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People with learning disabilities in the community: where do we go from here?

Sir,

There has been no fanfare announcing the almost complete emptying of the large mental handicap hospitals, where over 60 000 patients were accommodated 30 years ago. Now there are less than 3000,¹ many of whom may prove difficult to resettle.

Overall, the shift into the community is a great accomplishment, and patients have benefited from the freer structure of community care. The majority of people with moderate, severe, and profound learning disabilities² remain those who have always lived in the community, supported by their family and, as adults, often attending social education centres. All in all, there are roughly 200 000 such patients in the UK: a prevalence of about 3-4/1000.

How about the mental and physical health needs of these patients? Of course, those with complex neurological needs remain under the supervision of consultant psychiatrists specializing in learning disabilities. Reconfigured community learning disability teams include nurses and social workers, who support clients and their families, arrange respite care, and usually hold special needs registers.

All people with learning disabilities now in the community should be on the list of a GP. This means that the average GP with 1800 patients will now have six or seven patients with moderate, severe, and profound learning disabilities. A primary care group of 50 doctors may have over 300 such people; the community learning disability team may serve the same locality and may have identified these patients on their special needs register. The primary care team are the principal providers of general health care to people with learning disabilities in the community, and so should work closely

with specialist services by developing shared care arrangements.¹

Those on special needs registers may also have many additional health needs. These include problems with communication, sight, hearing, behaviour, epilepsy, continence, and obesity. Patients treated with CNS drugs, for example, anticonvulsants and antipsychotics, require monitoring. Some people with a learning disability underconsult and have difficulties accessing health services,³ including screening. For these reasons, many authorities recommend proactive health checks,^{1,3,4} but the few reports of health checks available confirm many unaddressed problems.^{5,6} Health checks need adequate funding and a good database. Commissioners in health authorities and primary care groups should consider how to implement them. Recommendations in the recent NHS Executive publication *Once a Day*⁷ include appointing a lead person, registers, regular checks, and establishing integrated care pathways between primary and specialist care teams. If implemented, these may lead to delivery of a service promising a healthier future for our learning disabled patients.

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Out-of-hours palliative care

Sir,

The letter by Munday *et al* (June *Journal*)¹ highlights several important points regarding out-of-hours palliative care. Their practice of faxing the cooperative with details of terminally ill patients is an excellent innovation, which will allow palliative care patients to be treated appropriately.

There is, however, a lack of understanding of the availability of 24-hour, on-call emergency pharmacy. While acknowledging that many GPs carry a limited supply of drugs and may not carry any opiates, the drugs that may be necessary to allow a terminally ill patient to remain at home can always be obtained at any time of day or night by contacting the duty on-call chemist, whose number can be obtained from the police. Additionally, local hospice staff are always available to advise on appropriate medication and will, in some circumstances, loan equipment (e.g. syringe drivers) and occasionally drugs out of hours.

The above measures should hopefully mean that palliative care patients are given

appropriate care out-of-hours regardless of whether the on-call GP is part of a deputizing service of cooperative.

Admitting a terminally ill patient to a hospice or hospital and sending them in an ambulance at 3 am because they need medication the doctor does not carry, is not good palliative care and leads to much distress to patients and their relatives.

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Defying the reaper

Sir,

All clinicians wonder, sooner or later, whether individuals can manage the timing of their deaths. Some patients seem to cling to life much longer than expected, only to decline precipitously after a family occasion or celebration of their birthday. The supposition that this happens more often than by chance has led to the concept of 'emotionally-invested deadlines'¹ — that a significant number of people delay their demise until after, for them, a significant life event. The evidence is, however, contentious and, some would say, dubious.²

One can test this phenomenon by examining the inter-relation, in a large population, between (a) the time centred on day of birth and (b) the day of death. The hypothesis is supported if there is a significant drop (a 'death-dip') in mortality leading up to the birthday anniversary compensated by a rise after the appointed day. We have performed such a study using the GP records of 2994 recently deceased Wiltshire residents selected at random. As would be expected, the majority of them had died in the sixth to eighth decade, the men earlier than the women.

We calculated, for every patient, the number of calendar days between date of birth and date of death (prefaced by + or -). The Poisson distribution was fitted to the data as the appropriate distribution³ to random counts in time. In fact, there were no differences in distributions of deaths before or after birthdays, the data following a totally random pattern.

Although 'proving the negative' is

always difficult, and although we may have failed to detect a real influence at work in selected patients only, at least our study was of a representative and well-defined sample.

