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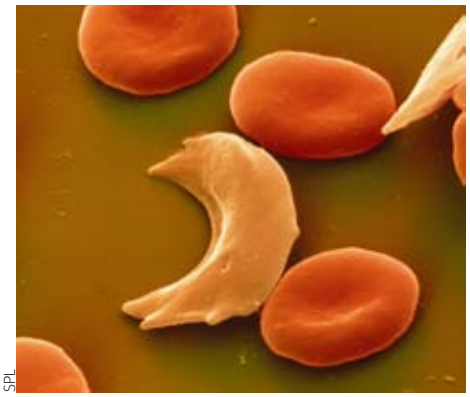
LETTERS

GP HAEMOGLOBINOPATHY SCREENING

Coding issues at the coalface



SPL

As GPs providing antenatal care in multiethnic inner city Tower Hamlets, we welcome Shakespeare's editorial on antenatal haemoglobinopathy that promotes general practice screening of the woman and her partner before or during early pregnancy.[1] We also welcome the SHIFT Study Group's trial which shows that screening uptake is better and earlier when both partners are offered screening immediately pregnancy is reported.[2]

A key sentence in the editorial is: "Done once and computer coded properly, sickle cell disease and thalassaemia screening does not need repeating." Urgent reform of coding in the pathology messaging implementation programme (PMIP) run by Connecting for Health is needed,[3] because currently result codes are not transmitted for non-value pathology results. This means that haemoglobinopathy results are received from laboratories into general practice computer records as free text and not as searchable codes. Although these may be coded on receipt, this is time consuming and not consistent.

Cradle to grave GP records need consistently coded results to be visible in the individual patient record, auditable, and transferable between practices by GP2GP electronic record transfer. Codes for non-value laboratory results should be included in the bound PMIP code list.

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Competing interests: None declared.

1 Shakespeare J. Antenatal haemoglobinopathy screening. *BMJ* 2010;341:c5243. (18 October.)
2 Dormandy E, Gulliford M, Bryan S, Roberts TE, Calnan M, AtkinK. Effectiveness of earlier antenatal screening for sickle cell disease and thalassaemia in primary care: cluster randomised trial. *BMJ* 2010;341:c5132. (5 October.)
3 Connecting for Health. Pathology messaging implementation programme (PMIP). www.connectingforhealth.nhs.uk/systemsandservices/pathology/edifact/pmip.

Cite this as: *BMJ* 2010;341:c6663

GPs may not be the answer

Shakespeare is correct that the current low level of uptake of early screening is unacceptable.[1] It is hardly surprising that offering screening at first pregnancy consultation rather than later increases uptake of early screening.[2] But I am unconvinced that the solution is to re-engage GPs.

Antenatal care, especially screening, changes so often that many trusts have difficulty in maintaining training for community midwives, who are heavily involved in this area. Haemoglobinopathy screening is just one part of antenatal care and screening, and it cannot be viewed in isolation. It is unrealistic to expect every GP to keep abreast of the requirements.

Furthermore, the onus is on the hospital to provide evidence that screening targets are met: even if GPs do provide early screening, the absence of standardised IT systems means that the hospital may have no evidence of the test and be obliged to repeat it to have any hope of meeting current screening targets.

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Competing interests: None declared.

1 Shakespeare J. Antenatal haemoglobinopathy screening. *BMJ* 2010;341:c5243. (18 October.)
2 Dormandy E, Gulliford M, Bryan S, Roberts TE, Calnan M, Atkin K, et al. Effectiveness of earlier antenatal screening for sickle cell disease and thalassaemia in primary care: cluster randomised trial. *BMJ* 2010;341:c5132. (5 October.)

