

Good Questions

Issue 17

May 2008

Introducing: 'The Patient'

"The Patient: Patient-Centered Outcomes Research" is a new journal which aims to change how we think about outcomes research in medicine. It is becoming more apparent with time that funding and decision-making must take into consideration the needs and values of patients and *The Patient* promises to be a vehicle designed to move healthcare professionals in that direction.



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Screening programmes: do they always lead to better health outcomes?

Many national health screening programmes exist to aid identification of disease, enable early treatment of the condition / complications to prevent morbidity and premature mortality. Screening programmes are wide ranging, from prenatal screening to programmes for the identification of cancers (breast, bowel, cervical, to name a few). With the emergence of newer screening techniques, the controversy surrounding the use of such programmes is increasing. In April, the British Medical Journal published a [debate](#) on screening for abdominal aortic aneurysm (AAA), the widening or ballooning of the abdominal aorta; a blood vessel that supplies blood to the abdomen, pelvis and legs^{1,2}. This follows a recent government decision to run pilots in five centres across England (see '*In brief*'). It is widely documented that screening can lead to improved health outcomes in the long term, but there is growing concern that such programmes may lead to more harm than good.

Screening for a particular disease or condition is usually aimed at specific subgroups of the population, who are asymptomatic at the time of screening and at average risk of developing the target condition. The primary aim of screening tests is the early identification of problems to enable treatments to be offered when they are most likely to be successful, thus reducing the mortality and morbidity related to the disease.

However, such beneficial effects are possible only if a high proportion of the population is screened, so that enough cases can be detected and treated leading to a decrease in overall prevalence and mortality. Although uptake of screening services has improved, it is clear that a significant proportion of the population still under-use screening services³.



Screening has the potential to save lives, but it cannot be considered a flawless process. Whilst simply being invited to screening can evoke a range of feelings (from terror to pleasure⁴), screening cannot offer a guarantee of protection. In any screening programme, there is always a risk of gaining false positive results (where people are inaccurately reported as having the condition) or false negative results (where people are inaccurately reported as not having the condition). Furthermore, detecting a disease at an earlier stage may not always improve a person's prognosis ...

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...because good questions outrank easy answers...

Screening programmes: do they always lead to better health outcomes?

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(as can be the case with some cancers, diabetes and AAA); it may just serve to increase the length of time that the individual is aware of having the condition. Such factors can lead to considerable psychological distress⁵ for the individual and his / her family.

To ensure that screening does more good than harm and at a reasonable cost, any UK screening programmes must be approved by the National Screening Committee. Screening programmes are tested according to stringent [criteria](#), including the need for efficacy data from randomised controlled trials. Such research may demonstrate the efficacy of screening in reducing mortality and morbidity, but it does not demonstrate how to overcome real-world issues such as low uptake and poor quality screening.

In health psychology, social cognition models offer a framework for understanding why some people use screening services others do not and, therefore, how people that do not attend may not be persuaded to do so. In particular, the Health Belief Model (HBM^[0]⁶) has been used widely in relation to screening behaviour. The HBM postulates that the likelihood of an individual participating in a screening programme is determined by the extent to which they believe their health is threatened by the condition. This is assessed in terms of the individual's 'perceived susceptibility to illness' and 'perceived severity of the illness'. Further, the 'benefits' of participating in screening must outweigh the 'barriers'. Consistent with this model, research has found that individuals believing themselves to be at

disease are more likely to attend^[0]^[0] screening⁷. Similarly, barriers to screening (e.g. embarrassment) are predictive of non-attendance⁸.

The principles underlying the national screening programme are to provide long-term benefits for the health of the nation. Debates rage over the suitability of the most recent addition to the national screening programme (i.e. AAA), with understandable concern about the well-being of those in whom an AAA is detected. Beyond such ethical dilemmas, however, it is clear so far that beneficial effects can be observed only if screening programmes are accessed equally by all to ensure the number of people screened is sufficient to make a difference. Health psychology models offer a framework for understanding the barriers to achieving widespread uptake of screening programmes.

References

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8. Vernon SW (1999) Risk perception and risk communication for cancer screening behaviours: a review. *Journal for the National Cancer Institute Monographs*, 25:101-19
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"Health psychology models offer a framework for understanding the barriers to achieving widespread uptake of screening programmes"

In the news...

To read about this month's breaking news, click on the links below

- [Psychological therapies toolkit launched](#)
- [Quality of life for brain tumour patients improved](#)
- [Children's well-being improves in Scotland](#)
- [NHS 'falling behind' on diabetes](#)
- [Schools start cervical cancer immunisation programme](#)
- [Sleep problems are more likely to cause depression](#)



In the Journals

Predictors of QoL in asthma

1 Children with asthma have a lower health related quality of life (HRQoL) than healthy children.

2 The extended stress-coping model suggests that coping style is an important psychosocial moderator between stress, negative emotions and HRQoL. Coping style is further moderated by external and internal resources. This study explored the predictors of HRQoL with the stress-coping model.

3 78 children with asthma and their parents completed questionnaires addressing the constructs of the extended stress-coping model at two time points 2-4 weeks apart.

4 Regression and path analyses revealed tentative support for the proposed relationships between predictors and HRQoL in the stress-coping model.

5 Consistent with the model, results indicated that HRQoL is only directly predicted by coping. Both 'emotional reaction' and 'avoidance' coping strategies were directly related to HRQoL (although the latter was non-significant).

