

FEATURE

INFORMED CONSENT

Patient information leaflets: “a stupid system”

The NHS’s multifarious patient information leaflets are inaccurate, inconsistent, and confusing, finds **Margaret McCartney**, and effort is duplicated because each trust commissions its own, often from the private sector

Margaret McCartney *general practitioner, Glasgow*

The so called patient revolution is nothing without quality information. And so the NHS is awash with patient information, especially leaflets, in hospital wards, outpatient clinics, and general practitioners’ surgeries. Some trusts commission leaflets from external, profit making companies; others write their own. But how efficiently does the health service coordinate them, and are leaflets tested for effectiveness on patients?

In a recent study researchers asked 128 trusts for leaflets given to patients after an inguinal hernia repair, and 93 trusts responded.¹ Almost one in five trusts sent a leaflet created by a private company, Eido Healthcare. Others had inconsistent guidance on when to return to office work (ranging 1 to 6 weeks) or manual work (2 to 12 weeks). Similarly, leaflets gave conflicting advice about when to resume driving, sex, and sport. This means that patients are being given very different information about the effects of the same surgery, depending on where they live and which leaflets are used.

A similar study examined leaflets provided to patients who had been offered extracorporeal shockwave lithotripsy. The researchers found that the leaflets did not consistently mention common recognised complications and some were not mentioned at all.² Another study, which examined patient information leaflets given for transrectal ultrasound guided prostate biopsy, again found wide variation, with drugs, analgesia, and complications often inadequately explained.³

“It’s a stupid system, a waste of money, and, without rigorous standards of searching and appraisal, much of the information is biased and misleading—especially in terms of fair representations of risk,” Muir Gray told the *BMJ*, reflecting on the current situation in the NHS. Gray is co-chair of the executive council of the Information Standard, an independent certification scheme funded by the Department of Health for organisations producing evidence based healthcare information for the public.

Gray said that a lack of coordination and slow uptake of the certification scheme by the NHS has meant that much information provided to patients is of poor quality. “Patients have a right to clean, unbiased information, but they can’t get

that off the internet,” he said. “It’s not possible to communicate to a patient in 10 or 20 minutes everything about a decision. Knowledge is essential, but you can’t rely on the consultation—you don’t have the time. Therefore we need to supplement and complement face to face. You need that to help people reflect on their values, to discuss their fears and anxieties.”

The Information Standard, which is run by the for profit company Capita, offers a kitemark if the information presented is evidence based, clear, and accurate. Patients should also be involved and have tested the information.

Some 400 UK hospitals use Eido, a private company, to produce information leaflets for them. Eido’s website says that the company produces “informed consent patient information leaflets,” which it says “improve the doctor-patient relationship, reduce the risk of litigation and increase patient satisfaction.” They advertise both their Information Standard accreditation and ability to customise information locally.

Simon Parsons, a consultant surgeon in Nottingham, set up the company when he was a surgical registrar out of concern that the informed consent process, which was subject to then new General Medical Council guidance, was using poor quality patient information leaflets. Eido’s information leaflets are indemnified, and Parsons said, “In the 10 years we have supplied in the UK, not a single claim has been brought against us in terms of inaccurate patient information.” The company supplied audit data in support of its claim of patient satisfaction. The leaflets are not publicly available except through a hospital or surgeon who has access to them.

Meanwhile, Guy’s and St Thomas’ NHS Foundation Trust has an online, freely available library of about 850 patient information leaflets, regularly updated, but all are produced in house.⁴ These are written by clinicians and healthcare professionals, and tested by patients or lay readers to ensure they can be easily understood. Anita Knowles, director of communications, told the *BMJ* that the trust ensures leaflets are necessary and would not duplicate a good leaflet from elsewhere. The patient publications team is made up of two staff team who

call on additional resources as needed. They made a decision not to use external agencies because “it was just as cheap to do it ourselves. We wanted the control, as well as the ability to change information rapidly,” Knowles told the *BMJ*.

The problem of varying quality of leaflets is not new; in 1998 the *BMJ* published an investigation into the quality of leaflets on asthma given out by general practitioners. It found inaccuracies and outdated information from the NHS, drug companies, and charities.⁵ In an accompanying editorial, Angela Coulter, now a researcher at the University of Oxford, called for a national strategy.⁶

She told the *BMJ* that “progress has been slow.” The problem is that “the NHS still fails to take this seriously.” For example, printable patient information leaflets are available as part of the Emis computer system used by general practitioners, which are Information Standard accredited but which come with advertisements attached.

“In the patient’s eye, that can devalue it,” Coulter said. “At the moment, in most NHS trusts, there is no one who has responsibility, or, if they are junior, often they have no budget. Often leaflets are written with the best of intentions in someone’s free time, but they can end up amateurish, with the evidence and uncertainties not expressed clearly. Yet there has been so much work internationally into setting standards,” such as the Delphi method, a structured communication technique.

A spokesman told the *BMJ* that NHS England is launching a “major project” in September to standardise all information going out to patients, which will then go to the Information Standards Board for Health and Social Care for approval.⁷ One of the aims of this board, which works throughout the NHS, is to reduce inefficiencies through reducing replication. A spokesman said that there needed to be “clinically endorsed,

consistent information available across the country,” which would “lead on the standardisation of all information going out to patients.”

The internet has given us a great gift of instant information sharing. The challenge now, Coulter emphasised, is to adopt high standards, updating information regularly, and making it easily accessible. The size of the NHS makes this hard to do, but it is wasteful to franchise out the core role of information provision to the private sector because each trust is paying again for the same information over and over. This is one area of the NHS where efficiency savings look ripe for the picking.

Competing interests: I have read and understood the BMJ Group policy on declaration of interests and declare the following interests: I am a general practitioner working for the NHS.

Provenance and peer review: Commissioned; not externally peer reviewed.

- 1 Grewal P. Survey of post-operative instructions after inguinal hernia repair in England in 2012. *Hernia March*, 2013.
- 2 Askari A, Shergill I. Patient information leaflets for extracorporeal shock wave lithotripsy, questionnaire survey. *JRSM Short Rep* 2012;3:35.
- 3 Shergill I, Bahl K, Farjad M, Phipps C, Fowles G. Patient information leaflets for Transrectal Ultrasound guided prostate biopsy: Results of North Thames deanery survey. *BMC Res Notes* 2010;3:27.
- 4 Guy's and St Thomas' NHS Foundation Trust. Our patient information leaflets. 2012. www.guysandstthomas.nhs.uk/patients-and-visitors/patients/patient-leaflets/patient-info-leaflets.aspx.
- 5 Smith H, Gooding S, Brown R, Frew A. Evaluation of readability and accuracy of information leaflets in general practice for patients with asthma. *BMJ* 1998;317:264-5.
- 6 Coulter A. Evidence based patient information is important, so there needs to be a national strategy to ensure it. *BMJ* 1998;317:225-6.
- 7 Information Standards Board for Health and Social Care. www.isb.nhs.uk.

Cite this as: *BMJ* 2013;347:f4748

© BMJ Publishing Group Ltd 2013