Cite this as: *BMJ* 2010;341:c6662

One more thing for GPs

Dormandy's group showed a mean gestational age at screening uptake of around 16 weeks, despite ongoing engagement with participating GP practices and significantly higher offer rates of screening before 10 weeks.[1] This highlights structural problems in antenatal services little changed since the Confidential Enquiry into Genetic Counselling by Non-geneticists a decade ago—52% of β thalassaemia major live births from 1990 to 1994 involved a service failure. Prenatal diagnosis was offered to 81% of Cypriot couples in their first pregnancy but only 29% of Pakistani couples.[2]

We identified serious difficulties facing non-geneticist practitioners providing genetic services. Of European GPs surveyed in 2005, only 38% thought their role included explaining inheritance patterns to patients.[3] In the linked midwife survey, more than half arranged antenatal serum screening at least monthly, but only 31% felt confident in identifying a family history of a potentially inherited condition. These midwives reported haemoglobinopathies as the most common "known" genetic condition in their practice, but none reported them as a condition from which patients could be "at risk."[4]

Shakespeare's editorial states "the challenge is to re-engage general practitioners in early maternity care."[5] However, GPs are deluged with initiatives and frameworks for care (depression, alcohol misuse, debt, chlamydia, etc). It is easy for those with specialist interests to state that GPs "should be more aware of condition X"; instead, the profession should tackle the organisational and structural obstacles in integrating evolving technology into practice.

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1 Dormandy E, Gulliford M, Bryan S, Roberts TE, Calnan M, Atkin K, et al. Effectiveness of earlier antenatal screening for sickle cell disease and thalassaemia in primary care: cluster randomised trial. *BMJ* 2010;341:c5132. (5 October.)
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Cite this as: *BMJ* 2010;341:c6661

DOCTORS AND WELFARE REFORM

And another thing

Bambra suggests that "General practitioners . . . hold the key to reducing receipt of incapacity benefit by tackling the root cause: ill health,"[1] which is strange because I thought we GPs already did "ill health." What I don't think we are able to do is to be occupational health physicians, rehabilitate 1.5 million sick people, and get them back to work; that is a completely different skill set. Although it is touching that so many groups regard GPs as infinitely adaptable and an infinitely expandable resource, it is worth mentioning that we are already quite busy tackling the existing and unmet health needs of 60 million ageing and increasingly impoverished citizens.

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1 Bambra C. Doctors are key to welfare reform. *BMJ* 2010;341:c6029. (27 October.)

Cite this as: *BMJ* 2010;341:c6655

Ask a social worker

Bambra states that people claiming incapacity benefits often have complex and multiple chronic health conditions.[1] Does she have any research work showing how many of these conditions have a sound organic basis on which to base an objective decision? I ask this because, in my experience, most chronically sick people should have a report from a social worker not a doctor for the assessment of their ability to work.

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1 Bambra C. Doctors are key to welfare reform. *BMJ* 2010;341:c6029. (27 October.)

Cite this as: *BMJ* 2010;341:c6656

INTERNATIONAL TOBACCO CONTROL

Still some way to go in China

Two news reports highlight the obstacles faced by antismoking endeavours in Russia and Spain.[1 2] China has outlawed cigarette advertising in such media as television, radio, newspapers, and magazines, but this year's global adult tobacco survey found that 8.7% of Chinese adults still noticed advertisements in the media (7.4% on television).[3]

MARK HENLEY/PANOS

Tobacco control in China has not greatly improved since the Framework Convention on Tobacco Control took effect on 9 January 2006. No nationwide antitobacco legislation has been scheduled. Progress has been limited to only a few large cities. Before this year's World Expo and Asian Games, Shanghai and Guangzhou introduced regulations regarding smoking in public places. However, smoking has not been completely banned in enclosed public places. Experience in Spain may show the loopholes in the cities' current regulations.[1]

The causes of poor tobacco control include the Chinese government's reliance on the tobacco industry for economic development, sociocultural factors related to cigarette smoking, and lack of effective antitobacco interventions.[4 5] Though central government has taken measures, such as calling for smoke-free schools in July 2010 and a complete ban on smoking in all workplaces and public places in health departments and medical institutions by 2011, more steps are required. Graphic warning labels for cigarette packs and raising cigarette prices and taxes could be priorities.

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Competing interests: None declared.

