Contents

- HINOW Round-Up
- Solution or distraction
- 2012: a challenging year for health informatics
- Telehealth – for better patient care
- Changing lives through accessible technology
- The changing face of medical terminologies
- Shorter waiting lists and raised productivity
- Creating leaders of the future
- Interview with Paul Woolman
- A real rollercoaster ride
HINOW Round-Up

2012: A Challenging Year for Health Informatics. This is the title of an article from Jean Roberts which sets the tone for many of the contributions that are included in this issue.

Jean, director of UKCHIP and board member of the Faculty for Health Informatics, discusses the current health informatics climate and addresses many of the most important challenges: how information systems are becoming increasingly critical to the quality and safety of care and treatment and to the integration of services and how training and professionalism can better equip the health informatician to respond to these challenges.

Patient access to medical records is the theme addressed by Matthew Swindells (Chair BCS Health) in his article. The NHS Future Forum recommends that patients have a right to online access to their medical records: a move supported by BCS Health. Matthew discusses how health informatics professionals should respond. He points out that online access also gives an incentive for hospitals, in particular, to move more quickly with the implementation of electronic patient records. If commissioners implement a financial penalty for providers unable to provide this service, Matthew argues, implementation progress will speed up.

We have three articles reporting on events held by BCS Health Northern. We also have an interview with Paul Woolman from BCS Health Scotland. How about other groups sending us similar reports? Now we are electronic, we have the room to publish them.

‘Changing lives through accessible technologies’ reports on a BCS Health Northern presentation by Anne Stafford and Neville Bramhall on the work of three charitable organisations that are helping disabled or disadvantaged people who need help with IT.

‘The changing face of medical terminologies’, another BCS Health Northern contribution, describes a presentation given by Denise Downs, from the Department of Health Informatics Directorate. She talked about the reasons for coding, coding systems in use and the implementation of SNOMED as the coding system of choice for the NHS. She picks up other themes that we address in this issue, particularly the need for common coding for the transfer of information across professional boundaries without the loss of quality of patient data: essential for the effective integration of care and treatment across boundaries.

The third contribution from BCS Health Northern is ‘Telehealth for better patient care’. Dr Nicholas Robinson, from NHS Direct, discusses recent developments in telehealth and how these methods can improve patient care. Patients with complex long-term conditions, particularly the elderly, can benefit greatly from these techniques which can be cost effective. Dr Robinson presented some costs: £500 to call an ambulance compared to 13p for a web based assessment of a symptom.
In ‘Shorter Waiting Lists and Raised Productivity’ Paul Chapman, clinical lead for IT at The Rotherham NHS Foundation Trust, discusses the use of digital pens for entering data: part of their EPR project. He sets out the issues and how they dealt with them.

In his article ‘Creating Leaders’, Justin Whatling, Vice Chair BCS Health Strategy and Policy, discusses creating the leaders that will take forward the pursuit of clinical benefit. He argues that clinicians must lead the demand and use of better information and tools in order to rise to the challenges of quality, safety and improved patient outcomes. BCS Health is a partner in the eHealth Insider Clinical Chief Information Officer (CCIO) campaign. He discusses the role and some successes that are coming through.

We have two interviews. The first is with Paul Woolman, chair BCS Health Scotland and working with the Scottish Government in the eHealth Architecture Team. He comments on the role of BCS and the Scottish conference, the promotion of professionalism and the other big challenges of health informatics. He echoes many of the messages from other articles.

Finally we have an interview with Dr Julie Greensmith of the Intelligent Modelling and Analysis Group at Nottingham University. It covers her career and work, including that on artificial immune systems and emotion discrimination - A fascinating end to this issue and an inspiration to anyone working in this domain.
Solution or distraction

The NHS Future Forum, Chaired by GP Professor Steve Field, has recommended that patients should be given the right to access their medical records online. Matthew Swindells, Chair of BCS Health, considers how health informatics professionals should respond to this initiative.

