

Why are people still dying of embarrassment?

April is 'bowel' month, hosting both Irritable Bowel Syndrome (IBS) and Bowel Cancer awareness months. How many people do you know with IBS? Perhaps more than you think. The incidence of diagnosed IBS in the general population is 10%-20%, although it is widely acknowledged that many people with symptoms may not seek medical help. As such, the actual incidence may be significantly higher. Bowel cancer is the third most common cancer in the UK. Every year around 36,000 cases are diagnosed.

The intimate and embarrassing nature of the symptoms experienced by people with either IBS or bowel cancer may

breed reluctance in speaking to health-care professionals about their symptoms. A late diagnosis of either condition may lead to exacerbated symptoms and even premature death. Half of those diagnosed with bowel cancer will die from their condition, but if it is detected early enough, 90% can be treated with medication. Although IBS is not as life-threatening as bowel cancer, it can significantly disrupt an individual's daily activities leading to poor quality of life (QoL)¹.

Why then, are we as a nation so avoidant of talking about our bowels; are we embarrassed, do we consider it impolite or politically incorrect?

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Bowel Cancer Signs and Symptoms

The most common symptoms to look out for are:

- Bleeding from the bottom without any obvious reason
 - A persistent change in bowel habit to looser or more frequent bowel motions
 - Abdominal pain, especially if severe
 - A lump in your tummy
- Visit your GP if you experience any symptom for longer than 4-6 weeks.

Irritable Bowel Syndrome Signs and Symptoms

The most common symptoms to look out for are:

- Pain and discomfort in various parts of the abdomen
- Bloating
- Change in bowel habits
- Other symptoms including: nausea, headache, belching, poor appetite, tiredness, backache, muscle pains, heartburn and bladder symptoms.

Patient satisfaction: achieving its full potential?

Currently, patient satisfaction is at the forefront of a variety of healthcare agendas. From Lord Darzi's report on healthcare in London¹, emphasising the need for services to focus on individual needs and choices, to the government's implementation at a national level of Local Involvement Networks or LINKs²,

designed to ensure patient and public influence within healthcare services. There is a growing tide of interest in engaging patients in healthcare planning in order to raise patient satisfaction levels. The challenge of engaging patients requires ...

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Why are people still dying of embarrassment?

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A review of patients' experiences of seeking medical help found that fear of embarrassment (i.e. of a sensitive area), and the attribution of symptoms to other medical disorders (e.g. piles, indigestion) were common reasons for delaying GP visits². Similarly, a recent poll commissioned by the Prostate Cancer Charity questioned men over the age of 45 about the barriers to getting their prostates checked³. It emerged that fear, ignorance, and lack of access were all factors in delay. The possibility of a rectal examination also deterred 16% of respondents. Such concerns are hindering people from seeking help when it comes to potentially fatal conditions.

Surely, it's about time that the stigma surrounding bowel problems subsided so

that awareness of such conditions can be raised and more people can seek help. If we were as frank with our GPs about our bowels as we are about discussing other ailments, then maybe so many of us wouldn't be dying from embarrassment.



References

1. Hahn BA, Yan S, Strassels S (1999). Impact of irritable bowel syndrome on quality of life and resource use in the United States and United Kingdom. *Digestion*, 60: 77-81.
2. Smith LK, Pope C, Botha JL (2005). Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *The Lancet*, 366: 825-831.
3. The Prostate Cancer Charity (2008). Fear, ignorance and lack of access to doctors stops men from having their prostates checked.

Retrieved from: http://www.prostate-cancer.org.uk/news/news_detail.asp?id=1111.

Health Awareness - dates for your diary

IBS Awareness Month

Bowel Cancer Awareness Month

National Depression Week (14 – 18 April)

World Health Day (7 April)

World Malaria Day (25 April)

National Stop Snoring Week (21 – 26 April)



How do healthcare professionals feel about insulin pumps to manage diabetes?

Matt Reaney recently attended the Diabetes UK Annual Professional Conference (APC) in Glasgow, for healthcare professionals and researchers working in the field of diabetes. This year's theme was "body, mind and science", a concept that conveys the importance of psychological as well as biomedical outcomes for people with diabetes.

