

# College fights on to change Health Bill



Dr Clare Gerada

**RCGP Chair Dr Clare Gerada has presented the College's final argument to the government in an appeal to make changes to the controversial Health and Social Care Bill before it enters the report stage in the House of Lords.**

Writing to the Secretary of State for Health in England Andrew Lansley, Dr Gerada revealed the results of the latest straw poll carried out by the College to gauge the views of the membership regarding the legislation.

The poll, launched before Christmas, revealed that nearly three-quarters of respondents now feel it is appropriate for the College to call for the withdrawal of the Bill. It showed that more than 98% of respondents either strongly supported or supported the College in calling for the Bill to be withdrawn as part of a joint approach with other medical royal colleges.

More than 90% of respondents said that, even without a joint approach, they either strongly supported (55.8%)

or supported (37.0%) the College in proceeding alone.

The report stage is the penultimate opportunity for the House of Lords to make amendments to the Bill, and has been given a provisional start date of Wednesday 8 February.

Dr Gerada said: 'With the report stage imminent, so it is timely for us to reiterate our concerns and show the government that we want to continue working with them to bring about positive change for the benefit of our patients.'

'While our list of recommendations and concerns is not new, this survey makes it clear that if any changes made are not strong enough to address these concerns, there is strong support within the profession not only for us to call for more change urgently but also, should the situation warrant it, for the withdrawal of the Bill itself.'

The poll, the latest of three commissioned by Dr Gerada over the last 18 months showed how, on each

occasion, unease about the Bill and its implications on patient care have remained.

On this occasion, more than 60% of respondents said that they felt more negative about the impact of the Bill on the NHS than they did at the time of the College's last survey in the autumn, and less than 14% of respondents (360) said that they believed the reforms would result in better patient care.

In addition, Dr Gerada stressed the importance of the survey in gauging the feelings of the membership. She said: 'When we look back on this unprecedented time of change in the NHS, I want there to be no misunderstanding of the College's position. More importantly, I do not want there to be criticism that the College and I did not do enough to engage and inform our members.'

At the time of *RCGP News* going to print, Mr Lansley had responded in the press but had as yet made no formal response to the RCGP Chair's letter.

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## College to elect new President

Nominations to succeed Dr Iona Heath as President of the RCGP are open from 1 February until 31 March 2012.

Unlike the other medical royal colleges, the RCGP President is the ceremonial head of the College. The presidential election is open to all members, and candidates are elected by a ballot of the membership, which will take place during April and May. The length of tenure is three years.

The process for nomination is outlined on page 8 of this issue. For further details and an application pack please contact: [jcheong@rcgp.org.uk](mailto:jcheong@rcgp.org.uk).

RCGP Chair Dr Clare Gerada said: 'I cannot believe that Iona's time as President comes to an end in November. She has done so much fantastic work to promote the College, to uphold its values and represent GPs across the UK and internationally through her work with Wonca.'



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# Launch of national bowel cancer awareness campaign

The first NHS national bowel cancer public awareness campaign in England launched on 30 January and will run for nine weeks until the end of March 2012.

This campaign forms part of the Department of Health's (DH) plans to tackle England's poor cancer survival rates compared with Western European countries. It is estimated that 1700 deaths from bowel cancer could be avoided every year if England's cancer survival rates matched the best in Europe.

The campaign aims to increase earlier diagnosis of bowel cancer to improve the chances of it being successfully treated. In addition to advertising across national media, advertising is also on local buses and over 100 public events are being held across England.

The campaign message is that 'loose poo' and 'blood in poo' for more than three weeks can be symptoms of bowel cancer. Real GPs feature in the campaigns and encourage anyone with these symptoms to see their doctor early.

This national campaign follows the successful regional pilot of a bowel cancer awareness campaign in the southwest and east of England at the start of last year. Results from the pilots showed there was high recognition of the campaign, an increase of 48% of people over 50 visiting their GP with relevant symptoms and significant increases in urgent referrals to secondary care. GPs in the pilot

bowel cancer regions reported that the impact on primary care was very manageable, equating to about one extra patient per practice per week.

Professor Sir Mike Richards, National Cancer Director, wrote to GPs in November about the plans for the campaign. In his letter, he stressed that the DH recognises that the three weeks' timescale is earlier than the NICE guideline for urgent GP referrals for suspected bowel cancer, which states six weeks. However, it is important that people with serious symptoms present to their doctor earlier. GPs will continue to exercise their clinical judgement about the appropriate handling for their individual patients.

A number of resources are being made available to support GPs during the campaign. Working with Bowel Cancer UK, the DH has developed a campaign factsheet for GPs,

and a separate one for practice managers. There is also further information on Bowel Cancer UK's website. The National Cancer Action Team, with the support of Cancer Networks, will be disseminating a risk assessment tool for colorectal cancer in early 2012. In partnership with Cancer Research UK, Doctors.net is currently featuring online learning tools, information and guidance on bowel cancer.

Alongside the national campaign, this year 17 projects across over 70 PCTs will run local Be Clear on Cancer campaigns focusing on oesophago-gastric cancer, the symptom blood in urine (common to kidney and bladder cancer) and breast cancer in women over 70.

**For further information on these public campaigns contact Beth Capper at [beth.capper@dh.gsi.gov.uk](mailto:beth.capper@dh.gsi.gov.uk).**

## RCGP Capital Appeal Grand Draw 2011

**The Capital Appeal Grand Draw 2011 was launched at the RCGP Annual Conference in aid of the refurbishment of the College's new headquarters at 30 Euston Square. The draw took place in December and raised much needed funds towards the appeal – we thank the many members who took part for their support!**

Sixteen members from all over the country won prizes including a year's free membership of the College, courses vouchers, wine tasting and Olympics tickets.