The Times on December 23 led its front page with, ‘Patients get right to see medical records online’. The Guardian reported the same story on the same day and also reported on November 30, ‘Patients to access online medical records by 2015’ as part of their coverage of George Osborne’s autumn spending review. By the time this article gets published the Future Forum report should be available to the public and we will know whether it is true, but I’m reasonably confident that this smells like a government orchestrated briefing and will turn out to be true.

The medical profession is split with doctors like Dr Amir Hannan, a GP at Haughton Thornley Medical Centres in the North West, who have utilised existing tools to give patients access to their records, extolling the virtues of changing the relationship between doctors and their patients through total openness; whereas others have raised concerns about confidentiality, the patient's ability to understand what they read and the doctor’s right to record things in the record that they don't want the patient to see in the record.

However, some of the medical profession's objections seem to be based on creating spurious problems that they can then use to damn the initiative. One professor wrote to the Times on December 27 with the following, ‘If the entry code for patients is to be the NHS number, then how will the confidentiality of, say, women with depression who report marital/relationship difficulties be protected from access by the partners about whom they have spoken and who will often know this number?’

Who suggested that the records wouldn't be password protected? My bank account number and sort code are available to anyone to whom I've ever written a cheque. These are the first two details required to access my bank account on line. You then need two out of five confidential pieces of information to actually access the account and a further passcode to do any unusual transaction.

BCS Health threw its weight behind patient online access to their records in our response to the information strategy consultation and addresses the issue in the first eleven of our one hundred recommendations. Recommendation 6 read, ‘We recommend that care provider organisations should have an electronic patient record in place within five years. This should include the ability for patient remote access and work towards enabling record extracts for patient-held electronic personal health records.’

However, we did not treat this as an easy exercise and also made a series of recommendations around how to do it, to address reasonable public and professional concerns including: action on a standardised consent model for the sharing of records; guidance for the public on the safe handling of records; and that
commissioners should ensure that services are in place to provide support to the public in accessing and understanding their record.

You will also note that we referred to all providers of healthcare. It is worrying that in Lord Howe's response to the Future Forum recommendation the government are already trying to dumb down the challenge by applying it only to GPs saying, 'We fully support patients having online access to their personal GP records.'

The right for a patient to access their record online can be a key driver to encourage the hospital and community sectors to go down the road that most GPs have already travelled. Primary care in the UK leads the world in paperless medical records. The reason it has sustained is because it is better, safer and cheaper than the paper alternative.

If patients have a right to demand online access to their hospital and community records, if commissioners withhold payments from providers who don't offer this service and providers are free to find their own way to meet these requirements; providers will have to digitise their records in a way that delivers cost savings as well as high quality, which will mean redesigning healthcare processes, not just implementing IT - a key failing of the national programme.

The key point about access to the online record is that in itself it adds very little value. There has not been huge public demand for the access to GP records, despite the fact that this is technically available in a number of places, and international evidence, where this is quite commonplace, shows that people tend to access their record only occasionally.

The real opportunity is for a Personal Health Record that changes the interaction between the individual and the health service - increasing their rights and their responsibilities - and creates the environment for a 21st century end-to-end digitised health system.

Online access to the personal health record should not just be a portal to view the information a doctor would see, it should be a secure tool that integrates a set of genuinely useful functions for the patient:

- Bringing together the patient's record from multiple sources - GP, several hospitals, community services, ideally social services too - so that the individual is master of their own information.

- Offering the opportunity for the patient to take administrative work away from the NHS by allowing them to make and change appointments, correct their personal details and enter pre-appointment data, as we choose to do in so many other settings.

- And, most significantly, integrating to the clinical workflow so that it encourages and supports patients in managing their health and condition, providing prompts to the patient and alerts to the clinical team.
The NHS Confederation has recently argued that 25 per cent of the patients in hospital could be cared for at home or in a sub-acute setting; many studies argue that the number is even higher than this. An active personal health record, connected to home monitoring devices, capturing patient entered data and allowing rules based clinical pathways to be extended all the way to the home will be a key tool in this shift from a hospital based NHS.

