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# **Paying for migrant healthcare**

Recent research allows no easy headlines

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Publication of research commissioned by the Department of Health on visitor and migrant access to the National Health Service (NHS) has put the issue of so called "health tourism"-where people travel with the intention of obtaining treatment to which they are not entitled for free on the NHS-centre stage.1 Earlier this year the government consulted on policy proposals for migrant access and financial contribution to the NHS in England.<sup>2</sup> These included a migrant health levy on non-EEA (European Economic Area) visitors of £200 annually. The Draft Immigration Bill published earlier this month<sup>3</sup> makes legal provision for such a surcharge.

The reports published this week by the Department of Health examine a wide spectrum of use of the NHS by visitors, including British ex-patriots and EU citizens, as well as irregular migrants and "health tourists."<sup>45</sup> Despite media announcements by the secretary of state for health that these groups taken together cost the NHS £2bn a year,<sup>1</sup> the report, which places several caveats on the validity of its data and is careful not to overstate its claims, estimates that in the region of 10000 patients would meet the definition of a "health tourist," costing around £70m a year.<sup>5</sup> This compares with, for example, £305m of chargeable costs incurred by EEA citizens, which could be reclaimed by the government under EU agreement, and British expatriates living outside the EEA, which are estimated to account for £50m annually.

The qualitative report highlights the complexity of issues involved in the pursuit of such reimbursement and charges from patients, including when these might be EU citizens or British expatriates living abroad. There is a clear sense among clinicians that they do not want to be involved in the clarification of entitlements of patients to care. It highlights the challenges in administering and implementing current regulation, such as those in relation to entitlements for patients from the European Union. In particular, ensuring that patients who are not legitimately registered with the NHS



Trick or treat?

are identified when they present to secondary or tertiary care would probably require a change in current remit of NHS staff. The findings highlight a perverse incentive-those NHS trusts proactive in charging patients have greater debt than those that do not.

The analysis omits the costs of administering stricter policies and monitoring of NHS use by migrants and visitors. Given the wide range of issues that this recent research touches on, it remains unclear what a streamlined efficient policy and administration might look like. Certainly it would require changes to the culture of the NHS, its way of working, and its management structures. The Home Office's impact assessment of the draft Immigration Bill estimates the income resulting from a government surcharge for migrants accessing the NHS as nearly £2bn over 10 years; the administrative cost over the same period of collecting this money is quoted as £3m.6 The complexities that have been unearthed by the government's own published research make it seem questionable whether the cost of such a policy has really been considered.

A recent OECD (Organisation for Economic Cooperation and Development) report on migration of inactive EEA citizens gives little support to the idea that intent to obtain health services is a major motivation for travel and migration.<sup>7</sup> It concluded that within the EEA, healthcare consumption linked to non-active EU mobile citizens is probably small compared with the size of total health spending (0.2% on average) and that most mobile EEA citizens migrated for work.

While the current UK debate has focused on the costs of visitors and migrants to the NHS, it has largely ignored wider issues of patient mobility. An emphasis of the government's consultations is the principle that "everyone makes a contribution" and has "full ties and permanent relationships that justify inclusion in our social welfare model."2 Affirmation of such entitlements is not something that the UK can deal with alone. Despite considerable limitations of data, it is evident that many more people-and patients-are travelling, including with the explicit intention of seeking treatment (whether as "health tourists" trying to fly in and out and evading payment or as medical tourists seeking cheaper, better, or simply accessible treatment for which they pay).<sup>8</sup> While we have limited information on exact numbers of patients travelling and levels of expenditure, figures from the UK International Passenger Survey suggest a growing number of UK patients travel abroad to seek treatment.9 Similarly, the experience of Spain and Greece has probably had implications for the UK health system as more British expatriates might be returning to the UK for NHS treatment as Spanish and Greek services become harder to access.9 10

Patient mobility also has other dimensions. There is incidental evidence of UK patients returning from treatment abroad with complications or infections.<sup>11</sup> These clearly highlight not only possible costs but also risks to patients and public health and ethical challenges that are inherent in patient mobility. These issues are not covered in any of the policy and research documents highlighted and deserve a fuller hearing in the current discussion around entitlement to services. While raising a levy and new systems of regulation and monitoring attempt to tackle issues, they seem unlikely to be resolved by action of one country's government alone but rather might require countries working together through bodies such as the World Health Assembly.

