ‘worrying, but curable’, rather than ‘close to death’, and they can feel cheated when precious time is lost because they did not appreciate their situation. Yet doctors may be convinced they communicated bad news adequately.

Patients need doctors and nurses to be ‘upfront’ and honest. A needle piercing flesh might bear no resemblance to ‘just a little scratch’. And why does patient pain become simply ‘discomfort’?

GPs now have a major sign-posting role to help patients understand treatment choices and make decisions,⁴ and can point out helpful websites such as www.doctorfoster.com and www.labtestsonline.com. A considerable body of literature supports the use of decision aids for patients.⁵ Perhaps GPs, still unconvinced of their effectiveness, simply do not have time to investigate patient-centred care?

Do you groan when you find a ‘heart-sink’ patient’s name on your list, or welcome the opportunity to hone your communication skills?⁶

Unconscious biases can weaken objectivity in the consultation.⁷ Technology can also be a challenge. ‘She’s typing on the computer as soon as I start talking’ is a familiar patient complaint. Shrinking consultation times and patients’ increased needs to understand and discuss choices may seem incompatible, but communication skills training can overcome these obstacles.⁸ As a simulated patient in medical education, I have watched student communication skills blossom. As a full participant in postgraduate education, I have marvelled to see diagnostic and communication skills expertly combine.

Skills for Communicating with Patients (one of a companion set) offers an evidence-based approach to communications skills learning and teaching.⁹ With a step-by-step approach, Silverman, Kurtz and Draper demonstrate how doctors’ communication skills can enable patients to become more involved in the consultation, at no cost in time, yet great gain in effectiveness. Having experienced both good and bad doctor–patient communication (and traumatic effects of the latter), I think communication skills should be a component for all doctors in the revalidation process. And I would like these outstanding books to be used as the ‘doctors’ bible’, for they have the potential to turn medical education on its head, and improve outcomes for both patients and doctors.

Access

Lack of continuity of care and reduced access are having a major impact on the doctor–patient relationship. People prefer to see ‘their own’ GP, someone they know and trust who has a rounded picture of their health. They do not want to have to explain their medical history repeatedly to different doctors, and fear that important details may be overlooked by someone unfamiliar to them. But, partly as a result of the 48-hour access target, continuity of care, especially for patients with complex medical and psychological needs, has been compromised and GPs ‘pressured to disregard their (patients’) different needs’.¹⁰ Nurse-led services are taking increased responsibility for chronic

disease management, more GPs are working part-time and GP practices are no longer responsible for out-of-hours care. There is some evidence that these changes have had serious consequences for patients in some areas: www.timesonline.co.uk/tol/news/uk/health/article1838285.ece

Misinterpretation of the 48-hour target has meant patients have not been able to book a GP appointment more than two days in advance. In one bizarre incident, a patient needing an urgent appointment thought she was being helpful by arriving just as the surgery opened, but was told she could only book an appointment by phone. She had to go outside to ring on her mobile.

A visit to relatives was ruined for another patient when lack of access to a 'stand-by' prescription for the specific antibiotic recommended by her consultant meant she spent Boxing Day in an accident and emergency department and trying to find an open pharmacy.

Access is vital to patient safety, but was not among the issues prioritised for concern at a world breast cancer conference.¹¹ Only the British voted for it.

Patient safety

Patient safety has been on the NHS agenda since *An Organisation with a Memory* was published in 2000, and is now a priority.¹²

Cancer patient referrals and the GP's gatekeeper role have long been under scrutiny: GPs' lack of familiarity with their disease is no consolation to patients when delay means a 'too-late' diagnosis. At the same time, since the pressure of two-week targets, GPs have also been criticised for making too many urgent referrals of patients with symptoms of possible cancer.¹³ Referral protocols may shrink doctors' morale: 'I don't want to be a tick-box merchant' said one GP, when the idea was being mooted. Maybe he saw few patients with cancer. But I had run a cancer support group and could think only of the countless patients whose cancers had been missed despite numerous visits to their GP with classic symptoms. Patient experiences elicited at the annual National Conference of Cancer Self Help Groups can furnish insight and overview.¹⁴

Perhaps it is easy to lose sight of what doctoring is about when change seems threatening. But it is also easy to miss NHS guidelines among mountains of paperwork. Cancer guidance needs to be emphasised and supported by training.

Quality in primary care and 'patient choice' can be frustrated when access to secondary care is blocked. What is the effect on GPs when patients have to wait

up to four months to find out if they have breast cancer, and months more to access life-saving treatment?¹⁵ Comments such as, 'It's a frightening time to be old' and 'The NHS is fine, as long as you're not ill' are frequently heard.