The best known author in this field, Phillips, published findings on 'famous Americans' in one instance,⁴ and those with 'Jewish-sounding surnames' in another.⁵ His work seems to have been accepted uncritically despite conflicting evidence.⁶

The power of 'death-dipping' may be weaker than Phillips has alleged. Nevertheless, it remains an intriguing psychosocial possibility that is often reported anecdotally. It would repay further formal study, and we wonder how many doomed individuals will be able to 'defy the reaper' in the weeks leading up to 1 January 2000? Difficulties with manpower in the caring profession may not be the only influence at work that weekend!

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Innovative methods in promoting primary care research

Sir,

In December 1998, the General Practitioners in Asthma Group (GPIAG) ran a weekend workshop to test a method-

ology to allow research questions to be rapidly developed into a detailed research protocol. The workshop design allowed practising clinicians (general practitioners and practice nurses) to be integral to protocol development, while simultaneously increasing their research expertise. The methodology and our results are reported elsewhere.¹ We feel that the ideas behind the workshop warrant further discussion and debate within primary care.

There is a need to enhance the research capacity of primary care.^{2,3} There has, however, been little discussion on how this is to be achieved without alienating primary care workers. While increasing primary care research funding and availability of primary care fellowships are welcome, such approaches may lead to a continuation of 'top down' research dominating primary care. Novel and innovative methods are required in order to increase clinicians' ownership of research projects. There is the need for primary care staff involvement in the development and planning of programmes of research, from their outset.

The (anonymous) feedback that we received indicated that participants' found the process useful, stimulating, and enjoyable, and were keen to see its continuation. Typical comments were that the workshop was 'challenging', 'novel', and 'creative', yet provided a framework in which participants felt they were 'listened to' and had the 'freedom to express views'. Many commented that the process gave a tangible 'sense of achievement'.

We are pleased to report that the workshop will be repeated in November 1999 by the GPIAG in Aberdeen (site of the new GPIAG Chair in Primary Care Respiratory Medicine) and also in February 2000 for respiratory nurses, organized by the Research Committee of the British Thoracic Society. These meetings should allow us to assess the generalizability of the methodology developed.

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Factors associated with the provision of anti-smoking advice by GPs

Sir,

After reading Coleman and Wilson's brief report on factors associated with the anti-smoking advice by GPs (July *Journal*),¹ we should like to suggest that more care is needed when deciding which articles are suitable for the 600 word limit.

It has never been more important that research evidence is clear and accessible to health professionals in primary care. New structures, such as the National Institute for Clinical Excellence, should alleviate some pressure on GPs in the future.² However, at the moment, patient expectations, the demands of clinical governance, and the need to contribute to primary care groups leave little time to sift the mass of information available. Around two million articles are published in medical journals annually, and new titles continue to appear every year.³ The pressure on academics to publish in peer-reviewed journals, both to secure funding and develop their own careers, means that there are few problems in finding articles to fill pages. In fact, journal editors are able to accept only a small proportion of material submitted to them.

In under 600 words, Coleman and Wilson described their study of 622 adults and reported the results for smokers who were advised or not advised by the GP, categorized by their attitude towards giving up the habit. Despite being fairly experienced critical readers, we had problems making sense of the figures. One hundred and forty-four of the 612 responders were smokers, 122 of these were patients and 20 accompanied a child. Two smokers are therefore not accounted for. Twenty out of 119 patients reported smoking-related problems, but the relevance of the denominator figure is unclear. If 34 of 122 smokers were advised, 88 were not, yet the denominators for those not advised vary from 79 to 81. We assume that this is due to item non response, but no explanation is offered.

With more space the authors could have explained their data and presented a more extensive discussion. For example, the possibility that GPs appeared to be advising the more motivated smokers because

they had made no progress with the others is not considered.

We draw the rather obvious conclusion from this paper that research worthy of publication should be allotted enough space to be explained clearly. Otherwise, it is of limited use to readers and a source of frustration for authors.

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Simulated surgery

Sir,

Burrows and Bingham (April *Journal*)¹ 'conclude that the simulated surgery is established as a feasible, valid, and reliable method of assessing the clinical skills of MRCGP candidates who are unable to submit a video-recording of their consultations'. Although we commend them on achieving high degrees of inter-assessor reliability and on improving feasibility, their claim of validity cannot go unchallenged.

By their own admission, their method does not include a test of diagnostic skills in the consultation ('diagnostic skills are tested elsewhere in the examination: diagnoses are usually obvious or provided in the simulated surgery...'). The ability of candidates to elicit abnormal physical signs is also not tested ('...the format prevents us from including children, emergencies, physical signs, and previously known patients'). Because of these crucial omissions, their consulting skills performance criteria are simply not credible, let alone valid. Moreover, the imposition of a fixed consultation length and the inability of the method to include children, emergencies, and previously known patients in the set of clinical challenges further subvert the validity of the process.