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Pouw and colleagues found that 20-30% of hospitals change their quality ranking when post-discharge deaths are included

### Mortality indicators used to rank hospital performance

Should include deaths that occur after discharge

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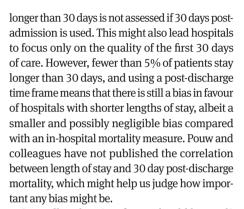
There is considerable debate about the value of using hospital mortality rates adjusted for case mix as an indicator of the quality and safety of care provided by hospitals. A linked paper by Pouw and colleagues investigate the inclusion of post-discharge deaths in these mortality indicators.<sup>1</sup> The main doubts about their value are that standardisation for differences between hospitals in the characteristics of their patients (the case mix) doesn't work, and that these indicators do not measure performance because they are not related to avoidable mortality. There is no doubt that the case mix adjustment is problematic. We know that different adjustment models lead to different results,<sup>2</sup> and that important measures of case mix are missing from models based on routine data.3 We also know that these measures are at best weakly related to avoidable mortality-models show that they would begin to be useful for identifying poor quality of care only when at least 16% of hospital deaths are avoidable.<sup>4</sup> Recent studies have shown that in the United Kingdom this figure is closer to 5%.5

Nevertheless, hospital standardised mortality ratios are being used to identify failing hospitals thanks to considerable social, political, and media pressure.<sup>6</sup> We must therefore make the measures as robust as possible. The Department of Health in England has recently introduced a revised measure, the summary hospital mortality indicator.<sup>7</sup> The main differences are that it includes nearly all conditions and mortality is recorded not only in

hospital but up to 30 days after discharge. Whether deaths after discharge should be used when calculating hospital mortality indicators has been discussed for years. Studies that have compared results using both approaches for some specific clinical conditions have concluded that they give similar results overall but detect different statistical outliers.<sup>8 9</sup> Recently, it was estimated that using mortality up to 30 days after admission, rather than in-hospital mortality, changed the quality rankings for only about 10% of hospitals, but that in-hospital measures are biased in favour of hospitals with shorter lengths of stay.<sup>10</sup>

Pouw and colleagues examined this question using data on more than one million admissions to 60 Dutch hospitals.<sup>1</sup> They compared in-hospital mortality with mortality at 30 days after discharge and 30 days after admission. They found that 20-30% of hospitals change their quality ranking when post-discharge deaths are included and confirmed a substantial correlation between the in-hospital measure and the average length of stay of patients in hospital. They concluded that in-hospital measures are subject to "discharge bias," and that post-discharge mortality should be included in hospital mortality indicators. It is now clear that if post-discharge deaths are included the relative performance of some hospitals changes, and that short lengths of stay are associated with low in-hospital mortality and a discharge bias, so that it is not appropriate to use only in-hospital mortality. But this leaves at least three questions unanswered.

Firstly, should a fixed time frame after admission or after discharge be used? The Department of Health chose the post-discharge option in the summary hospital mortality indicator because part of the care of patients who stay in hospital



Secondly, what time frame should be used? All the studies we know have used 30 days after discharge or after admission, but why 30 days? Clearly, the longer the time after discharge the smaller the influence of the quality of hospital care and the greater the influence of community care, or care in any subsequent hospital admission. It follows that as short a time frame as is necessary to pick up all the effects of the quality of hospital care should be used. English hospital episode statistics data for 2005-10 show that, for all deaths that occur up to 30 days after discharge, 7% occur in the first week, then 5%, 4%, and 4% in weeks two to four. This suggests that a two week window after discharge might be more appropriate.

A third question is whether post-discharge mortality should be combined with in-hospital mortality at all. Deaths after discharge are an indicator of the quality of care during the stay in hospital, the appropriateness of the discharge decision, and the quality of care provided by post-discharge community services. English hospital episode statistics for 2005-10 show that deaths in the 30 days after discharge varied from 12% to 30% of all deaths from admission to 30 days after discharge. This suggests that the appropriateness of discharge decisions or follow-up care may vary greatly. It might therefore be better to have two indicators of performance-an in-hospital measure and a two week post-discharge one. This would enable hospitals and commissioners to identify any problems with discharge decisions and post-discharge care. Competing interests: None declared.

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The never ending discussion: where to fix the goalposts

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• News: Teenagers and young adults with cancer need better access to clinical trials (*BMJ* 2013;346:f1959)

## Improving the timeliness of cancer diagnosis in young people

A comprehensive programme of research is needed to find out

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More than a third of young people attending this year's Teenage Cancer Trust conference, "find your sense of tumour," were diagnosed through emergency presentation, with a quarter having previously visited their general practitioner with symptoms. This has resulted in a considerable amount of "GP bashing" by young people and an angry but passionate call for interventions to improve the timeliness of cancer diagnosis. The problem seems to be real, but the research evidence is missing.