Informaticians should embrace this policy, but also be concerned that it will become a one-off gimmick. As I have argued before, the current financial pressures are a key moment for informatics to demonstrate whether they are an overhead that can be cut when money is tight or an indispensable tool in creating a better, cheaper NHS. I believe passionately that we are the latter and that if we fail to demonstrate the truth of this the NHS will fail in the ‘Nicholson challenge.’ We should welcome this policy, push for it to be all the things it could be, rather than a short-lived press release, and focus on how we use education and technology to surmount the legitimate concerns about confidentially and exclusion.

The first eleven BCS Health recommendations in response to the government’s information strategy consultation

Information Revolution purposes

(1) We recommend that the information strategy is clear on the purposes of the Information Revolution and that they are individually approached with patients (and their care professionals) in the right way to achieve the desired outcomes.

(2) We recommend separation of the following purposes:

- enabling patients to become equal partners in their health care and take control of managing their own health;
- enabling patients to make choices about where, who and what health services to use, liberating the patients and incentivising providers to improve;
- creating transparency so that the public can hold the NHS to account.

Utility and patient engagement

(3) We recommend that the information strategy should encourage care providers to use technology and media as a tool to engage patients and the public in taking responsibility for their own health and wellbeing. The NHS should utilise existing technologies that people use on a daily basis and harness fresh and exciting technology, including web 2.0 approaches, to leverage social capital and to meet patients’ desire for better interactions with health and care systems.

(4) We recommend the development and use of decision aids that help patients weigh up their benefits and concerns in order to decide on how to engage in their health and care through the use of information and communication services and that
existing patient information standards, such as The Information Standard, are more widely publicised and adoption encouraged.

(5) We recommend that the NHS Commissioning Board contracts with NHS providers, the third sector, commercial organisations and others to develop, carry out and be recognised for performing roles as health ‘intermediaries’ and ‘navigators’ for patients and the public.

**Patient access to medical records**

(6) We recommend that care provider organisations should have an electronic patient record in place within five years. This should include the ability for patient remote access and work towards enabling record extracts for patient-held electronic personal health records.

(7) We recommend that work is carried out with patient and carer groups, and others, to simplify and make consistent a consent model (for information to be accessible to others) across England and liaise with other countries on the essential elements of a universal consent model.

(8) We recommend that further work is carried out to understand what patients want and expect in terms of ‘access’ and ‘control’ of their medical records and to use this as a basis for determining requirements. Robust and easily comprehensible audit trails of who has been accessing patients’ medical records are an essential, cost-effective tool for helping patients manage risk associated with sharing their medical data and should be implemented.

(9) We recommend that guidance is put in place on the safe handling of patient data for patients who are storing and sharing their personal medical data, including sample sharing agreements.

**Inclusion**

(10) We recommend that procurement contracts specifically address the needs of people for whom new ways of delivering the NHS through technology and information may not be naturally inclusive and that service redesign addresses the needs of those people.

(11) We recommend that the NHS partners with voluntary sector organisations to ensure that best practice in engaging harder-to-reach patient groups is firmly embedded in the information strategy implementation.
2012: a challenging year for health informatics

According to a recently circulated Department of Health document (Future Strategy Engagement Activity: Summary Report, Dec 2011), in 2012, health informaticians will need to ‘step up to the plate’ and not be backward in coming forward about the value that health informatics (HI) contributes to patient care. With this in mind Jean Roberts presents her own thoughts on the current informatics climate and proposes how health informaticians can improve their lot.

Healthcare in the home countries (and the NHS in England in particular) is in a continuing state of flux. The Health and Social Care Bill is not yet refined to an acceptable state. Structures for health and care delivery remain in confused transition. Underlying all this, patient safety must be maintained through recording complete, consistent, comprehensive patient histories, an accessible evidence base and informed decision making. According to various consultations and pronouncements during 2011, great emphasis has been put on systems solutions that can / should be able to deliver these requirements. It’s rare that public documents give appropriate weight to the fact that IT solutions are not magic and a workforce with appropriate competences and time are crucial but not sufficient to satisfactory design, development and delivery of these necessary tools.

