

NHS GENETICS EDUCATION CENTRE

UPDATE

Summer 2009



Centre wins continuing funding and will continue to pioneer developments in genetics education

Welcome to the summer edition of the NGEDC newsletter. We are pleased to announce that the NHS National Genetics Education and Development Centre won a competitive tendering process for funding for the next 5 years from the Department of Health. This will allow us not only to continue with our current work but also to look at new streams of work such as therapeutics and common complex conditions. We are producing new factsheets, powerpoint presentations and videos for both teaching and learning and will have some new 'stories' around some common conditions with a genetic component such as cardiac disease and cancer. Our work with colleagues in dietetics, medicine, pharmacy and nursing continues, developing learning outcomes and educational tools.

Our 'Teaching Genetics' courses have received excellent feedback and we are interested to hear of any other courses which would be helpful. We also welcome feedback on the resources available on the website or any suggestions for new resources. Please contact us at enquiries@geneticseducation.nhs.uk

Professor Peter Farndon, Director

Genetics education facilitators are here to support you!

The Centre now has eight regional Genetic Education Facilitators. The facilitators work part-time to liaise with and support local education providers in delivering genetics education, based on learning outcomes in genetics which the Centre has developed for a number of health professional groups. Examples include 'Genetics in Primary Care' (the Royal College of General Practitioners' curriculum statement) and the 'Fit for Practice in the Genetics Era' framework for nurses, midwives and health visitors.

NHS Evidence - the new home for information on genetic conditions

NHS Evidence, the new NHS information portal with its distinctive iris logo, was launched on 30th April 2009. It replaces the National Library for Health (NLH) which was established in 1999 to bring to the desktop of healthcare professionals the best available evidence in over thirty medical areas. NHS Evidence offers an improved search engine based on Microsoft FAST software, and is broadening the scope to include both clinical and non-clinical information. The Centre has been responsible for the Genetic Conditions Specialist component of the NLH since 2007. Renamed as NHS Evidence – genetic conditions, this specialist collection will continue to make a vital contribution to the new service. NHS Evidence can be found at: www.evidence.nhs.uk



This support includes the development of educational resources as well as the delivery of 'training the trainers' courses, illustrating educational approaches and teaching tools for providing clinically appropriate genetics education.

Hundreds of health professionals practise taking a family history

Sarah Downing and Nicola Drury, two of the Centre's Genetics Education Facilitators presented a workshop at the Primary Care 2009 conference on 'Communicating Genetic Information'. This workshop encouraged midwives and health visitors to reflect upon the relevance of genetics to their role and how they could incorporate appropriate genetics activities into their practice. Several hundred health professionals attended the session, which included an interactive family history drawing activity. The response from attendees was incredibly positive and the Centre's stand was subsequently inundated by health professionals seeking further information and educational resources.



Sarah Downing



Nicola Drury

Training sessions have been well received by healthcare educators who have subsequently reported increased understanding of genetics concepts, how they can be successfully integrated into their curricula and how they can be taught.

For more information about the Centre's work, or to contact your local facilitator, please email: enquiries@geneticseducation.nhs.uk

A keynote of the session were the video scenarios which will be available shortly from the Centre's website.

Study day for nurses highlights the importance of genetics and how to improve quality of care

To highlight the importance of clinical genetics in hospital and primary care settings, the East Anglian Medical Genetics Service, based at Addenbrooke's Hospital, Cambridge, organised a study day for local nurses of all specialities. Our aim was to give nurses a basic understanding of genetics and to help them identify patients and families who may benefit from a referral to a clinical genetics department. The presentations were given by local genetic counsellors and consultant clinical geneticist, Dr Joan Paterson.

We explained the role of the genetic counsellor, and demonstrated how to take a family history, assess cancer risk based on a pedigree, and consider ethical issues. New developments in cancer treatments were also discussed. The talks were supported with information packs and pedigree templates provided by the NHS National Genetics Education and Development Centre and staff from the Centre were on hand to answer delegates' questions and discuss the Centre's work. The packs and templates were extremely helpful teaching aids and well received by the delegates. 70 nurses from a wide range of clinical specialities attended, from breast care to urology. At the end we exchanged a completed feedback form for a certificate of attendance. Delegate feedback was overwhelmingly positive with many requests to organise another study day. We were grateful for the enthusiasm of local speakers - using 'in house' teams kept expenses to a minimum so there was no charge to those attending. This is so important when many nurses lack a study leave budget. We hope that nurses, from many clinical departments, will be able to improve the quality of the care they provide to the families and patients they meet.