Patients with an uncommon condition such as lymphoedema (which nevertheless affects an estimated 100 000 people or more in the UK and can be a side effect of cancer treatment) may find that their GP does not identify their symptoms.¹⁶ After diagnosis they may find that relevant local services are 'poor to non-existent' because they are not included in Primary Care Trust Service Level Agreements, funding is not ring-fenced and encompasses palliative care services, and treatment elsewhere is barred due to lack of resources. The GP is then left to deal with the considerable psychological consequences of disease progression. With lymphoedema services becoming increasingly community-based, primary care surveys are needed to determine the level of patient need along with training and resource implications.

Sharing and learning

Risk training should include openly sharing mistakes, but also risk awareness, with briefings on 'how to recognise and deal with situations in which patient safety can be compromised'.¹⁷ For example, the drive to reduce antibiotic prescribing (public health) needs to be balanced by raising awareness of conditions that still merit their use, such as chest infection or bronchiectasis (individual patient safety). A patient-centred approach would include feedback from significant event meetings to the affected patients.

Information

Open sharing of information drives better consulting, and should also highlight the need for a lifelong commitment to regular consultations skills training.³

Concordance is likely to improve when patients receive unbiased health information in a form they can understand.¹⁸ Information which explains medical terminology is likely to be especially useful to patients.^{19,20}

Many doctors, as well as patients, find risk difficult to understand. If consent is to be genuinely informed, doctors need to communicate risks and benefits clearly so that comparisons can be made. The high level of lay input into the Royal College of Anaesthetists' patient information project ensured their model

series of booklets is suited to 21st century patients' needs.²¹ *Anaesthesia Explained*, for example, is made meaningful by the inclusion of an index (1–10: very common to 1–100 000: very rare) for side-effects and complications.²²

Sadly, some national patient charities have not kept pace. Their patient information is rendered meaningless by words such as 'most' and 'usually'. Patient contributions for the purposes of revision are limited by nurses, who still decide the final draft: professionals deciding what information patients want.

Innovation

Quality in primary care may be judged by attitudes and environment as well as by medical care. Community art projects can involve patients and enhance surgeries (Kirkbymoorside, North Yorkshire). Schemes, such as a waiting-room touch-screen facility that enables patients to access their health records, and a practice-based, personally tailored exercise scheme for patients, indicate GP enthusiasm has not dimmed. One memorable GP I met invites his patients to write their own referral letter (stretching the consultation time) along with his, because new information emerges when someone is able to recall things in their own time. He also uses the arts and literature as patient therapies. Dedicated, innovative, *caring* – this is the type of doctor whom patients will remember as truly 'great'. Good practice might spread more quickly if awards were given not only for innovation, but to those who copy, saving time and resources *for the patient's sake*, rather than re-inventing the wheel.

Information sharing has become part of rebuilding trust and requires a change in professional attitudes.³ As well as writing my own referral letters, I ask for copies of all medical tests and correspondence relating to my care – and found one referral letter had taken 12 days to leave the surgery.

Information prescription pilots are expected to be rolled out nationwide in 2008, allowing people with long-term medical conditions to be clear about the content and outcome of discussions with health professionals (www.informationprescription.info), but shared correspondence is still vital to openness. Patients do not want information that is dumbed down, but prefer to use accessible information (for example a glossary of medical terms²³) or ask their GP if there is something they do not understand. It should be a matter of patient choice whether letters, even those containing bad news, are sent direct to patients because 'not knowing' is worse than the worst news.

Discrepancies and inaccuracies in medical records can create a sense of unreality (I was surprised to read I

had two children, when I had given birth to four) as well as disclose attitudes when personal remarks are included. The notes of a breast cancer patient whose GP took five months to refer her to a breast clinic stated, 'There was some delay between her finding the lump and diagnosis'. As is so often the case, delay could be interpreted as 'patient delay'. Nowhere in hospital records will you read of 'GP delay'. A patient was told the results of a scan 'showed no bone metastases relating to cancer'. No one thought it important to tell him what else was revealed, yet this might have affected insurance cover and other aspects of his life.

Patients can sometimes suffer the consequences when doctors are unable to acknowledge they 'do not know'. 'Psychosomatic' can be a damaging label with no chance of appeal. It can ruin a doctor–patient relationship and lead other doctors to be dangerously dismissive. It took five years before one 'psychosomatic' patient was finally diagnosed with both multiple sclerosis (MS) and myalgic encephalitis (ME). Even classic indicators of cancer can be ignored if a GP is biased by accepting another doctor's label without question.

Pain relief

Good pain relief is so basic to good doctoring that the public often assumes medical education is built around it. What use is a doctor who cannot relieve pain? Although effective pain relief requires specialised knowledge,²⁴ the Gold Standards Framework programme of palliative care is not compulsory, adequate palliation is patchy, and few people die well. Many of today's cancer patients survive, only to become sufferers of long-term side-effects of cancer treatments (of which most GPs have little knowledge) including severe and chronic pain. Additionally, because the cancer survivor stereotype is someone whose every twinge means cancer has returned, those reluctant to fit this image may suffer in silence rather than bother their GP (but risk being blamed for 'patient delay' if they ignore symptoms).