Dr Simon Abrams, winner of the top prize of one-year's free membership, was presented with his prize at his surgery in Everton by Dr Kishor Vithlani, Honorary Treasurer of Mersey Faculty. The second prize of a three-day pass to this year's annual conference was won by Dr Torquil Duncan-Brown, Lichfield, Staffordshire, who was presented with his prize by Dr Helen Stokes-Lampard, Assistant Honorary Treasurer.

Prof. David Haslam, past President of the College and Chairman of the Capital Appeal, was delighted at the response to the appeal, 'which will help the RCGP continue to raise standards in primary care and to be a beacon of excellence for general practice'.



Dr Duncan-Brown receiving his prize from RCGP Assistant Honorary Treasurer, Dr Helen Stokes-Lampard.

For those of you who missed out or would like to take part once more, we are planning to make the Grand Draw an annual event.

For more information on the RCGP Capital Appeal, visit [www.rcgp.org.uk/fundraising](http://www.rcgp.org.uk/fundraising) or contact **Charlotte Roden**, Fundraising Officer, on **020 3188 7504** or at [charlotte.roden@rcgp.org.uk](mailto:charlotte.roden@rcgp.org.uk).

## RCGP Revalidation ePortfolio

**Revalidation will be a new way of regulating doctors and giving assurance to patients that doctors are up to date and fit to practise.**

The process will be underpinned by regular appraisals based on the core guidance for the medical profession, *Good Medical Practice*. GPs will provide supporting information for their appraisals in line with the RCGP *Guide to the Revalidation of General Practitioners*, which itself is based on *Good Medical Practice for GPs*. Following appraisal, a responsible officer will make a recommendation to the GMC that a doctor's licence to practise should be revalidated. This will normally happen every five years.

The RCGP Revalidation ePortfolio has been devised by the RCGP to meet GPs' continuing professional development (CPD), appraisal and revalidation needs. It provides a secure and reliable solution for revalidation, developed in line with national policy developments.

For the appraisee and appraiser the RCGP Revalidation ePortfolio is a comprehensive system to record CPD and integrates this with personal development plan (PDP) objectives. It provides an at-a-glance traffic light dashboard to show progress towards both appraisal and revalidation, and uses a credit scoring mechanism that includes demonstration of implementation of learning in practice. The system is dynamic enough to allow both agreed and proposed PDP items and documentation of outcomes in a format suitable for revalidation. All appraisal material entered is stored securely for future reference and is easily accessible throughout the year.

For PCOs and responsible officers the RCGP Revalidation ePortfolio provides a single solution where all supporting information is organised and validated during the appraisal process, meaning decision-making is streamlined, rapid and efficient. Organisations can easily manage their entire performers' list, allocating appraisees to appraisers and scheduling appraisal dates within the system.

The RCGP Revalidation ePortfolio has continued to evolve in line with national guidelines on appraisal and revalidation, as well as user feedback. The tool will soon offer integration with other RCGP online products, including the Online Learning Environment, the PEP learning needs assessment tool and the RCGP Trainee ePortfolio.

The RCGP believes that the Revalidation ePortfolio is the best product on the market for GPs and is confident that it will be the revalidation tool of choice for the majority of PCOs. Designed by GPs for GPs, it is free for RCGP members and Primary Care Organisations (PCOs) and available at a reasonable charge for non-members.

The GMC expects to introduce revalidation from late 2012 and is encouraging licensed doctors to have regular appraisals. The RCGP Revalidation ePortfolio is ideally placed to support your development, appraisal and revalidation needs.

For more information contact [gpeportfolio@rcgp.org.uk](mailto:gpeportfolio@rcgp.org.uk), telephone **020 3188 7667** or visit [www.rcgp.org.uk/revalidation\\_eportfolio\\_home.aspx](http://www.rcgp.org.uk/revalidation_eportfolio_home.aspx).

# RCGP/RCPE symposium: Struggling Trainees – the hardest bit

9 December 2011, Royal College of Physicians of Edinburgh (RCPE)

**Dr Mei Ling Denney**

MRCGP Research & Development Lead, RCGP

**The management of trainees in difficulties is of interest to those responsible for their training and assessment, as well as trainees themselves.**

Problems become evident at different stages of training and may be obvious through workplace-based assessment and trainees' engagement with the ePortfolio, as well as the outcomes in the AKT and CSA summative exams.

This symposium attracted a cross-specialty audience including those with undergraduate responsibilities, regulatory responsibilities, and responsibilities for remediation and performance management. However, a high proportion of the audience was from general practice, and contained GP educators and representatives from both AKT and CSA exams. Drs Mei Ling Denney (RCGP) and Andrew Elder (RCPE) chaired the day, with the morning devoted to presentations on the relevant research findings, and the afternoon on diagnostic models and practical solutions. After both the morning and afternoon sessions delegates had opportunities in their facilitated groups to discuss the issues, and consider the implications and possible ways forward.

**Predictors and costs of poor performance**

Following an introduction by RCPE President Dr Neil Dewhurst, Prof. Bill Reid, the Postgraduate Dean for South East Scotland, set out the prevalence and consequences of issues surrounding poor performance – the numbers of trainees presenting with performance, conduct or health issues, and the subsequent possible costs to the individual and the organisation of dealing with these.

Two psychometricians, Chris McManus (University College London and RCPE) and Richard Wakeford (University of Cambridge and RCGP), presented in the morning. Chris outlined research evidence on the predictors of poor performance before entry to specialist training programmes, highlighting examples of past performance predicting future performance in exams, but being mindful of individual variation. Richard discussed international medical graduates and the factors contributing the most variance in performance exams, the need for transparency in a selection in assessment processes, and predictors of suspension by the GMC.