Jacqueline Hodgkinson, Genetics Counsellor, Addenbrookes Hospital Cambridge



Supporting the genetics education of GP trainees

The Royal College of General Practitioners (RCGP) and the Centre have developed two resources to help GP trainees meet the learning outcomes specified in the new RCGP genetic curriculum statement 'Genetics in Primary Care'. These include an on-line e-learning resource (e-GP), and InnovAiT, a monthly educational journal. Both resources are available free to GP trainees and to members of the RCGP.

The Centre was invited to write a series of articles for Innovait based around the genetic learning outcomes, published in August 2008. Copies are available from the Centre, or can be downloaded from our website www.geneticseducation.nhs.uk/about_us/index.asp?id=93



eGP is a joint project between the RCGP and e-learning for Healthcare, made up of a series of interactive on-line learning modules. The genetics module contains ten sessions covering topics such as: taking and drawing a family history; interpreting family histories; communicating genetic information; and the genetics of common conditions. The sessions are presented using clinical scenarios. In each session GP trainees can complete self-assessment questions, with feedback tailored to their responses. Completion of the module is recorded in the trainee's e-portfolio, as evidence of professional development.

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If you would like any further information about either of these resources please contact Michelle Bishop: michelle.bishop@geneticseducation.nhs.uk

Courses for Regional Genetics Centres

Teaching Genetics: An update day for Consultant Clinical Geneticists

Thursday 10th September 2009, 10.30 - 4.30pm

Teaching Genetics: An interactive three day course
24th September, 29th October and 2nd December 2009

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Genetics in practice - Education: an education

Dr Paul Brennan, Consultant in Clinical Genetics

In the development of the UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare staff, the National Genetics Education and Development Centre and Skills for Health worked with a range of stakeholders. One of the stakeholders, Dr Paul Brennan, discusses his own experiences in implementing genetics education and developing competences within the Macmillan Service Development Project in Middlesbrough.



"I look forward to seeing the competency framework, then", said a buoyant woman from the nursing education department. Competency framework. The words were said with that look you see on the face of someone who has achieved a far greater understanding of spiritual life than you will ever be able to manage in your dark and sinful existence. "Oh of course" – I croaked – "I'm sure we'll have that done by the end of the month..."

In January 2004 I secured funding from Macmillan Cancer Relief and the Department of Health to spend the following three years piloting a Cancer Family History Service, based in Middlesbrough and covering a population of just over 1 million in Teesside, South Durham and North Yorkshire. A key component of the pilot – developed following a blue skies brainstorming stakeholder focus event – was 'education'. Our first plan was to pilot a new type of post: the Genetic Risk Assessment Practitioner ('GRAP'; we considered 'Cancer Risk Assessment Practitioner' but the acronym is a bit unfair). We recruited three GRAPs, all from a nursing background. Our first task was to educate them. Two of them had no previous genetics experience and we wanted to train them to be able to assess cancer genetic risk using information from family histories with a view to seeing people at a moderately increased cancer risk in clinic for consultation.

"Our first plan was to pilot a new type of post"

Designing an in-house bespoke training package for a small number of people is relatively straightforward, especially if you have access to educational materials from other activities that can be recycled and adapted. Genetics can become a very abstract concept and it was important to maintain clinical relevance as much as possible. Most of the foundation training took the form of 'chalk and talk' sessions followed by practical sessions supervised by a genetic counsellor. Introduction to the clinic setting was gradual (nurses do not usually sit in clinic seeing patients on their own) but within three months or so the GRAPs were starting to see their first patients. Working with a group of three people highlights the often big differences in learning styles between individuals and it is easier to adapt your teaching style in that sort of setting. One GRAP, though, still drops her blood pressure when we mention the word 'polymorphism'.

"Genetics can become a very abstract concept ..."