In the United Kingdom, five year cancer survival for children and young people (0-24 years) varies between 50% and 95%, with survival in some cancers hardly having improved over the past two decades.<sup>1 2</sup> Although cancer is the leading cause of death from disease in this age group, it is rare around 3500 cases a year. Morbidity from both the treatment and disease is considerable, and interruptions to social development, education, and employment are likely. Caring for a child or young person with cancer can cause serious stress within the family, and the economic consequences for the family and society are considerable.

Evidence exists that children and young people experience a prolonged diagnostic journey,<sup>3</sup> with wide variations in duration of symptoms and time taken to investigate and treat. Some of the delay occurs in primary care. People aged 16-25 years are twice as likely as older adults to have three or more GP consultations before referral.<sup>4</sup> They are also more likely than adults to be diagnosed through emergency presentation.<sup>5</sup> Many describe their diagnostic experience with a sense of loss, anger, and frustration, and studies have found that perceived diagnostic delay is associated with increased anxiety in patients and parents.<sup>6</sup> <sup>7</sup>

Young people are unaware of the more common cancers that affect their age group—embryonal, brain, and germ cell tumours; leukaemia;



Why are we waiting?

lymphoma; sarcomas; and other solid cancers.<sup>1 2</sup> This means that even if they attribute a symptom to an illness, it is unlikely to be to cancer. A quarter of young people cannot name a cancer symptom, and confusion about cancer abounds—for example, some think that hair loss is a symptom.<sup>8</sup> If symptoms are judged as serious, barriers to seeking help include worry about what the doctor might find (72%), embarrassment (56%), or being too scared (56%).<sup>8</sup> This, coupled with inexperience of communicating serious symptoms, may further impede the diagnostic process.

Most patients consult their GP about their symptoms. In adults the predictive value of 'alert' symptoms has generated risk assessments for some cancers.<sup>9</sup> Analysis of pre-diagnostic consultations in children finds a positive association between "alert" symptoms and a cancer diagnosis, although the positive predictive values of individual symptoms are low.<sup>10</sup> <sup>11</sup> <sup>12</sup> Even when specified alert symptoms are combined with multiple consultations over a short time, the probability of a cancer diagnosis ranges from 11 per 10000 children to 76 per 10000 <sup>12</sup> with similar results reported for young people.<sup>11</sup> <sup>12</sup>

A recent *BMJ* paper highlighted the problems faced by healthcare professionals in identifying children and young people with brain tumours.<sup>13</sup> For 10 000 children presenting to their GP with visual symptoms, only six will be diagnosed as having cancer within three months. If the child also had multiple consultations, this increases to 23/10000.<sup>12</sup> Although a considerable increase in the likelihood of a cancer diagnosis, for proponents of a "three strikes and refer" policy in young people with alert symptoms, the low predictive value is disappointing and likely to overwhelm services and cause unnecessary anxiety and investigation.

What can be done? Young people and their parents want early diagnosis to become a research priority.<sup>14</sup> Whether timely cancer diagnosis in this age group affects survival is unknown, but improvements in the timeliness of the diagnostic process may reduce treatment related morbidity and psychological distress associated with a bad diagnostic experience. Research directed towards optimising the diagnostic experience and identifying relevant outcomes for children and young people is urgently needed.

From a medical perspective, an "optimal diagnosis" includes starting treatment before delays have affected outcomes. For a patient, however, optimal diagnosis further implies the calming of fears which a cancer diagnosis generates. Once diagnosed, patients invariably view their diagnosis within the context of their medical history. Consequently, they may think of their diagnosis as suboptimal, especially if they can relate symptoms of an earlier illness to cancer, regardless of how realistic this may be. This can cause young people to question themselves-whether they should have taken symptoms more seriously-and the medical professionals overseeing their care. Thus, the quality of communication with all the medical professionals encountered during the diagnosis pathway may determine how patients view their diagnosis. As a result, even an optimal diagnosis, from a medical viewpoint, can still be perceived as suboptimal by the patient.

Much of the existing evidence has been generated from research on adults with cancer, which limits its generalisablity. We need researchers and funders to respond to the specific needs of this age group. A comprehensive programme of research is needed to identify which parts of the diagnostic journey matter most for young people and to suggest which interventions might best inform policy and practice. Then these interventions need to be tested quickly and robustly. The "find your sense of tumour" audience deserves no less and will expect to be vital and enthusiastic contributors to such important work.