During the conference, Matt presented the results of a survey¹ examining healthcare professionals' (HCPs) attitudes toward the use of insulin pump therapy (CSII) among people with Type 1 diabetes. The Attitudes to Pump Therapy (APT) Survey found that HCP attitudes were generally positive; HCPs did not consider CSII to be a constant reminder of illness, increase feelings of 'burnout', require clinicians to give up too much control or result in DKA. However, HCPs agreed that CSII may work only for those who are highly motivated, and may be too expensive to allow widespread access. In addition, and perhaps most salient to the theme of this year's conference, HCPs

understanding of the patients' experience was generally limited, highlighted by neutral responses (neither 'strongly agree' nor 'strongly disagree') to psychosocial issues.

The presentation was well received and Matt was asked how the results compare to patient attitudes toward CSII. In 2007, Jane Speight collaborated on a qualitative study of children (and their parents') experiences of insulin pump therapy (also presented at the APC 2008). All children and parents reported a positive impact of CSII on their QoL, and findings showed that health is not the major QoL priority for children using CSII. However, we have not yet developed a patient version of the APT, so we can't yet compare the views of healthcare professionals directly with those of their patients. What an interesting study that would be! Please [contact us](#) for a copy of either poster.

¹ funded by unrestricted grant from Roche Diagnostics

"perhaps most salient to the theme of the conference, HCPs' understanding of the patients' experience was generally limited"



In the Journals

Oncologists' recommendations of clinical trial participation to patients

1

An oncologist's recommendation that a patient participates in a clinical trial, is often the subject of controversy. Some consider this as an unfair influence on the patient while others argue that it is necessary for clinical trial uptake, and that nondisclosure results in inadequate patient care.

2

38 interactions were recorded between oncologists and outpatients. Frequency, context and type of recommendations inviting patients to participate were observed. Patient self-report questionnaires were completed immediately post-interaction, and telephone interviews were conducted at two week follow-up.

3

68% of interactions included explicit recommendations from the oncologist, unprompted by the patient or patient's companion. There was a significant ($p < 0.05$) positive relationship between the oncologist's recommendations and the patient's decision to participate.

4

Female patients with higher education were more likely to receive a recommendation to participate.

5

The authors conclude that oncologist do make recommendations routinely when presenting clinical trial participation options. These recommendations can have a significant influence on the patient. Oncologists need to ensure that they are not coercing participation through their recommendations.

Eggy S, Albrecht TL, Harper FWK, Foster T, Franks MM, Ruckdeschel JC (2008). Oncologists' recommendations of clinical trial participation to patients *Patient Education & Counseling*, 70: 143-148

In Brief

■ [Drug industry anxious about scrapping price regulation scheme](#)

A recent survey by the Association of the British Pharmaceutical Industry (ABPI) and the Confederation of the British Industry (CBI) revealed that almost half (46%) of all British pharmaceutical companies are expecting to cut back on clinical trials in the next year due to the uncertainty of drug pricing. Stability is needed to make long term investments within the pharmaceutical industry but a new Pharmaceutical Price Regulation Scheme (PPRS) is due to be revealed in September 2008 and, until the details are confirmed, there is much uncertainty. This is the first time a PPRS, which sets the price of prescription drugs, has been reviewed in fifty years.

■ [Autism: fact and fiction](#)

Awareness of autism has been increased substantially within the last decade due to controversial studies in the UK and significant celebrity endorsement in the USA. With April 2nd marking the first world Autism Awareness Day, debates surrounding the possible causes of autism and the services and support that need to be made available continue. A recent ruling in the USA confirmed that, in one case, child vaccines had aggravated an underlying mitochondrial disorder that led to autism-like symptoms. Although this case involved an underlying disorder, it was the vaccines that attracted the blame. Genetic and environmental research continues to find the cause of autism.