In view of the currently amoebic (constantly shape-changing) organisational structures and the still pending information strategy, I predict there will be much pressure for role changing / job shifts in 2012. Individuals must do all they can to keep ahead. Health informaticians must take action to keep ‘street sharp’ – attend learned society meetings, read the trade blogs/journals and get their skills and domain competence professionally registered. NHS monitoring bodies’ future plans include the assessment of the adequacy of informatics resources (and are considering using numbers of professional registrants in an organisation as an initial proxy to indicate this). In the light of this, local operational organisations will need to start to review their own HI team capacity and capability and may need to consider selectively choosing whether to provide service(s) in-house, as a shared service or from a third party provision.

Pressures can be internal or external

Pressure for appropriate information and information handling across the spectrum of health (and emerging social) care can come from many angles. To meet such pressure requires specialist professionals to build interfaces, ensure there are robust sharing protocols and embed the principles of ethical (re)use etc in order to maintain records that are consistent and contemporaneous and that all data can be appropriately interpreted by authorised clinical practitioners and service managers.

Newspaper headlines such as the recent ‘NHS patients “will be able to view medical records online”’ imply imminent success; However, integrating primary, secondary and tertiary material and giving controlled access to each will take some
considerable time and require input from expert health informaticians amongst others to ensure such linkage has validity and utility.

There is a philosophical dilemma regarding whether data should be collated, with subsequent access by any authorised persons who can update the one shared source or whether live linkage should be (re)created on each cross-boundary access with updates being carried out on the original source. Issues regarding the necessary contextual material for decision making, minimisation of risk of inconsistent interpretation and the avoidance of ‘deadly embrace’ or inappropriate sequential amendments will need in-depth dialogue between domain-aware professionals and end-users to resolve.

Health informaticians assume that the clinical professionals they interact with are certified professionals, and the converse should also be expected from those who develop the tools and handle the data.

Sites such as the rapidly developing www.howareyou.com, www.patientslikeme.com and in-house facilitation of patient record access in primary care (epitomised by that in the Hyde GP practice (http://www.htmc.co.uk/) are slowly developing a population of competent citizens who expect ubiquitous health data access.

The NHS Futures Forum indicates that ‘The declaration of ‘no decision about me, without me’ must be hard-wired into every part of the system and every encounter between a patient and a healthcare professional’. That Forum also recognises that: ‘There has been too much focus on different parts of the system – GPs, hospitals, public health – and insufficient attention to how they all join up to provide the integrated care that patients need’.

Laudable words that will require considerable expert effort to design, develop and deliver, especially to cope with the complex mosaic of data requirements that will result from satisfying the patients’ choice aspect of ‘any qualified provider (AQP)’! Under AQP, provider organisations can be selective about which interventions and procedures they deliver. That will add significant complexity to the challenge of maintaining a holistic record or even managing linkage between multiple source records based in a plethora of different care providers (public or private).

The scenarios outlined above continue to require expert health informaticians who understand health policy and strategy, working alongside clinicians and NHS business managers who understand informatics capabilities, can communicate their needs/wants/desires, are released to do necessary acceptance testing on proposed solutions and who also support investment in informatics.

Discussion of third party/secondary use of patient clinical data continues to be contentious. Reassurance to individuals whose data is to be used and support to practitioners handling it can be given by stressing that such data use will only be used where legislative, ethical and professional practice are adhered to – another area where certification through common registration standards can contribute to reassurance.
HI successes

Initiatives can be highlighted that endorse the contribution of health informatics to care delivery, for example, the winning developments described during the e-Health Insider awards and practical demonstrations such as a recent telemedicine use in the South West, which resulted in the successful treatment of a premature baby without significant delay, expensive air ambulance transport and by expert (local) clinicians. Health informaticians should be instrumental in further promoting the value of such types of occurrence more widely in order to reinforce the need to bring their services from the ‘back office’ to support the front-line in 2012.

2012 is the year Health Informaticians should step out of the shade

In this time of exciting potential and continuing fluidity, the health informatics resource, located in vendor organisations, third-party / secondary user organisations (infomediaries), academia, or in in-house service providers must work consistently under the same professional standards and code of practice. The health structures, through which public safety and patient respect is maintained, will continue in a state of flux for a considerable time to come.