On a different note, Dr Anjla Sharman, Programme Director for the East Midlands Deanery, explained how the deanery had used GP selection scores to target doctors for early intervention training, highlighting the importance of early identification of struggling trainees and avoidance of stigmatisation. Of particular interest was using scores on personality and empathy to target those who might benefit from additional training in patient-centred consultation skills.

**'Failing to fail'**

Prof. Charlotte Rees from Dundee gave a fascinating presentation on the research findings into 'failing to fail' – illustrating the factors that impact on the reluctance of teachers to identify and confirm failure in students. She stressed the importance of accurate documentation of problems, and explained that the reluctance of supervisors to fail trainees was linked to the educator's conception of failure, and that how we view failure is apparent from the metaphors that we choose to use for it.

Despite a good lunch, there were no signs of flagging enthusiasm or alertness from the audience to the presentations by four experts in the field on frameworks and models for supporting doctors in difficulty and making defensible difficult decisions.

**Managing difficult performance issues**

Tim Norfolk, an independent occupational psychologist specialising in the diagnosis and management of doctors in difficulty, gave a whirlwind presentation on his 'RDM-p' (relationship, diagnostics, management and professionalism) model, a diagnostic approach that mirrors patient-centred consulting. Sadly, the amount of time that he had did not really do justice to this important model, which has been adopted by many working in general practice education. Delegates heard of the need to frame properly the performance review, and consider the context. The model spans medical specialties and can be used through foundation, specialty selection, specialty training, and post-CCT for doctors in difficulty.

Dr Jenny King (Edgecumbe Consulting) introduced the Edgecumbe Model, highlighting some very practical approaches to the difficult performance issues relating to a doctor's personality and his or her behaviour. How a whole variety of personality traits, which could be seen as strengths, determined difficult behaviour patterns and became 'derailers' when doctors are seen to underperform were made clear. She also posed the question of how much investment was warranted at the really difficult end of the performance spectrum.

Dr Jo Jones (East Midlands Deanery) gave an overview of findings and practical solutions from six years' cross-specialty experience in the East Midlands Training Support Service (TSS), raising the issues of the importance of externality and supporting faculty. A variety of support options are used by the TSS, including educational and occupational psychologists, and specialist occupational health physicians.

Finally, Claire McLaughlan (National Clinical Assessment Service, NCAS) updated delegates on the NCAS's 'back-on-track' resources and the

National Patient Safety Agency's use of 'security plans'. Although dealing with trainees at the more serious end of the performance spectrum is a relatively rare event, trainees who present with multiple episodes of failure, conduct or health problems need action plans with specific directed learning.

**Conclusions**

The symposium did much to raise the awareness of the many predictors of struggling trainees, the ongoing research evidence from different royal colleges, including the RCGP, and the available models for diagnosis and management of trainees in difficulty. General practice often leads the way

in the documentation and transfer of evidence, but there is still much work to be done, particularly in the area of transfer of information, achieving consistency across the UK, and supporting and up-skilling the educators in the identification and management of these trainees.

Delegates on the day fed back that they thought the symposium was very useful, relevant and thought-provoking. Selected parts of the symposium were later web-streamed to those who requested it but were unable to attend. Many presentations are now available via [www.rcpe.ac.uk/struggling-trainees.php](http://www.rcpe.ac.uk/struggling-trainees.php) for those wishing to explore the subject more.

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# Health visitors and primary care



**Dr Janice Allister**

RCGP Clinical Champion for Child Health

This article emphasises the continuing importance of health visitors (HVs), with a special focus on their relation to GPs. It also explains the new Department of Health (DH) initiatives regarding HVs and challenges GPs to ensure we're working with HVs in an integrated and communicative way.

**Health visitors and GPs**

Many GPs in England have been expressing concern at losing their HV. This is a valid concern. HV numbers, especially those based in or attached to practices, have been declining rapidly since 2001 (currently there are around 8000 left). Reasons for this include:

- variable investment in children's services and prevention services
- lack of confidence in the evidence base after the Hall report<sup>1</sup>
- commissioning moving from 'universal' services to re-deployment to more 'needy' areas including children's centres – this has been driven by a shortage of HV workforce and an increase in 'needy' families
- retirement – HVs have traditionally been an older nursing workforce, and numbers lost will continue to outnumber recruits until the end of 2012

- excessive caseloads, both in number and intensity including increasing safeguarding concerns, with social care raising the threshold for accepting referrals, thus leaving more safeguarding issues in the hands of HVs
- general feeling of loss of status, loss of ability to provide universal/community services, and low morale in the service.

HVs, together with midwives and district nurses, have always been important members of the primary healthcare team, but have never actually been employed by or contracted to GPs. Historically they were volunteers, later coming into local government employment to help combat high infant mortality in the late nineteenth century. Currently HVs are employed by a range of providers, which hold contracts with Primary Care Trusts as commissioning organisations.

Current HV responsibilities include:

- leading the implementation of the Healthy Child Programme<sup>2</sup> and working with GPs and others to provide these services
- providing family health services for 0–5-year-olds, making every contact count – with some different packages of care for different families
- championing wider health and wellbeing, prevention and public health, building family and community capacity
- utilising resources, delegating and referring, and transitions.

The 'window' in a child's life from conception to school is crucial, with increasing evidence of the importance of both antenatal and early childhood care, as well as attachment, for long-term physical and mental health.<sup>3</sup> HVs have traditionally worked to foster this attachment and answer concerns. They have been widely respected by parents and carers as wise, yet approachable and accessible, sources of advice and support within the community. Families with complicated problems in particular often rely on HVs as pillars of support.

Historically, GPs and HVs have always worked together closely at the boundary of preventive and acute care. It is important that this relationship should continue and strengthen.

**The Department of Health's vision of health visiting**

In response to declining HV numbers, and increasing evidence of the importance of antenatal and early childhood care, there is

stated strong political intention to improve services for families. There is a specific and absolute commitment, part of the Operating Framework for the NHS, within the coalition agreement, to raise the number of HVs by 4200 against the 2010 baseline during the course of this parliament.