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Cite this as: *BMJ* 2010;341:c6659

DECISION AIDS AND SCREENING

Information *v* promotion

Bekker expresses concern that "uncritical acceptance of informed choice initiatives may cause more harm than good."[1] She notes that in a study of decision aids for bowel cancer screening a smaller proportion of patients given a decision aid accepted screening than did those given the usual promotional leaflet.[2] She suggests it may be better to pursue a policy of "informed uptake rather than informed decision making."

Screening reduces bowel cancer mortality by around one death per 1000 people screened over 10 years, with no demonstrated effect on all cause mortality.[3] People deciding whether to take part in screening must balance this small potential benefit against the potential harms (false positives, risks of colonoscopy, overdiagnosis, and false negatives). This decision requires access to clear accurate information about the screening programme, and a decision aid is one way to provide this. The value of such an aid should be assessed by its ability to provide this information not, as this editorial suggests, by its ability to increase participation. If we uphold people's right to make informed decisions about their healthcare we must accept that some decisions will not coincide with what we think is best. To suggest otherwise implies a return to a more paternalistic age.

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Competing interests: None declared.

1 Bekker HL. Decision aids and uptake of screening. *BMJ* 2010;341:c5407. (26 October.)
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Cite this as: *BMJ* 2010;341:c6650

Editorial was amoral

Bekker's editorial is amoral.[1] Neither immoral or moral, but written with no moral sensibility, in an ethics-free zone. It suggests that an aid to improve decision making may be inappropriate because it reduces uptake in the better informed. But this is just fine. The editorial notes that faecal occult testing is evidence based, and because screening programmes aim to increase uptake it would be more appropriate to "structure the facts" to effect "a policy of informed uptake rather than informed decision making." Really? Surely informed decision making always trumps informed uptake from an ethical perspective?

This worrisome contention reflects a view encapsulated in the following statement: "Decision aids are appropriate when there is insufficient evidence to indicate the best medical choice, patients' preferences are central to the choice, or the consequences of the options involve serious risks (or a combination of all three)."

When are the patient's preferences not central to the choice of screening? A huge sociocultural chasm exists between the public and those who research and operate screening services. Across that chasm huge differences occur in how risks are perceived and tolerated and in the valuing of present and future scenarios. We public health practitioners sometimes envision a society that is structured in the image of our work. While health screening is elevated to a moral good for us, for the autonomous other it is just a lifestyle choice.

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Competing interests: None declared.

1 Bekker HL. Decision aids and uptake of screening. *BMJ* 2010;341:c5407. (26 October.)

Cite this as: *BMJ* 2010;341:c6648

MEASURING PATIENT SATISFACTION

Theoretical foundation needed

Haggerty defines patient satisfaction as "a judgment about whether expectations were met."[1] She qualifies this seemingly one way influence by quoting the Health Technology Assessment review which highlighted that patient satisfaction is influenced by varying standards, different expectations, the patient's disposition, time since care, and previous experience.

Many uncertainties surround the definition of satisfaction, some of which were raised more than 30 years ago. Firstly, some believe that a consensus on the definition of the concept of satisfaction is still lacking; secondly, satisfaction is a multidimensional concept determined by a variety of factors; and thirdly, many satisfaction studies lack a conceptual or theoretical basis.[2-5] Hence, various researchers have argued that satisfaction studies should not be used to allocate resources and patients are unlikely to evaluate care in terms of satisfaction. Without identifying the theoretical foundation of the concept of (patient) satisfaction it is debatable how we can link it usefully to the quality of services provided.

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Competing interests: None declared.

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Cite this as: *BMJ* 2010;341:c6319

STICKY LABELS

Labels unstuck

The European Food Safety Authority (EFSA) panel should be applauded for evaluating health claims. For too long the onus has been on small public bodies to object to food and drink manufacturers' dubious assertions; perhaps now food corporations will have to prove their claims.

Payne's article highlights the major disparities between the standard of evidence expected in the scientific community versus the corporate food industry.[1] The suggestion by Danone's director of healthcare professional relations that inferior evidence of efficacy is acceptable in her field because "we are talking about food here, not drugs" is worrying. Peddling a false health claim, while unlikely to have a direct detrimental effect on health, constitutes a major probity issue. Moreover, these claims may have other consequences.