It is widely accepted that a supportable assessment method is a combination of five different parameters: validity, reliability,

costs, acceptability, and educational impact.² Furthermore, the relationship between the parameters is 'multiplicative, because if one of them is nil, the usefulness of the examination would be nil'.² Accordingly, before recommending the simulated surgery as an alternative to the videotaped submission for the consulting skills component of the MRCGP examination, we believe that the validity of the method must first be established.

Finally, Burrows and Bingham state that 'the simulated surgery measures competence while the video measures performance'. Competence is not something that can be directly measured: competence can only be inferred on the basis of systematic observation of performance judged against valid performance criteria.³

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Retention of young GPs

Sir,

I write with reference to Taylor *et al*'s article (April *Journal*)¹ about the retention of young GPs entering the NHS from 1991–1992.

The Medical Practices Committee would like to make absolutely clear that, contrary to the statement made by the authors on page 279, the Committee has never had a policy of 'not refilling single-handed partnerships'.

On receipt of an application from a health authority for a change in the local medical workforce, the Committee assesses whether the specified locality is served by sufficient, but not excessive, numbers of doctors working in general practice. The initial criteria used by the Committee

are based upon the average list size per whole-time-equivalent GP in England and Wales. However, the patient profile within the specified locality is also very important. The Committee therefore takes account of information on a range of other factors reported by health authorities, and these may often override the influence of the simple average list size assessment.

The Committee continues to exercise discretion and judgement in reaching decisions on whether or not vacancies should be declared.

In summary, each case is considered on its individual merits, and the Committee does not refuse applications for replacement GPs simply because the practice is single-handed.

Further information on the MPC and its policies may be found on the website: www.open.gov.uk/doh/mpc/mpch.htm

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Antibiotic prescribing for sore throat

Sir,

Kumar *et al*¹ imply that increased antibiotic prescribing for sore throat may reduce the already very low incidence of acute rheumatic fever and post-streptococcal glomerulonephritis in the UK, and perhaps prevent a resurgence of these conditions. En route, they also recommend an increased use of throat swabs and streptococcal antigen tests in general practice. None of their recommendations stand up to scrutiny.

In a review of 22 placebo-controlled trials of antibiotics in sore throat, a Cochrane review² concludes that 'the absolute benefit of antibiotics for reducing complications of sore throat is small in settings where rheumatic fever is rare'. Similarly, the Scottish Intercollegiate Network (SIGN) guideline³ on management of sore throat and indications for tonsillectomy states that 'sore throat should not be treated with antibiotics specifically to prevent the development of acute rheumatic fever and acute glomerulonephritis'. In addition, the same guideline does not support the routine use of

either throat swabs or rapid antigen testing, as neither tends to alter management decisions. Apart from the inaccuracies associated with both investigations, there is a high asymptomatic carrier rate of around 40%⁴ for group A β -haemolytic streptococcus (GABHS).

It is inappropriate for Kumar *et al* to associate the cases of acute rheumatic fever with pressures to reduce costs in general practice. Genuine public health campaigns aimed at reducing inappropriate antibiotic prescribing are not enhanced by such alarmist proposals.

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Primary care software should be dragged into the next millennium

Sir,

The state of GP computing leaves much to be desired. Jon Emery (July *Journal*)¹ suggests that any genetic computer support program will need to communicate with the practice computer system and also with Windows. It has taken a long time for some primary care computing systems to start becoming Windows compatible. The problem is, there are too many software packages for primary care. They are all different, take time to learn and master (if you are able), and seem very poorly supported. None seem to be geared towards the GP getting the most out of his record system. We don't even know if they are millennium friendly yet.

There is a gap in the literature concerning how many GPs are unable to use their computer systems properly. The government should be trying to address this. NHSnet is all very well, but how about a single, windows and research compatible software package, which is free, with NHSnet? Perhaps then we could all access genetic decision support by remote access,

with no need for costly upgrades.

There seems to be a tremendous gulf between innovations in IT in primary care and grassroots level uptake. We know that research evidence in general is variably implemented.² New developments in IT seem never to be actioned; though there are many programs out there for decision support, how many GPs do you know who actually use them? Although the authors are absolutely correct to suggest that primary care IT could aid genetic support, more GPs need IT support first.

The business world has grabbed hold of the Internet and new IT technology ferociously, determined to use it for its own means. Primary care remains passive, waiting for IT to get *it*. In a world where soon most business will be conducted through the web,³ isn't it time that, as a profession, we started becoming computer whizzes?