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The Canterbury experience offers ... the uncomfortable message that frequent reorganisation of the system, and particularly of the commissioning function, undermines local attempts to make significant and sustained changes to services

### What can England's NHS learn from Canterbury New Zealand?

That integrating health and social care in a similar system is possible

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A recent King's Fund report describes impressive progress made by Canterbury New Zealand.<sup>1</sup> It moved from a situation in the mid-2000s when the main acute hospital was regularly "gridlocked" with no possibility of affording additional capacity, to one where there is an extensive system of care coordination across hospital, community, social, and primary care. As a result, emergency medical admissions, lengths of stay, and readmissions have fallen appreciably. This raises two important questions: how was this achieved; and what can the English NHS learn from Canterbury, given the strong similarities between the two countries' systems?

What did Canterbury do? From the mid-2000s, Canterbury District Health Board (which is the statutory local funder of health and social care, and also the manager of hospital and some community health services) began a process to persuade local health professionals and the public that provision in the district was financially and clinically unsustainable. The board argued that it needed to plan for the coming 20 years on the basis of "one system and one budget," transcending the usual organisational and financial divisions. New strategic goals and principles were agreed locally, in particular, to deliver "the right care, in the right place, at the right time by the right person."

Over 2000 staff and contractors were trained to identify and bring about service change, enabling design and implementation of new "health pathways" across general practice, social care, and hospitals. Activity based payments for hospitals were replaced with bottom-up budgeting for each specialty, and contracts for externally provided services were moved from a competitive, often fee for service basis—to a form of alliance contracting that was derived from the construction industry. This entails organisations agreeing contracts in which maximum collective gain can only be realised if all parties support one another and agree to share any losses.<sup>2</sup>

What enabled this to happen? In 2008, an incoming, right of centre coalition government pledged that it would not impose reorganisation



**Canterbury tale** 

on the system, and has kept its word through two parliaments. Sustained policy goals have focused on clinical leadership, service integration, and delivering locally to a set of national outcome measures.<sup>3</sup> This wider stability of the health system seems to have given local health managers (most of whom have been long in post by English standards), clinicians, and board members space to implement plans that meet local needs and national outcomes. Critical to this has been a longstanding, highly developed network of general practices established in the early 1990s,<sup>2</sup> which had steadily built a culture of collective peer review, service development, and practice support across Canterbury. This network, Pegasus, has enabled Canterbury to involve primary care in new ways of developing and using clinical guidelines and pathways, sharing data, and working with the wider healthcare community.

Canterbury has largely removed two factors frequently cited as obstacles to service integration in England<sup>4</sup>: the goal of competition between providers; and a payment system that tends to incentivise hospital activity. In New Zealand, the bruising experience of aggressive pursuit of quasimarket reforms in the 1990s seems to have ruled out any return to the use of market forces between hospitals.<sup>5</sup>

Unlike the current context in England, Canterbury's budget grew reasonably in real terms: between 3% and 6% per year throughout the process. This allowed it to invest the increases outside the hospital while restraining the rate of growth in hospital spending. Efficiency improvements in hospitals did not lead to the removal of funds from hospitals—rather, they allowed more elective work to be done.

Alliance contracting is widely regarded as important for service integration. How far it rep-

resents true sharing of financial risk and reward, and can withstand the future challenge of reducing hospital capacity to extend primary care provision further, is yet to be proved. The contracts have not been through the stress of renewal, but they have enabled a more collective approach to local health funding that seems to encourage service integration.

A final factor impossible to quantify is the effect of the 2011 Christchurch earthquake in reducing hospital capacity in the city by over 100 beds, bringing health and social care staff together to develop innovative solutions to deliver safe services, and quickening the plans for service integration that had been long in discussion.

The Canterbury experience offers several insights for the NHS in England. Firstly, there is the uncomfortable message that frequent reorganisation of the system, and particularly of the commissioning function, undermines local attempts to make significant and sustained changes to services.<sup>6</sup> The New Zealand government has upheld its promise not to reorganise the system. Likewise, at a local level, continuity of clinical and managerial leadership is an important enabler of changes to services.<sup>7</sup>

Secondly, organised general practice is a vital prerequisite to developing new forms of coordinated care. This is something that English general practitioners have sought at various times over the past two decades, and with the current interest in general practice federations and networks, seems closer than ever before.<sup>8</sup>

Thirdly, as noted in analyses of evidence on integrated care, district-wide coordination of care benefits from careful crafting of governance, contracting, funding, and information sharing to support the overall approach.<sup>9</sup> In particular, a focus is needed on sharing risk and responsibility across health organisations as a way of driving out care fragmentation, rather than encouraging competition between organisations.

Finally, it seems that having a local statutory funder with responsibility for both health and social care helps integration of care for frail older people in particular.

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