The DH has led the development of a new service model, which will be provided locally in ways that meet local needs. The Chief Nursing Officer is managing the change. The model has four stages of involvement for HVs, together with a more general role of developing and supporting community projects that seek to improve outcomes in those crucial early years and beyond.

1. *Your community*: working with local communities and services to provide a range of services, including services provided by communities themselves such as breast-feeding support.
2. *Universal service*: for all families – the Healthy Child Programme (including the two-year check and school readiness).
3. *Universal plus*: some families, some of the time – particular help such as breast-feeding support, and assessment and support for women with postnatal depression, addressing specific issues that arise.
4. *Universal partnership plus*: some families all of the time – children or parents with ongoing difficulties (this includes social difficulties and health issues such as a child with a disability or illness). For some families this will include intensive multi-agency support.

Safeguarding is a key role for professionals working with children and families, and is a priority at all four of these levels.

Twenty-six sites have been given the challenge of implementing the new service model by 2012 with:

- local managerial and commissioner support and local partnerships
- normal health visiting team staffing levels
- improving services and outcomes for local families, for example with breast-feeding groups to improve breast-feeding rates, and smoking cessation programmes for pregnant women and mothers of young children
- testing new policy and practice, such as improved antenatal contact and preparation for parenthood, an integrated two-year review, and new technologies for efficiency
- teaching and mentoring new trainees
- developing, auditing and monitoring outcomes for children such as school readiness, speech and language, and general development.

Each of these sites has increased CPD and support, reflective learning opportunities, and partnership with the Family Nurse Programme.

In the new policy, there is an increasing emphasis on the importance of localities deciding how all local services and professionals, including GPs, community nurses, early-years (now called foundation-years services) schools and the police, can pull together, to better meet the needs of children and families. Nationally, policy does require HVs and other family services to be better aligned, but it doesn't make specific comment on local organisation or audit.

The DH and the Nursing and Midwifery Council (NMC) have published *Educating Health Visitors* to ensure that university courses reflect changing needs and service models.<sup>4</sup>

The NMC requirement for HV training has not changed (i.e. registration as a nurse/midwife for entry to HV with a further year of graduate or Master's study – a total of four years including the nurse training). There are, however, pilots of more flexible ways of doing postgraduate training and making run-through training smoother, such as children's registered nurses undertaking a 12-month postgraduate programme on health visiting as soon as they have completed their undergraduate course.

There will be a review of the Specialist Community Public Health Nursing register to ensure that there are appropriate standards for entry to health visiting and school nursing professions.

### Some implications of this vision

Not all aspects of the DH strategy or its implications have yet been fully realised.<sup>5</sup> Further guidance and discussion may be required. For instance, how can growth in HV numbers make the most difference and how can a skill mix (with family nurses, nursery nurses and different grades of community nurses) help give the required outcomes without leading to a reduction in services to families?

The HV leadership feels that the changes present huge workforce challenge in terms of the training and creation of posts. Whilst supportive of the commitment and the

programme, there remain concerns about some potentially difficult issues:

- sustaining, integrating and embedding HV work within public health
- transferring responsibility for commissioning HVs from PCTs to the Commissioning Board by 2013 and to public health and local authorities by 2015
- demonstrating outcomes.

Furthermore, the funding for changes has been weighted against demographics and deprivation. It is not yet clear where that funding will sit. Current issues are:

- PCTs having to begin funding the implementation plan, including increased numbers and 'call to action', out of existing resources
- PCTs having to balance central government policy with response to local need, in some areas meaning a reduction in local HV services to families.

The way HVs approach and structure their work is also likely to change. HVs have traditionally described and quantified their work through caseloads and numbers subject to special observation – such as those subject to child protection plans. In the move to population approaches to health, HVs will increasingly have to quantify their work through populations, such as the number of under-fives in an area. This will only be sustainable with support from leaders and other professions.

- For HVs, there should be recognition of intensity of working such as the numbers of those who are 'looked after', have a disability or are seeking asylum.
- There is already a requirement of a named HV liaising with every GP practice; providers are in breach of contract if this is not happening.
- Payment by results plans for some children's centres could risk excluding those most in need.
- By 2015, one-third of the health visiting workforce will be newly qualified and relatively inexperienced, so there needs to be strong local leadership and support, including support for and rewards for challenging work. They should receive professional credit and increased status.

### A GP response

In the future, we as GPs need to ensure that we are working in an integrated and communicative way with HVs.

Ultimately, the new DH strategy should result in more HVs being available within communities. But this will take several years to implement fully and will require GP support. Even while the strategy is being detailed and developed, a national HV Taskforce, on which the RCGP is represented, is responsible for challenging the DH on the progress of the programme and informing individual professional bodies and networks.

The Building Community Capacity Programme, aiming to refresh skills among HVs and school nurses, will be implemented early in 2012 with funding going directly to SHAs. There may be initiatives to re-establish links.

Both health visitors and GPs complain about a lack of shared information in primary care. Although one of the reasons for this may be

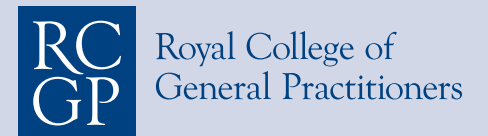
that they simply do not see each other, other problems include incompatibilities of information systems and difficulties in accessing these remotely. There is also underuse of nhs.net.

There are plans to produce a series of case studies and narratives to help in this, but nothing can replace simply establishing and maintaining good working relationships with local health visitors. Shared knowledge and experience is crucial if families are to receive good levels of care.