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Speaking out

Sir,

The recent case of Katie Atkinson, a nine year-old from Sheffield who was denied a referral for heart transplant because she has Down's syndrome,¹ continues to illustrate how negative expectations are influencing the behaviour of individual professionals or health services and are resulting in self-fulfilling prophecies. Low or negative expectations of an individual's health can lead to the acceptance of a lower state of health as 'normal' for this group of people. Such incorrect attitudes and low expectations are contributing to a situation that is little short of scandalous.

Studies show that people with learning disabilities are not always receiving equal access to health services and the right level of individual support to use it effectively.² Clearly, discrimination of over one million people (2% of the population)

with a learning disability needs to stop.

The life expectancy of people with a learning disability has increased by 40 years over the past 50 years.³ Although the life expectancy of people with Down's syndrome remains between five and 10 years lower than the overall population of people with learning disabilities, this still represents a considerable increase in life expectancy for these people.⁴ This is partly due to advances in medical and surgical treatments being made available and clearly demonstrates how correct attitudes and high expectations do save lives.

Health professionals need to reflect on their willingness on the one hand to prolong and intervene in treatments that are beyond normal limits of viability and on the other to make decisions based purely on what professionals consider to be 'quality of life'.

The message that appears to be sent (unwittingly or not) by health professionals to Katie and her parents is that their vibrant daughter is not worthy of equal treatment or consideration. It is a message that has disturbing consequences, not just for Katie and her parents but for all marginalized groups in Britain.

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UK medical charities and clinical trials

Sir,
Evidence-based medicine largely depends on data from clinical trials. Its progress obviously relies to a considerable degree on the financial resources available for such investigations. In the UK and elsewhere, medical research is mostly funded by charities. To determine how dedicated these institutions are towards sponsoring clinical trials in general and of complementary medicine (CM) in particular, a questionnaire was sent to all 100 medical research charities listed in *The Association*

of Medical Research Charities Handbook 1998-1999.¹ It contained five short questions related to their annual budget and commitment to funding clinical trials both in general as well as of CM. A total of 63 completed questionnaires were returned. One had to be excluded because the answers given were meaningless.

The total annual budget of the responding institutions amounted to £133 218 617. Asked whether they would fund clinical trials, 23 answered with yes, 35 with no, and three indicated they would consider funding clinical trials if they received applications. In total, 544 clinical trials were supported in 1998, which corresponded to £3 144 396. Asked whether they supported clinical trials in CM, 13 answered positively and 37 denied. Ten charities indicated they would consider funding it if they received applications. A total of three clinical trials were supported in 1998, which amounted to £70 000.

These data imply that medical research charities invest an average of 2.3% of their annual research budgets into clinical trials of all areas of medicine and only 0.05% into trials of CM. A similar result was generated by a previous survey that related to NHS funding for CM research.² We believe that, vis à vis the importance of clinical trials for the progress of evidence-based medicine, this funding policy urgently requires to be considered. There is an overt imbalance between the popularity and the evidence in CM. Therefore, the lack of involvement of medical research charities in CM research seems particularly regrettable.

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A treatment for constipation

Sir,
Old people, particularly in retirement or nursing homes, often complain of consti-

pation — possibly from a lack of exercise and poor fluid intake, or from excessive concern with their bodily functions.

I recently discovered that some patients benefit from rocking to facilitate evacuation. This appears to promote peristalsis, independent of increased abdominal pressure or deep respiration. All that is necessary is to rock back and forth, on the toilet, say for four or five seconds each way. Quite probably someone has described this manoeuvre in the past, but I was never taught it, nor is it specifically mentioned in general medical textbooks.

Some patients in an old people's home confirmed that it can be of help. A proper randomized, double-blind, placebo-controlled, crossover trial would certainly be desirable but is obviously not feasible. On the other hand, there is probably scant scientific evidence, for example, for tepid sponging feverish patients or refusal to strap a fractured rib. So perhaps some colleagues may give this simple manoeuvre a trial and tell me of their experiences. After all, they have little to lose and can be sure that no side-effects will haunt them, which is more than can be said for many well-researched, evidence-based treatments.

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The future of the BJGP

Sir,
Dr Gillies' ideas for the future of the BJGP (*August Journal*) are highly pertinent, timely, and well expressed. There seems little more to be done than to put them into action.

The rate of citation seems roughly inversely proportional to the popularity of the *Journal* among GP registrars and most 'ordinary' GPs. The introduction of the Back Pages finally provided such readers with something interesting, entertaining, and relevant to read. Unless the 'science' of the main papers and the 'art' of the Back Pages are integrated, the *Journal* will fail to engage most of these doctors who are the future of our profession. I was only a small cog in the organizing wheel, so I can say without arrogance that the 1999 Spring Meeting in Cambridge on 'Rational General Practice — Art AND Science' was a model of how such integration could happen.

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