Effective information handling needs to be ‘agile’ to support care delivery, tactical facilities operation and health (and social) care strategic planning in order to be efficiently delivered on an ongoing basis. Therefore, you should take pride in your health informatics identity, stand firm on the need for good practice and promote the added value of informatics in health.

About the author

Jean Roberts is a time-served health informatics consultant, Director (Standards) for the UK Council for Health Informatics Professions and is also on the Board of the UK Faculty of Health Informatics.
Telehealth – for better patient care

With the words telehealth, telecare, and telemedicine being bandied about so much these days it was perhaps apt that Dr Nicholas Robinson, Associate Clinical Director, Long-Term Conditions & Telehealth, NHS Direct, gave a talk about telehealth to the BCS Health (Northern) Group. Tom Sharpe reports.

As well as holding the post of Associate Director for Long-Term Conditions and Telehealth, Dr Nick Robinson continues to work as a GP two days a week, so he is aware of the reality of conditions in the NHS. His seminar set out to describe current developments in telehealth, and to discuss the motivation for using these methods to improve care for patients.

‘Telehealth’ simply means ‘looking after patients remotely’ (from the Greek ‘tele’, meaning ‘at a distance’). Dr Robinson revealed that the first known use of telehealth was described in the Lancet in 1879. Instances of remote consultation occurred throughout the 20th century, leading to the emergence of nurse call-centres in the 1970’s, and culminating in the UK with the setting up of NHS Direct and NHS Direct Online.

The case for considering techniques like telehealth is driven firstly by the changing demographic profile of the population. It is no longer uncommon for a patient, 100 years old, to receive care from her children who are themselves 80 years old. Another factor associated with longer survival is the existence of complex long-term conditions like hypertension, chronic obstructive pulmonary disease (COPD), arthritis, and mental health problems which together affect 30 percent of the population. A third factor is the reduced availability of health professionals, as both doctors and nurses take early retirement and are currently not recruited in sufficient numbers to fill the gap.

The so-called Kaiser-Permanente Triangle (or ‘pyramid of doom’) in the USA is a model for long-term care in which patients are grouped into three levels. Level-Three patients are the 5 per cent with multiple and complex conditions and very limited mobility who need expensive treatment under case-management. Level-Two patients are the 15 per cent who are at high risk and suffer from diseases like COPD, but who can be managed at home with substantial professional support. Level-One patients are the remaining 80 per cent who may be starting to suffer from problems like hypertension - these are potentially serious, but can be managed by self-care with minimal professional support.

Outside of the triangle are those in the general population who are not yet ill. But it is very important to encourage them (by initiatives like the NHS Health Check Programme [1]) to follow a lifestyle which promotes ‘better health’. This, along with regular health-monitoring and early intervention, should keep them out of the triangle for as long as possible.
Long-term conditions are those that are progressive, incurable and need on-going care. They include arthritis, diabetes, heart failure, COPD, mental health problems, dementia, renal failure, cancer, HIV/AIDS and certain other conditions, accounting in total for 65 per cent of deaths worldwide.

Patients, especially those suffering from these conditions, want to feel that they are safe in their own homes and that someone will notice if they need help. They want information about their illness and the medication they are taking to control it. They now also expect to be able to contact NHS Services at home, or at work, at any time of the day or night.

One way the NHS can improve the patient experience is to offer better pathways, e.g. to ensure continuity of care from hospital admission to discharge and care at home. The ‘30-day support- after-discharge for planned admissions’ is now becoming mandatory: this will be the case for all admissions from April 2012.

The need for long-term support in times where resources are limited opens up the possibility of using telehealth techniques. There is a good evidence base for using them to support chronic-care management, involving patients in their own care, and supporting them by giving them the means to learn about and monitor their own condition. Perhaps surprisingly, there is less evidence for case management, evidence-based care-pathways and sharing data between organisations. The evidence comes from a number of sources, but will be underpinned by results from the King’s Fund Whole Systems Demonstrator Action Research Network [2].