It is important to remember that preventive child health is one of a GP's core responsibilities. Every member of the healthcare team is now expected to demonstrate basic competences consistent with their role and responsibilities.<sup>6</sup> In the context of the Healthy Child Programme for 0–5s, HVs are one of our key partners in providing the best outcomes for those in our care.

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## Election of members to serve on College Council for 2012–15

Six nationally elected members will retire from College Council at the AGM on Friday 16 November 2012.

Six new members will therefore need to be elected to serve on the Council for the three-year term of 2012–15. Any fellow or member of the College in good standing<sup>1</sup> may propose another for election to one of the six vacancies.

Nomination forms and further details may be obtained on application from the Returning Officer, 1 Bow Churchyard, London EC4M 9DQ or by email from: [jcheong@rcgp.org.uk](mailto:jcheong@rcgp.org.uk). Tel: 0203 188 7532.

Please note all nomination forms must be returned no later than **noon 31 March 2012**.

### Ballot of members

In the event there are more nominations than places to be filled, a ballot of College members and fellows will be held. Voting papers for the ballot will be sent to all fellows and members during April 2012. A single transferable vote (STV) system will be used for the election. The result of the ballot and names of the six successful candidates will be formally declared at the 16 June 2012 Council Meeting and subsequently published in the *British Journal of General Practice*.

1. The member so designated has paid all fees and subscriptions due to the College.

# Call for course and conference ideas

We are looking to enhance our already diverse course and conference programme in order to continue providing members and GP trainees with quality, timely and relevant education to support their training and continued professional development.

**Running your own course or leading a conference via the RCGP is very rewarding – sharing your knowledge, skills and experience with your peers and colleagues, helping the College to promote excellence in primary care.**

If you have a course idea or wish to run your own event or conference via the RCGP, please contact RCGP National Educational Conferences, Courses and Events at [conferences@rcgp.org.uk](mailto:conferences@rcgp.org.uk) or on 020 3188 7493.

**We look forward to receiving fresh ideas for new courses!**

# Improving uptake of annual health checks for adult patients with intellectual disabilities: the ostrich effect?

**Dr Matt Hoghton**

RCGP Clinical Champion for Learning Disabilities

**Dr Graham Martin**

Intellectual Disabilities Lead, RCGP Health Inequalities Standing Group

**The RCGP clinical priority programme sits within the Clinical Innovation and Research Centre of the College. Learning disabilities was selected as one of the RCGP's clinical priorities in 2009.**

A three-year programme of work began in January 2010 aimed at raising the profile and awareness of learning disabilities within general practice and among the wider primary care community. One of the most important aspects on which we have collaborated since that date has been to promote and enhance the provision of an annual health check for every adult with a severe and moderate intellectual disability.

Now that the English directed enhanced service (DES) has reported on three annual cycles, and with Primary Care Trusts (PCTs) passing on their responsibilities to clinical commissioning groups (CCGs), it seems a good time to take stock of progress towards the goal of all adult patients with intellectual disabilities (ID) being offered an annual health check by their GP.

PCTs have been sending their data to the NHS Information Centre for analysis, and the Improving Health and Lives (Learning Disabilities Observatory organisation) (IHAL) has been

reporting annually on the uptake of health checks for adults with ID by PCTs in England since 2008–9. The full results for your own PCT may be found at [www.ihal.org.uk/gsf.php5?f=11295](http://www.ihal.org.uk/gsf.php5?f=11295) (the number of people with intellectual disabilities receiving a health check in 2010–11 as a proportion of people with intellectual disabilities).

In England, in 2010–11, the reported uptake by PCTs varied from 5% to 87% of those eligible; average uptake increased by 8%, from 41% to 49%. Three PCTs are to be congratulated on managing to achieve >80% of their target population receiving an annual health check this past year.

Although target populations show some variation, the prevalence of ID in England ranges between 0.3% and 0.48%; average 0.35%.<sup>1</sup> Given this prevalence an individual GP could probably offer and check eligible patients on the learning disabilities register in one annual session, working with a practice nurse, or specialist learning disability nurse. Advice regarding the process of health checks for patients with ID is available from the RCGP.<sup>2</sup>

CCGs will wish to take steps to narrow their local health inequality gap by addressing this issue

and improving the quality of service provided in this area. DES health checks attract reimbursement. There is statutory responsibility (i.e. via the public sector equality duty) to ensure that public bodies and providers make reasonable adjustments for people who are disabled; the provision of an annual health check for each adult with ID would be regarded as such a reasonable adjustment. In addition to reducing the health inequality gap for our patients, an energetic drive to bring all localities up to the level of the best performers is desirable.

To achieve this, commissioners with responsibilities for their population with ID should consider:

- 1) Creating a group involving the PCT/CCG ID commissioner, Community ID Team and local GP Champion
- 2) Monitoring monthly practice figures for the number of annual health checks completed and circulating this data around practices
- 3) Focusing on practices with a large number of patients with ID
- 4) Providing support and training on how to carry out the first check
- 5) Providing alternative providers who can conduct annual health checks, preferably in the GP surgery, if a practice continues to decline to offer this service to its group of eligible patients.

**A poultry farmer was concerned about the poor performance of his laying hens. He obtained an ostrich egg and put it where all the hens could see it. 'Keep your eyes on that and do your best', he said.**

The RCGP has just published draft commissioning guidance with IHAL (Learning Disabilities Observatory) to help commissioners address the health inequalities faced by people with ID. [www.improvinghealthandlives.org.uk/publications/1020/Improving\\_the\\_Health\\_and\\_Wellbeing\\_of\\_People\\_with\\_Learning\\_Disabilities:\\_An\\_Evidence\\_Based\\_Commissioning\\_Guide\\_for\\_Emerging\\_Clinical\\_Commissioning\\_Groups\\_\(draft\).](http://www.improvinghealthandlives.org.uk/publications/1020/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence_Based_Commissioning_Guide_for_Emerging_Clinical_Commissioning_Groups_(draft).)