■ [UK doctors warned not to allow personal beliefs to affect patients' treatment](#)

The General Medical Council (GMC) has issued new guidelines to advise GPs how their personal, religious and/or moral beliefs need to be separated from clinical practice. The guidance covers such issues as respecting patients who might refuse blood products due to religious beliefs, the provision of fertility treatment for homosexual couples and the need for doctors wearing a veil to uncover where it may threaten good communication. It has been suggested that up to 20% of GPs refuse to refer women for an abortion because of personal moral beliefs and, therefore, the guidelines stipulate disclosure of anti-abortion beliefs when treating a patient seeking relevant advice. It is thought that these guidelines will allow patients' healthcare decisions to be respected and will protect them from discrimination within the healthcare setting.

Patient satisfaction: achieving its full potential?

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a strong focus on patient reported outcomes (PROs). Using PROs, researchers and clinicians can understand the patients' perspective and collect evidence regarding the contributors to patient satisfaction.

Fortunately, the importance of patient satisfaction appears to have been taken into consideration in much research and evaluation of healthcare treatments over the last decade. A literature search (using Scopus, within the healthcare field including "satisfaction" in the title or keywords) reveals over 50,000 papers published since 2000. While this suggests a strong focus on patient satisfaction, examination of the current literature illustrates that some fundamental issues, such as achieving consensus on the definition and measurement of the concept of patient satisfaction, remain a challenge. Despite its widespread use as an endpoint in clinical trials, patient satisfaction is still vague and has been described as:

- "the extent of an individual's experience compared with his or her expectations"³
- "the patient's evaluation of the process of taking the medication and the outcomes associated with the medication"⁴

The vast array of patient satisfaction measures further compounds the problem. While it is apparent that different conditions, populations and interventions require specific and focused methods of

measurement, standardisation (allowing for comparisons across conditions, populations and interventions) is also of prime importance.

A recent innovation in this area is the development of the Dynamics of Care (DoC) assessment approach⁵. Based on the idea that a more in-depth approach is needed when defining and assessing the patient's perspective, the DoC measures patient satisfaction at different junctures in care, with the focus each time steered by what the patient feels to be most important at that time. The assessment draws on specific problems in context so that problem areas (e.g. barriers to adherence) can be identified and resolved. Information from a recent longitudinal study using the DoC has shown it to be valuable and capable of immediate application in the real world, being used to inform programmes and access to resources that patients value⁵. The ability not only to record patient satisfaction but also to influence directly a patient's further experience of treatment is surely a substantial step toward ensuring that assessment of patient satisfaction achieves its full potential.

References

1. Darzi A (2007) Healthcare for London: A Framework for Action. NHS.
2. Department of Health (2007) Local Involvement Networks explained. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_077483
3. Asadi-Lari M et al (2004) Patients' needs, satisfaction, and health related quality of life: towards a comprehensive model. *HQLO*, 2:32
4. Shiklar R, Rentz AM (2004) Satisfaction with medication. An overview of conceptual, methodologic, and regulatory issues. *Value Health*, 7:204-15
5. Rapkin B et al (2008) Beyond satisfaction: Using the Dynamics of Care assessment to better understand patients' experiences in care. *HQLO*, 10:6(1):20

Forthcoming events

11-13 April 2008

PsychoSocial Aspects of Diabetes (PSAD) Annual Meeting:

Sardinia

24 April 2008

PCOS UK Spring Conference:

Birmingham, UK

3-7 May 2008

ISPOR 13th Annual International Meeting:

Toronto, Canada

14-15 July 2008

BREATHE Workshop:

UCL, London

In the news...

New guidance on patient choice

http://www.hsj.co.uk/announcements/2008/03/new_guidance_on_free_choice_for_patients.html

Alcohol ban advised for pregnancy

<http://news.bbc.co.uk/1/hi/health/7312708.stm>

Vascular screening of over 40s will save 2000 lives a year

<http://www.bmj.com/cgi/content/extract/bmj.39539.369977.4Ev1>

Infection risk for patients with inflammatory bowel disease identified

<http://www.medicalnewstoday.com/articles/102620.php>

Daily caffeine 'protects brain'

<http://news.bbc.co.uk/1/hi/health/7326839.stm>

Sight-saving drug to be available on NHS

http://news.netdoctor.co.uk/news_detail.php?id=18533400