Although virtually unchanged in the last 20 years, telehealth monitoring equipment is able to monitor blood pressure, pulse rate, blood-oxygen levels and temperature. Thus if a COPD patient has increased heart-rate and temperature, and reduced blood oxygen, a message can be sent electronically to a call centre for evaluation. The call centre may then refer the problem to nurses to handle and the GP will later be informed that an intervention has taken place.

Currently 10,000 patients are being monitored by telehealth where the focus is on congestive cardiac failure (CCF) and COPD. Some of the challenges to the success of the project so far are that it does not operate 24/7; patients with various disabilities are excluded; patients are only covered in the home; and clinical engagement has been limited.

Telehealth does seem to offer clear benefits to patients by helping them to stay healthy and to know more about their own illness. The data collected is potentially valuable for research, although the volume of data generated (e.g. by continuous PO-2 monitoring) is challenging. Telecare has also proven its value and could be even more useful if integrated with telehealth. However, it will be necessary to convince both doctors and patients that telehealth offers focused services based on patient needs and is not just a cost-saving exercise.

Costs are a major issue. It is estimated that it costs £500 to call an ambulance, £25 for a patient to visit their GP, £20 to call NHS Direct, £10 to call the new 111 service
(due to replace NHS Direct), £1 for a telehealth ‘consultation’, but a web or app-based assessment of a symptom costs 13p. The patient uses the same decision support tools as the nurse to achieve a final disposition: less waiting, and cheaper!

This means that telehealth would be affordable for a condition like CCF, which affects 1 per cent of the population, but not for diabetes which affects 8 per cent. There are practical issues about exactly how connectivity would be achieved, e.g. would it be through a mobile device or through a broadband hub? If the latter, would it be through an existing domestic hub, or would a separate one need to be installed?

Results from a questionnaire given by North Yorkshire PCT to patients in their telehealth project [3] were positive, with three-quarters of patients saying that it gave them peace of mind and nearly two-thirds saying there was nothing they disliked about it. Perhaps surprisingly, only one per cent said they would prefer a nurse to visit.

**Issues and discussion**

Members of the audience voiced concern that the routine use of telehealth might reduce the amount of personal contact between the GP and their patient and damage the relationship between the two parties. As a GP, Dr Robinson felt that the concept of the doctor providing personal care was a thing of the past. Only with the help of technology would the GP be able to provide more focused care for the patient.

What can we learn from experience outside England? Telehealth has been very successful in Scotland, although it must be remembered that the population is smaller (six million) and more scattered so conditions are somewhat different. Also in Japan much use has been made of robotics to help care for an ageing population. It will be a challenge to introduce telehealth on a large scale in England because funding will be limited and, in the short-term at least, it will have to be run in parallel with existing systems.

Standards are likely to be another issue – four incompatible telehealth systems are known to be in use, though provided by a single supplier. It may be that standards will have to be imposed for telehealth in the same way that the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is to become mandatory for health records.

So while we await the results from the Whole System Demonstrator Action Network Project (WSDAN)* with interest, it does seem very likely that many, if not most, of us will be able to evaluate telehealth on a personal basis at some time in the not-too-distant future.
References

http://www.healthcheck.nhs.uk/  
http://www.kingsfund.org.uk – see WSDAN  
http://www.nytelehealth.co.uk/  

* WSDAN is managed by the King's Fund with DoH support and with the objective of evaluating telehealth in a practical context. It is claimed to be the largest randomised controlled trial of its type ever carried out.
Changing lives through accessible technology

IT can transform the lives of disabled people, especially those who are alone or housebound. With this in mind Anne Stafford, Manager of iT4Communities and Neville Bramhall, NW Organiser for ITCanHelp recently described the work of three related charitable organisations that match skilled IT volunteers with disabled or disadvantaged people in need of IT assistance at a BCS Health northern event. Dr Barry Speed, MBCS, MIET reports.

AbilityNet, ITCanHelp, and iT4Communities are changing lives through accessible technology, supporting disabled people with IT problems, and offering IT support to charities. iT4Communities, for example, started its life in the Information Technologists Company (a Livery Company in the City of London) and ITCanHelp, was formed within BCS. BCS is providing financial support for ITCanHelp as it settles into AbilityNet.