## References

1. Emerson E, Copeland A, Glover G. *Health Checks for Adults with Learning Disabilities: 2008/9 to 2010/11* Bath: National Development Team for Inclusion, 2011. [www.ihal.org.uk/publications](http://www.ihal.org.uk/publications).
2. Hoghton M and the RCGP Learning Disabilities Group. *A Step by Step Guide for GP Practices: annual health checks for people with a learning disability* London: RCGP, 2010. [www.rcgp.org.uk/pdf/CIRC\\_A%20Step%20by%20Step%20Guide%20for%20Practices%20\(October%202010\).pdf](http://www.rcgp.org.uk/pdf/CIRC_A%20Step%20by%20Step%20Guide%20for%20Practices%20(October%202010).pdf).

## Research Ready self-accreditation for UK practices

Research Ready is a web-based self-assessment tool covering the minimum requirements for practices undertaking primary care research in the UK. It has been developed in conjunction with the NIHR Primary Care Research Network.

**Research Ready is aimed at practices taking part in research as well as those that wish to become involved in research studies. There are currently over 800 accredited and 1300 registered Research Ready practices in the UK.**

Practices are required to meet criteria based on the Research Governance Framework and provide details

on their practice demographics and research interests. Practices will also be provided with information about research opportunities.

The scheme has a one-off charge of £150 for a three-year period of accreditation.

**More information is available at: [www.rcgp.org.uk/researchready](http://www.rcgp.org.uk/researchready).**

## RCGP Research Paper of the Year Award: call for nominations

**The Research Paper of the Year Award is now in its fifteenth year. A number of new award categories designed to highlight the excellent research across primary care will be seen in 2012: diabetes; mental health; stroke; dementias and neurodegenerative diseases; cancer; and medicines for children.**

According to Prof. Helen Lester, Chair of the RCGP Clinical Innovation and Research Centre, 'The fifteenth year of the RCGP Research Paper of the Year Award promises to be the most exciting so far. The introduction of six new award categories means we are now better able to celebrate the richness of research excellence in primary care.'

The sub-category winners will be announced in early summer 2012; each will receive a prize. The overall winner, selected from the sub-category winners, will be announced at

the awards ceremony, supported by Novartis, in June 2012. The authors of the overall winning paper will also be invited to present at the RCGP annual conference.

Papers may be submitted either directly by their author(s) or be nominated. To be eligible, the paper must:

- relate to a research project in general practice/primary care undertaken within the UK and/or the Republic of Ireland
- have been published in print in a peer-reviewed journal between 1 January and 31 December 2011
- have at least one author who is an active GP.

**Deadline for submissions: Wednesday 29 February 2012.**

**To nominate a paper or for more information, please visit: [www.rcgp.org.uk/circ](http://www.rcgp.org.uk/circ) or email: [circ@rcgp.org.uk](mailto:circ@rcgp.org.uk).**

# Recognising rare diseases: Alström syndrome as a case study

**Dr Mike Hales**

Programme Manager, Alström Syndrome UK

What is a rare disease? Defined in the USA as one that affects <200,000 of the population and commonly in Europe as <1 in 2000 patients, a few rare conditions will be seen in a GP's practice lifetime.

Whichever definition, there will be a spectrum of conditions ranging from rare to very rare. Cystic fibrosis is rare, affecting about 1 in 6000 people in the UK, while Alström syndrome (AS) affects only a handful. Many GP practices may therefore have several cystic fibrosis patients but few with even one very rare disease like AS. Nevertheless, with more than 6000 'rare' diseases, every GP is almost certain to encounter one such condition more than once in his or her career. Furthermore, since many are genetically transferred, geographic hot spots may occur in patient groups that through culture or circumstances tend to intermarry. Ignorance or denial of the risks is widespread, even among the highly educated.

Diagnosing cystic fibrosis is not difficult – symptoms are well known, family history is easy to discuss and genetic tests are available if there is doubt. Rarer conditions are too numerous to teach individually in medical school, may appear only once in a GP's lifetime and may easily be misdiagnosed. Unsurprisingly, they are often not recognised until well developed – missing the opportunity for early intervention. Alternatively, access to web knowledge bases, burgeoning patient registries and patient support groups can be of great help. After diagnosis, use can sometimes be made of specialised NHS commissioning provisions.<sup>1</sup>

This article uses AS as an exemplar of the challenges and opportunities presented by a very rare disease.

AS is an autosomal recessive condition caused by mutation of the ALMS1 gene. It is one of a group of rare diseases classed as ciliopathies in which the affected gene(s) compromise cell cilia. Bardet-Biedl syndrome, polycystic kidney disease, primary ciliary dyskinesia, and nephronophthisis also form part of the group, with more categorised all the time. This has prompted clinicians and individual patient groups to come together to foster research and focus support.<sup>2</sup>

Ciliopathies sometimes exhibit common features – particularly loss of sight or hearing. AS is unusual in being caused by a single gene mutation while still affecting almost every organ in the body. Typically, nystagmus and photophobia develop in the first year due to retinal dystrophy, leading to blindness in childhood or young adult life. Infant cardiomyopathy occurs in 30%, but apparently recovers in many cases. Other features include obesity, insulin resistance with acanthosis nigricans and sensorineural hearing loss. However, such unpredictable complications may not be linked with earlier retinal problems until adulthood when cardiomyopathy (recurrent or *de novo*), renal impairment, hepatic fibrosis,

diabetes and hyperlipidaemia can occur, making the diagnosis more obvious.