Firstly, such claims, if unfulfilled, increase public confusion and mistrust in science, further muddying the public understanding of "evidence" versus "proposition." Secondly, these so called evidence based claims make a mockery of rigorous scientific endeavour in the food science world and beyond.

Doctors must now work with EFSA and like minded bodies to deal with the confusion surrounding regular products, such as cranberry juice, and supplements, such as glucosamine, so that patients can make educated choices on the high street.

If approached creatively, this clash between the European Union and industry could become a catalyst to educate both corporations and the general public in what "good science" really involves.

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Competing interests: JCBS is a member of the Voice of Young Science network.

1 Payne D. Sticky labels. *BMJ* 2010;341:c5861. (26 October.)

Cite this as: *BMJ* 2010;341:c6652

OBESITY RELATED ILLNESS

Beware swallowing whole

The *BMJ* news section reported on a working paper of the National Bureau of Economic Research (NBER),[1] which concluded that genes rather than environmental factors play the most important role in obesity, "contrary to conventional wisdom."[2] This would explain why dieting, exercise, and drugs seem to provide only temporary reductions in body mass: such interventions don't change genes.

However, the authors should think twice before concluding that everybody else is wrong. The evidence against this proposition is the dramatic increase in obesity prevalence over the past 30 years. From an evolutionary point of view, this would require that people with alleged obesity genes (and because environment doesn't matter, they would have been obese) suddenly acquired an enormous reproductive advantage, but of course this did not happen.

The authors cite literature on correlations of weight between family members, but such studies tend to suffer from a form of myopia: environmental exposures are too similar to show effects on body mass. The debate about genes versus environment is futile anyway,[3] because an obesogenic environment may have more effect on genetically susceptible people.

As for the *BMJ* publishing this news item, NBER working papers are just that—working papers. They are not peer reviewed. The *BMJ* should be a bit more critical about such papers, even in news items.

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Competing interests: None declared.

1 Cawley J, Meyerhoefer C. *The medical care costs of obesity: an instrumental variables approach*. NBER Working Paper Series. National Bureau of Economic Research, 2010.
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Cite this as: *BMJ* 2010;341:c6660

SEEKING TREATMENT ABROAD

Challenge of migrating patients

Legido-Quigley and McKee raise some of the thornier issues faced by healthcare authorities dealing with patients seeking medical care outside their own country.[1] As with countless other tertiary hospitals throughout Europe, our centre, the largest public paediatric facility in Italy, has had to come to grips with this

new emergency. Particularly relevant since the enlargement of the European Union are the numbers of children coming from former Soviet bloc states, where below par healthcare standards cannot—as shown in survival curves[2]—guarantee adequate early diagnosis and advanced treatment.[3 4]

Beyond the medical issues, the migration of patients entails a myriad of difficulties (financial, administrative, logistical, psychological) and involves scores of individuals, both inside and outside the hospital (embassies, patient organisations, non-governmental organisations).

Admittedly, a significant decade long rise in the number of foreign inpatients admitted to our centre has begun to level off—thanks chiefly to intervention by foreign governments, which must now authorise admission (and reimburse medical costs) only for seriously ill children.

But here's the rub: although foreign admissions are down, the severity and complexity of cases inevitably require highly specialised staff, costly resources, and prolonged stays of weeks (if not months). Particularly burdensome in this context are the communication difficulties that often arise between patients' families and care providers.[5 6] On top of this, waiting lists, especially for complex procedures, continue to grow.

Further exchange on the sustainable management of migrating patients is needed and most welcome.

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Competing interests: None declared.

1 Legido-Quigley H, McKee M. Patients seeking treatment abroad. *BMJ* 2010;341:c5769. (18 October.)
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Cite this as: *BMJ* 2010;341:c6665

FORCING TREATMENT ON PATIENTS

Guidelines, please

The court judgment requiring that a woman without capacity be forced, under restraint, to undergo life saving treatment for aplastic anaemia represents but the tip of an iceberg.[1] Thousands of people with a learning disability need to be restrained to benefit from essential procedures, ranging from toenail cutting to urgent life saving care.