Cancer treatments can cause severe side-effects, and patients may need expert pain relief between different stages of treatments, but lack of communication between secondary or tertiary and primary can invite neglect, and patients may not speak out because they feel information is being limited to their assessed coping capabilities.^{25,26} One caring GP has suggested that consultants provide GPs with a letter at the end of each part of treatment, forewarning them of possible or expected side-effects. Patients need warning, too.

Macmillan Cancer Support hopes its report, *Yesterday's Women*²⁷ will stimulate discussion about chronic survivorship conditions in general, and the late effects of radiation treatment in particular. Among the six areas they will be focusing on are the need for a national register of consequences of cancer treatments and the need to improve communication between primary and secondary care. Health systems should ensure medical treatments are delivered as safely as possible, but if these are likely to have serious consequences,²⁸ surely both GPs and patients deserve to know and to be given help to combat problems?

In patient eyes, primary, secondary and tertiary care needs to be more joined up so that each is fully informed about patient needs. GP surgery teams need to train together, but so do primary- and secondary-care clinicians.

User involvement

Writing prescriptions is easy, but coming to an understanding with people is hard. (Franz Kafka)

Layered posters compete for wall space, but patients' eyes are more likely to be drawn to the surgery announcement given prominence by its stand:

NUMBERS OF PATIENTS WHO DID NOT ATTEND FOR THEIR APPOINTMENT IN THE MONTH OF MAY = 43!!!

it exclaims in enormous letters. Shock tactics. I'm already silently protesting my innocence and siding with the establishment. But the admonishment rants on wordily like a nagging parent to explain what these figures represent in terms of GP hours wasted in a week ... a month ... a year. 'Please' does not feature in the demand to notify the surgery if appointments cannot be met. The figures indict patients. The confrontational approach creates barriers. No user involvement here then.

I am sympathetic, but it takes real effort to wade through the overkill. Only my interest in writing patient information and partnership working persuades me to persevere. If the culprits should ever attend, would they, I wonder, read further than the first line?

Patient expectations may have been raised to the point where they are impossible to meet and the GP is dehumanised.²⁹ However, 'user involvement' is the key to quality in health services and should saturate medical education. Resistance to power sharing can be overcome by training,³⁰ and those least in favour often become the most enthusiastic advocates.

There can be various ways of discovering patient views and different forms of user involvement.³¹

Patient articles in professional journals used to be seen as an invasion of territory. Now patients are invited to contribute. We need to share each others' space if we are to understand one another.

How patient-centred is your GP practice? Do you know what patients do not like about it? Do you hold regular patient surveys? Are survey questions decided by clinicians or patients? Do patients write your information? Are they involved in audit – as equal members of a team? If you have formed a patient involvement group, is it meaningful? Is there a lay chair, a lay agenda? If you use patient speakers at conferences or in medical education, are they given poll position, or the 'graveyard' slot at the end of the day? How do you show patient representatives that they are appreciated?

The Medical Royal Colleges have pioneered good practice with their patient liaison groups. The level of openness and responsibility I experienced with the Royal College of General Practitioners (RCGP) and the Royal College of Pathologists (RCPath) fostered mutual respect and trust. Tokenism was outlawed. Being able to discuss thorny issues, understand each others' perspectives and make a difference was extremely rewarding. We lay people devised patient information with input from health professionals for medical accuracy only, wrote in college journals and reviewed medical books, were privy to confidential enquiries and were full team members during hospital reviews. We gave presentations, organised symposia, helped write national guidelines, sat on committees and (as chair) attended College Council meetings. We became integral to College working. An invitation to prestigious annual dinners (RCPath) demonstrated inclusiveness. 'We need people who do not doubt our good intentions, but are prepared to tell us things others are not', wrote Dr Helen Williams,³² RCPath registrar. This epitomises the level of acceptance needed if primary care services are to meet the challenges ahead.

REFERENCES

- 1 Irvine D. *The Doctor's Tale: professionalism and public trust*. Oxford: Radcliffe Medical Press, 2003.
- 2 Smith R. All changed, changed utterly. *BMJ* 1998; 316:1917–18.
- 3 Jelley D and Walker C. Sharing information with patients. In: Harrison J, Innes R and van Zwanenberg T (eds). *Rebuilding Trust in Healthcare*. Oxford: Radcliffe Medical Press, 2003, pp.131–42.
- 4 Coulter A, Entwistle V and Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999;318:318–22.
- 5 O'Connor A, Rostom A, Fiset V *et al*. Decision aids for patients facing health treatment or screening decisions: systematic review. *BMJ* 1999;319:731–4.
- 6 Blennerhassett M. Should GPs Manipulate the system? *GP* 11 November 2002:77.