We developed a competency framework for the GRAPs to place their education in a professional and service development context. Doctors don't (yet) use competency frameworks, so this was a new and difficult challenge for me. It seemed like old hat for my nursing colleagues, though. It is not intended to be a proscriptive document (it runs to 16 pages) but the GRAPs use it as a guide to achieving a high standard service with highly competent staff. Such a framework, I learned, can be used in three main ways to develop staff's knowledge and skills: as

a formal appraisal system, using the framework to assess competency and identify training needs; as an individual self-assessment and reflection tool; and as a team training plan – where the lead professional can assess the whole team's competence and training needs, encompassing appropriate skill mix. I think I've got the hang of it now.

Our second plan was to roll out a new clinical service into a cancer network where before there was none. The service is very simple in concept: all cancer family history referrals are sent to the GRAP team for genetic risk assignment before any surveillance recommendations are made. Any referrals made to surveillance units and individual cancer clinicians are also diverted to the GRAP team. All we had to do was educate primary and secondary care about the importance of cancer family history, introduce the service and tell them how to use it. Three acute NHS Trusts, six hospitals, ten PCTs, countless millions of GPs, surgeons, oncologists, physicians, radiologists, practice nurses, ward nurses, Macmillan nurses, radiographers: all potential targets for our education raids.



We split primary care education into 'level one' and 'level two' packages. Level one training – two 40 minute presentations with a refreshment break in between – was aimed at as many GPs and practice nurses as we could reach. The first two sessions were part of PCT 'protected time out' days. They proved a great success and we reached 100 professionals. Feedback was encouraging. The other sessions were planned as stand-alone sessions. These were not my greatest hour. There is nothing more demoralising than standing in a lecture room on a dark mid-Winter's evening, talking over the rattle of sleet on the window to a small bunch of disinterested GPs who have really only popped in for an instant coffee and a sandwich on their way home.

“One unexpected issue... insistence by most PCTs that we reimburse them for one of their staff to attend a training afternoon.”

Very few of these sessions were well attended. We subsequently discovered that many of the invitation letters – which had been sent to practice managers for cascading within their organisation – were either unopened at the bottom of an in-tray or discarded. We solved matters by offering GRAP-led teaching sessions to individual PCTs in a more targeted way, usually in the form of a lunchtime seminar. The GRAPs first identified one willing 'link' professional in each GP practice who would be willing to organise a teaching session and later undertake 'level two' training. This person was usually a nurse and teaching sessions were mainly attended by nurses and a relatively small number of self-selected, interested GPs.

In the development phase of the project we consulted GPs and asked them what they wanted primary care's role to be in the service.

They suggested that one person in each GP practice should at least know a bit about cancer genetics and the process of risk assessment, how to help a patient complete a family history questionnaire and how to link with the GRAP team. The level two training package therefore provided a practical exercise in drawing a pedigree from a family history questionnaire, using cancer registries and other resources to confirm reported diagnoses and interpreting the family history using simple risk assessment tools (this material was recycled from an undergraduate web-based learning package that I had designed a couple of months before). We were impressed at the way in which most of the participants engaged in the process, and most felt that this had helped them understand the service and their role within it. One unexpected issue we encountered was the insistence by most PCTs that we reimburse them for one of their staff to attend a training afternoon, often to the tune of up to £200. We gave them £50 each and have heard nothing since.

“Maybe people just weren't interested. Or maybe they are sick of my voice. Education has been a real education.”

We have remodelled this training approach for secondary care, learning from our experiences with primary care. Most of the work so far has been with nurses, using lunchtime seminars. Doctors are more difficult to reach, but they do have formal 'grand round' teaching and I am about to embark on a series of case-based grand-round sessions to introduce the concept of cancer genetics and genetic risk assessment.

Of course, most of the teaching has been based on what we think the learners need to know in order to use our service efficiently. On the whole this has worked. However, my very deepest depression occurred earlier in the year when I decided to host a whole-day genetics update covering cancer, therapy, paediatrics and cardiology. Despite invited speakers, BMJ advertising and sponsored places the response was pitiful and I had to cancel the event. In part this may have been due to the venue in Middlesbrough (which is a wonderful place if you like chemical sunsets) but I wonder if it was also because I decided what the programme would be? Maybe people just weren't interested. Or maybe they are sick of my voice.

Education has been a real education.

Dr Paul Brennan
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