6 The authors conclude that the extended stress-coping model is a useful theoretical framework for understanding the impact of the illness on HRQoL in children with asthma. Consequently, the factors suggested by this model need to be taken into account when designing optimal psychosocial-care interventions.

Peeters Y, Boersma SN, Koopman HM (2008). Predictors of quality of life: A quantitative investigation of the stress-coping model in children with asthma. Health and Quality of Life Outcomes, 6: 24

In Brief

■ [Football and mental health webpage launched](#)

The Football Association (FA) has joined up with The Care Service Improvement Partnership of the Department of Health to launch a new mental health awareness website. The website will demonstrate the positive effects that playing football can have on both physical and mental health. It is thought that taking part in a group activity and being part of a team allows for the removal of social "barriers" and as a consequence, those with mental health problems will be empowered. Further networks combining football and mental health projects are also under development.

■ [Doubts over new screening plans](#)

Debate rages around current NHS plans to initiate a screening program for abdominal aortic aneurysm (AAA) for men over 65 years in England. Although pilots of the screening program have been backed by the Vascular Society, it is widely acknowledged that the preventative treatment for AAA can be risky. Mr. Johnson, vascular surgeon and ex-Chairman of the British Medical Association has suggested that risk of death while undergoing reparative surgery is relatively high (1 in 14) and that without surgery the anxiety of living with an unrepaired aneurysm can be akin to living with a "ticking time bomb". Mr. Johnson has stated that the implications of the new screening program need to be considered very carefully. For a recent debate on this issue, see the BMJ.

■ [Holistic care as important as technology – NHS Alliance](#)

Coinciding with the 25th anniversary of the British Holistic Medicine Association (BHMA), the NHS Alliance has issued a statement warning of the possible risks of marginalising holistic health care. The Chairman for the NHS Alliance has suggested that technological medicine has become very effective in successfully treating single and acute episodes of illness, but has warned that it is severely lacking in regard to long-term and multi-factorial conditions. If healthcare systems do not recognise patients as "a whole" then there is the risk of care becoming inhumane and ineffective. The BHMA was set up to combat this dehumanisation and proudly supports clinicians and NHS planners in identifying ways to retain compassion.

ISPOR 13th Annual International Meeting, Toronto (3-7 May)

This year's meeting incorporates many interesting discussions on patient reported outcomes (PROs) and their applications. Our selection of sessions of interests to PRO researchers includes:

Monday 5 May

ISPOR PRO Forum - Changing Culture or Language of a Instrument Task Force: Multinational trials - what translations are required, what methodology should be used and what methodology supports pooling the data? (7.15am - 08.15am)

One for the early birds! This session will provide an update on the current ISPOR good practice guidance for translation and linguistic development, including the following discussion points:

- How to select the number and specific languages required for translation in a particular country - Tool: a table to help determine which languages are required per country
- What methods to use when the same language is required for multiple countries Tool: a scenario-based decision tree for adaptation methodologies
- Discussion of the issues and evidences around pooling trial data across countries

Educational symposium: Why does medication non-compliance exist? (1.30pm - 2.30pm)

Despite nearly 40,000 articles having been published on the topic of medication compliance since 1966, the latest examples from most therapy areas demonstrate that the problem persists. Why is this? Have we studied the wrong questions? Have we failed to translate good evidence into practice? What are the clinical, administrative, and economic barriers? Are there best practices that should be implemented more broadly? The 2008 IMS Health ISPOR Symposium will feature an interactive and dynamic discussion of these questions.

Tuesday 6 May

Educational symposium: Obtaining a PRO label claim. What evidence do you need? (1.30pm - 2.30pm)

In February 2006, FDA published its draft guidance for industry on the use of PRO measures to support labelling claims. To obtain such a claim, industry sponsors need to provide evidence that the outcome was measured using a validated instrument in a clinical trial that was properly designed for that purpose. To meet this objective, it's important to understand label claim wording and structure. This workshop will review what is a label claim, what evidence is needed to support the claim, and how to design a conceptual framework and endpoint model for a PRO Evidence Dossier.

Third plenary session: PROs – implementing good research practices (3.45pm - 5.00pm)

PROs are sometimes viewed as inherently subjective because they are derived from patients' self-reports. There are objective ways to gather and analyse PROs, which must be explored amidst the mounting evidence of international and cultural differences in HRQoL that reinforce the subjectivity of responses. This session will review recent guidance & recommendations and explore improvements in methodology and application of PROs.

Wednesday 7 May

W10: Selecting, evaluating and documenting support for existing instruments for making labeling claims: content validity (8.30am - 9.30am)

W17: Health behaviour chance: leading models and their practical applications (9.45am - 10.45am)

W20: Developing an improved measure of health outcomes: EQ5D in transition (9.45am - 10.45am)

W26: Training considerations for PROs (11.00am - 12.00noon)

Forthcoming events

3-7 May 2008

ISPOR 13th Annual International Meeting:
Toronto, Canada

14-15 July 2008

BREATHE Workshop:
UCL, London

7-11 September 2008

EASD 44th Annual Meeting:
Rome, Italy

9-12 September 2008

Health Psychology Annual Conference:
University of Bath, UK

Health Awareness - dates for your diary

National Smile Month

Hepatitis Awareness Month

National Thrombosis Week (14-18 April)

World Asthma Day (6 May)

World Lupus Day (10 May)

M.E. Awareness Week (11-18 May)



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