- 7 Barrows HS and Pickle GC. *Developing Clinical Problem-solving Skills: a guide to more effective diagnosis and treatment*. New York: WW Norton and Company, 1991, p.35.
- 8 Hobma S, Ram P, Muijtjens A, van der Vleuten C and Grol R. Effective improvement of doctor–patient communication: a randomised controlled trial. *British Journal of General Practice* 2006;56:580–6.
- 9 Silverman J, Kurtz S and Draper J. *Skills for Communicating with Patients*. Oxford: Radcliffe Medical Press, 1998.
- 10 Campbell J (ed). *The Future Access to General Practice-based Primary Medical Care*. London: NHS Alliance and Royal College of General Practitioners, 2004.
- 11 National Breast Cancer Coalition Fund. Second World Conference on Breast Cancer, Brussels, Belgium, 11–14 March 1999. Report by National Breast Cancer Coalition Fund, Washington DC, www.natlbcc.org
- 12 Department of Health. Making patient safety a priority. *CMO Update* 2006;45:1.
- 13 Shapley M, Jordan J and Croft PR. A systematic review of postcoital bleeding and risk of cervical cancer. *British Journal of General Practice* 2006;56:453–60.
- 14 National Conference of Cancer Self Help Groups www.nationalcancer.org (accessed 8 May 2007).
- 15 Martin D. Two-week wait to see a specialist becomes four months of anguish. *Daily Mail* 26 February 2007.
- 16 Moffatt CJ, Franks PJ, Doherty DC *et al*. Lymphoedema: an underestimated health problem. *Quarterly Journal of Medicine* 2003;96:731–8.
- 17 Sandars J. A positive approach to patient safety. *Quality in Primary Care* 2006;14:63–4.
- 18 Dickinson D, Theo Raynor DK, Kennedy JG, Bonaccorso S and Sturchio JL. What information do patients need about medicines? *BMJ* 2003;327:861–4.
- 19 The Patient Partnership Group of the Royal College of General Practitioners. *Medical Abbreviations*. London: The Patient Partnership Group of the Royal College of General Practitioners, 2002.
- 20 Humber and Yorkshire Coast Cancer Research Network Consumer Research Panel. *How to Appraise Research Proposals: a lay member's guide*. Hull: Humber and Yorkshire Coast Cancer Research Network Consumer Research Panel, 2006.
- 21 Lack JA, Rollin AM, Thoms G, White L and Williamson C. *Raising the Standard: information for patients*. London: The Royal College of Anaesthetists and the Association of Anaesthetists of Great Britain and Ireland, 2003.
- 22 The Royal College of Anaesthetists and The Association of Anaesthetists of Great Britain and Ireland. *Anaesthesia Explained*. London: The Patient Information Unit. www.youranaesthetic.info (accessed 8 May 2007).
- 23 Plain English Campaign. *How to Write Medical Information in Plain English*. High Peak: Plain English campaign, 2001. www.plainenglish.co.uk
- 24 Garry A. Palliative care. In: Baker MR (ed). *Modernising Cancer Services*. Oxford: Radcliffe Medical Press, 2002, pp. 175–91.
- 25 Blennerhassett M. Deadly charades. *BMJ* 1998;316:1890–1.
- 26 Blennerhassett M. What cancer patients need. In: Baker MR (ed). *Modernising Cancer Services*. Oxford: Radcliffe Medical Press, 2002, pp. 152–64.
- 27 Hanley B and Staley K. *Yesterday's Women. The story of R.A.G.E.* TwoCan Associates: research on behalf of Macmillan Cancer Support. London: Macmillan Cancer Support, 2006.
- 28 Tytko K and Blennerhassett M. How the NHS could better protect the safety of radiotherapy patients. *Health Care Risk Report* 2006;12:18–19.
- 29 Ruth Etchells. The patient's perspective. In: Harrison J, Innes R and van Zwanenberg T (eds). *Rebuilding Trust in Healthcare*. Oxford: Radcliffe Medical Press, 2003, pp. 5–14.
- 30 Kohner N and Leftwich A. *Partnerships: a training pack for training with patients and clients*. London: College of Health and Health Development Partnerships, 1998.
- 31 TwoCan Associates. What are the best ways to listen to the views of people affected by cancer? In: TwoCan Associates. *Finding out about the Priorities of Users and Making them Count*. Research on behalf of Macmillan Cancer Relief. TwoCan Associates, 2005, pp. 10–23, 28.
- 32 Williams H. Registrar's Report. *Bulletin of the Royal College of Pathologists* 2003;124:33–4.

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