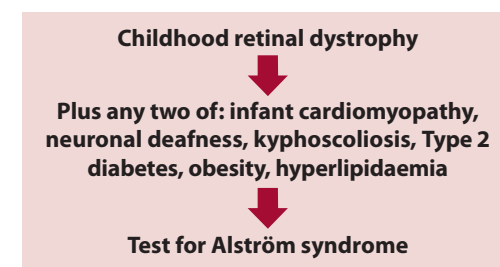
Unsurprisingly, this daunting list of complications leads to reduced life expectancy and compromises quality of life, also placing a major burden on parents of children with so many physical and emotional needs. Though there is no specific therapy, careful management for diabetes, hyperlipidaemia, renal and cardiac dysfunction improves the journey for both child and parent. Preserved intelligence has enabled some to complete a university education and go on to work. Such successes depend upon best medical care following a correct diagnosis, together with social and educational support.

Identifying AS is challenging. Features appearing individually are often treated individually with referral to a specific symptom-oriented specialist. Often it is only holistic observation that allows a causative diagnosis to be made; the GP is often best placed to do this.

Knowing and treating a family enables links to be made with relatives, who possibly have a similar set of problems or history of infant death due to a heart condition. In common with other recessive conditions, AS is especially prevalent in ethnic groups where consanguineous marriage is a tradition. Tactful questioning about similar issues can sometimes help to diagnose not only the attending patient but also perhaps alert a similarly affected member of the wider family.

There is an opportunity for prompt diagnosis of AS by association of unexplained disparate conditions in a child or young adult. Moreover, being a single gene condition, confirmation can be obtained from a genetic test.<sup>3</sup> In this respect it is a model for rare disease awareness.

The following decision chart can help.



**Source:** with acknowledgement to Dr Richard Paisey, South Devon Healthcare NHS Foundation Trust, Torbay Hospital.

The charity Alström Syndrome UK (ASUK)<sup>4</sup> provides whole-family support, information and guidance to treatment centres. Since 2006 ASUK has worked with Torbay Hospital, Birmingham Children's Hospital and the National Commissioning Group to provide regular multidisciplinary clinics. In 2009, with the same hospital partners and a world-leading research group at the University of Cambridge, ASUK was awarded a BIG Lottery Medical and Scientific Grant. One aspect of this is to raise awareness of the condition so that those affected will have access to the best medical care, social support and maximised life chances. BIG Lottery support is acknowledged for this article.

## References and further resources

1. NHS Specialised Services: [www.specialisedservices.nhs.uk](http://www.specialisedservices.nhs.uk).
2. Ciliopathy Alliance: [www.ciliopathyalliance.org](http://www.ciliopathyalliance.org).
3. Local regional genetics laboratory service or: Carol Hardy, Principal Clinical Scientist, West Midlands Regional Genetics Laboratory, Birmingham Women's NHS Foundation Trust, Edgbaston, Birmingham, B15 2TG.
4. Alström Syndrome UK: [www.alstrom.org.uk](http://www.alstrom.org.uk).

Rare Disease UK, the national alliance for people with rare diseases and those who support them: [www.raredisease.org.uk](http://www.raredisease.org.uk).

## Unique – supporting families with rare chromosomal disorders

**Dr Beverly Searle (CEO),  
Dr Jennifer Hague,  
Prisca Middlemiss**

**Unique ([www.rarechromo.org](http://www.rarechromo.org)) is a UK-based charity whose aim is to support families worldwide affected by a rare chromosomal disorder. Unique is a source of information for families and individuals affected by any rare chromosome disorder and for the professionals who work with them – GPs, paediatricians and geneticists.**

At least one child in every 200 is born with a balanced or unbalanced chromosomal

disorder. At least one in 1000 will have physical and/or learning difficulties. Affected children can also have complex medical problems, severe behavioural difficulties and dysmorphic features.

Having a child with a rare chromosome disorder can trigger lifelong stress and distress as well as an urgent desire to learn more about the disorder. As part of its services, Unique runs telephone, postal and email helplines for new and existing member families and medical professionals to find out more about specific rare chromosomal disorders.

Unique has developed and maintains a comprehensive database detailing the lifetime

effects of specific rare chromosomal disorders among members. At the end of October 2011 more than 8573 families worldwide, representing in excess of 11,000 individuals with a rare chromosome disorder, were registered, the vast majority being new cases never reported in published medical journals. New cases are being added daily.

We are keen to raise awareness of our charity amongst GPs, many of whom will at some point share the care of a child with a rare chromosomal disorder. Membership for medical professionals is free and provides access to information and support services,

including free online family-friendly information guides and articles; a helpline and email service for individual queries; and the provision of tailor-made information and help relevant to individual diagnoses.

We try to ensure that hospitals, doctors, health authorities, genetic clinics and other professionals are aware of our group so that early contact is available to families who need it. Please take the time to look at our website and get in touch if we can help in any way.

**Contact Unique on 01883 330766 or at [info@rarechromo.org](mailto:info@rarechromo.org), or visit [www.rarechromo.org](http://www.rarechromo.org).**

# RCGP First5<sup>®</sup> courses in 2012

## Dr Clare Taylor

RCGP First5 Clinical Lead

The annual appraisal and, in the future, revalidation require all GPs to demonstrate continued learning throughout a professional lifetime. Following a survey of First5 members, the RCGP has developed and piloted a series of courses specifically to meet the educational needs of GPs in the first five years after training. However, the courses are not exclusive to First5 GPs and any RCGP member, or non-member, is very welcome to attend. Each course has around 30 delegates and a single facilitator – which allows interactive learning to meet the needs of individuals.

### First5 Leadership

First5 Leadership is a one-day course that combines the theory of leadership with practical ways to apply it in everyday practice. Leadership skills are vital to ensure new GPs feel empowered to play a key role in the practice team and local healthcare system. The first part of the day focuses on understanding the qualities of a good leader, describing different leadership styles and identifying delegates' own styles, understanding sources of power in a practice and knowing the effect of different leadership styles on the team. The afternoon covers the practical skills of being a leader including how to make a difference as a leader, how to chair a meeting, effective decision making and managing difficult behaviours.