As an example, a proportion of people with Down's syndrome—which accounts for almost one in every three people with a learning disability—strenuously resist physical examination, never mind procedures as minor as phlebotomy. Yet trisomy 21 is responsible for a host of complications, including both auditory and visual disorders in 50% of patients, and 10% prevalence rates of both hypothyroidism and coeliac disease, all of which mandate regular screening.

In 2002, the Department of Health (DH) published guidance for restrictive physical interventions in people with a learning disability who behave in ways that may be harmful and require physical intervention from staff.[2] At the time I asked the British Institute of Learning Disability, which had advised the DH on restraint, to produce analogous national guidelines that legitimise humane restraint in pursuance of essential health interventions.

No such guidelines were published, with the result that important health interventions are often neglected or delayed because of a perceived stigma associated with restraint in the absence of a medical crisis.

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Competing interests: PLH has specialised in physical healthcare for people with a learning disability for 33 years.

1 Dyer C. Doctors can force woman to have lifesaving treatment. *BMJ* 2010;341:c5951. (21 October.)
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Cite this as: *BMJ* 2010;341:c6657

OPIATE SUBSTITUTION AND DEATH

GPs need guidance, please

I was alarmed to read of the great excess mortality on stopping methadone maintenance treatment in the study by Cornish and colleagues.[1] In 2003 Strang and colleagues reported the same finding in the *BMJ*, commenting that it needed urgent replication, and practice to be reassessed if confirmed.[2]

Now that it is seemingly confirmed, may we at the coalface have guidance? We use a lot of resource on these patients, and it would be disastrous if, as it seems, the reduced death rate with treatment is simply compensated for by a large increase after treatment. It also has implications for the frequent occurrence of treatment centres discharging patients for bad behaviour. Perhaps it would be safer for them not to start.

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Competing interests: None declared.

1 Cornish R, Macleod J, Strang J, Vickerman P, Hickman M. Risk of death during and after opiate substitution treatment in primary care: prospective observational study in UK General Practice Research Database. *BMJ* 2010;341:c5475. (26 October)
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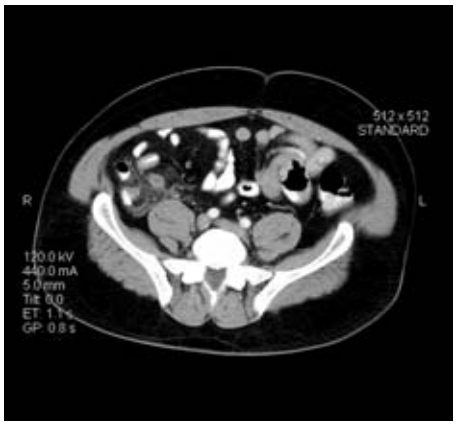
Cite this as: *BMJ* 2010;341:c6515

OBSOLETE CLINICAL SIGNS

Signs of the times



LIVING ART ENTERPRISES LLC/SPL

I successfully diagnosed acute appendicitis with classic clinical signs, including Rovsing's,[1] just yesterday. Wikipedia lists nine signs in appendicitis: Rovsing's, psoas or Obraztsova's, obturator, Dunphy's, Volkovich-Kocher (Kosher)'s, Sitkovskiy (Rosenstein)'s, Bartomier-Michelson's, Aure-Rozanova's, and Blumberg.[2] The only one of these nine that I have not obtained 10 years out of medical school and six years into orthopaedics is the psoas sign.

If you see a classic sign even once as a medical student you rarely forget it, and I still keep my old copy of *Hamilton Bailey's Demonstrations of Physical Signs in Clinical Surgery*. I wonder whether I should recommend Wikipedia rather than *Macleod's Clinical Examination* to my medical students?[1]

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Competing interests: None declared.

1 Douglas G, Robertson C. Time to update. *BMJ* 2010;341:c5809. (19 October.)
2 Wikipedia. Appendicitis. http://en.wikipedia.org/wiki/Appendicitis.

Cite this as: *BMJ* 2010;341:c6316