### First5 Practice Management

Practice management was the number one learning need identified in the First5 survey. This one-day course addresses key aspects of practice management by focusing on two key questions: how does a practice work as a business and how can a First5 GP influence and improve the way a practice is managed? The first half of the day covers key knowledge areas such as how money flows into the practice (global sum, QOF, DES, LES and other acronyms!), how practice partners and staff are paid, and the important balance between maximising efficiency and valuing each team member.

The second half of the day explores the importance of robust planning activities in order to keep the practice on course, considers what internal and external drivers for change exist and how practices can take the right opportunities at the right time. Delegates will learn practical techniques for being a successful change manager, anticipating potential difficulties, how to help the team to start doing things the new way and the importance of celebrating quick wins.

### First5 Becoming a Partner

Partnership is a career position that many new GPs aspire to, but achieving this can be challenging in the current climate. There are many career pathways (salaried, locum, academic, etc.) that are fulfilling but, in the First5 survey, new GPs expressed a wish to know more about what is involved in being a partner and how they might go about making the leap from trainee or sessional GP to partnership. This one-day course is designed to specifically address these issues. The day starts with discussing delegates' ideas about being a partner and what they might bring to the role, then explores the key things that are essential to find out when looking for a partnership. The afternoon session gives very practical tips to help new GPs sell themselves in a CV, perform well at interview and also addresses the things to consider before saying 'Yes' to any offer.

### First5 Advanced Consulting Skills

The training years equip new GPs for consultation but this skill continues to develop over a lifetime of practice. New GPs may be keen to develop their own consulting style, wonder how they can successfully keep to time and how safely to manage the patient who comes with a list. This two-day course, run by Dr Roger Neighbour, past-RCGP President, addresses these issues and more in a friendly, interactive environment. The course has been very popular with past delegates: 'Absolutely excellent. Pitched at exactly the right level. Will change the way I practise.'

### First5 Commissioning

The world of commissioning is new to most First5 GPs and with the ever changing political landscape can seem at times bewildering. This one-day course introduces the concept of commissioning and its potential relevance to the First5 GP. First5 Clinical Commissioning Champions explain both the theory and give real-life examples of what clinical commissioning might actually look like. The focus is on the vital role of commissioning within healthcare systems generally rather than the pros and cons of the proposed changes to health care in England, so is relevant to a wide audience.

### First5 Presentation Skills

First5 GPs may need to present to colleagues, to medical students, in a job interview or to patient groups. Developing effective presentation skills early in a GP career can be a real asset. This one-day workshop limited to 15 participants is specifically tailored to First5 GPs and aims to prove the apparently simple concept that we all present best when adopting a positive, conversational style. In other words, our personality comes over well and our listeners find our message easier to digest when we are ourselves. Vital to this concept is analysis of normal conversation. The objectives of the course are to give participants an understanding of the principles of effective presenting, the confidence to present their ideas with clarity and conviction, to encourage participants to be less reliant upon visual stimulus when presenting and to show participants how to get the maximum impact by taking control of the presentation process.

### Book now

- *Leadership* – 16 February, Maidenhead/ 1 March, Newcastle/20 July, London
- *Becoming a Partner* – 2 May, Edinburgh

- *Practice Management* – 16 May, London/ 17 October, London
- *Advanced Consulting Skills* – 6–7 June, London/26–27 September, London

Book online at [www.rcgp.org.uk/courses](http://www.rcgp.org.uk/courses). You can also join our Facebook group 'RCGP First5'; follow us on Twitter @RCGPfirst5 or email us at [first5@rcgp.org.uk](mailto:first5@rcgp.org.uk).

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## Nomination for the office of President of the RCGP, 2012–15

At the Annual General Meeting to be held on Friday 16 November 2012, Dr Iona Heath will have completed her three-year term of office as President. Nominations are therefore now sought for the office of President, to serve for the three-year period, 2012–15.

Members of the College may propose another for election to the office of President. Such nominations, signed by 12 members in good standing, must be received by the Returning Officer no later than noon, 31 March 2012.

Nomination forms and further details may be obtained from the Returning Officer, 1 Bow Churchyard, London EC4M 9DQ, or by email from [jcheong@rcgp.org.uk](mailto:jcheong@rcgp.org.uk).

### Postal ballot

In the event of more than one nomination being received, voting papers for a postal ballot will be sent to eligible fellows and members during April. A single transferable vote system will be used for the election. Candidates standing for election will be informed of the results in the week before the Meeting of Council on 16 June 2012, when the results will be formally announced. The result will also be published subsequently in the *British Journal of General Practice*.

## Eric Gambrill Memorial Fund

Applications are invited for up to TWO Eric Gambrill Travelling Fellowships, to be awarded in spring 2012. The value of each award is £3000. Those eligible for the award will be fully trained and practising UK general medical practitioners.

In recognition of Dr Eric Gambrill's interest in general practice, education and travel, the

successful applicants will be expected to undertake a study or project as part of his or her professional career development.

The closing date for the receipt of applications is **31 March 2012**. Application forms and further information may be obtained from: **The Honorary Secretary to the Trustees Eric Gambrill Memorial Fund** Altyre House, Church Lane Grayshott, Hindhead, Surrey, GU26 6LY email: [vanessambmason@aol.com](mailto:vanessambmason@aol.com) [www.ericgambrillmemorialfund.co.uk](http://www.ericgambrillmemorialfund.co.uk).

## RCGP News invites your comments

### Please write to:

The Editor, RCGP News  
Royal College of General Practitioners  
1 Bow Churchyard, London EC4M 9DQ  
email: [rcgpnews@rcgp.org.uk](mailto:rcgpnews@rcgp.org.uk)



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