AbilityNet

AbilityNet (www.abilitynet.org.uk) has staff in five regional offices, located in large IT companies, for example, IBM, and Microsoft. With BCS representation on the board, it aspires to be the IT ‘Charity of Choice’. AbilityNet works to ensure technology is accessible to all, and aside from its volunteering programmes discussed here, it offers other paid-for services and works on European research projects.

One of the main points made by both speakers was the difficulty in reaching those who are most in need of help – the more disadvantaged or disabled tend to be more isolated, inarticulate and less aware of the possibilities of charitable help. If anything, AbilityNet has a surplus of volunteers and insufficient worthwhile projects for all the willing and skilled volunteers who are available. With some 500,000 small charitable organisations, 10 million people without internet access in the UK, and 10 million people registered disabled, the speakers felt sure there was an abundance of untapped need for IT assistance in the community. There was a general plea to assist with promoting the name of AbilityNet within communities, in the hope of raising awareness and reaching more of those in need of help.

iT4Communities

iT4Communities consists of some 8,000 volunteers across the whole of the UK, assisting small charities, community groups and social enterprises, with volunteers supporting over 250 separate charities a year. Some examples of volunteer projects include:

- setting up donated PCs in a school in Kenya;
- getting an environmental charity the database it needs to run effectively;
- helping a children’s charity have an easy-to-update website, thereby saving them expensive developer costs.
In total, iT4Communities volunteers deliver IT assistance worth some £0.6M every year.

**ITCanHelp**

The mission of ITCanHelp is to provide free IT-related assistance to disabled people in their own homes, whoever and wherever they may be, using a nationwide network of some 300 volunteers. The assessment-of-need is made initially over the phone, and ITCanHelp then matches a local volunteer to the person in need. There is minimum bureaucracy and very often everything is arranged with just a single phone call. The organisation maintains an extremely liberal view of disability, and as long as the person is in genuine need of IT-related help, which they cannot obtain from family or friends, then assistance will usually be given. In particular there are no assessments of disability carried out, and no assessments of device accessibility.

In the last year the organisation carried out around 1,700 assists, or an average of six per volunteer. For some reason the average is much lower in the North West, at approximately two assists per volunteer, and one of Neville Bramhall’s roles was to discover the reason for this and to promote a greater take-up – there is a danger that volunteers will leave if they aren’t given enough assignments.

An ITCanHelp volunteer in the audience gave an example of a typical ‘assist’, namely visiting a blind lady in Prestwich and enabling her to communicate with the outside world using the Internet and accessible tools.

**AIDIS**

A member of the audience described the Manchester-based organisation AIDIS, which also provides assistance with assistive technology to the disabled. All assistance is provided remotely over the phone using relatively few volunteers. AIDIS can be reached at www.aidis.org and the helpline is 0800 800 0009.

**Questions / discussion**

**Are the aforementioned charities able to give donations to those in need?**
No, but they are often able to refer to grant-giving agencies.

**Accessible software tends to be very expensive (eg Dolphin). Are there any open-source versions?**
This seems a good idea, perhaps using some of the volunteers, but none is available at the moment to the speaker’s knowledge.

**How do you manage where a volunteer has gaps in their skills?**
AbilityNet is able to give IT training to its volunteers.

**Do the volunteers have to be vetted?**
Yes, all volunteers are Enhanced CRB checked, and references are taken. This will soon be governed by the new independent Safeguarding Agency.
Do clients have to sign disclaimers and what happens if the assistance causes a problem or introduces a virus into the client’s computer?
Currently clients do not sign any sort of disclaimer, but this is under review. Problems caused by volunteers are extremely rare and all volunteers carry professional indemnity insurance.

Useful contacts

Any ideas should be forwarded to josie.ray@abilitynet.org.uk or 0207 796 2144.

Other contacts: anne.stafford@abilitynet.org.uk
The changing face of medical terminologies

SNOMED CT, which stands for the 'Systematised Nomenclature of Medicine Clinical Terms', consists of comprehensive scientifically validated content and is now available in more than fifty countries. It has even been adopted as the standard clinical terminology for the NHS in England. But it wasn’t always this way, as speaker Denise Downs, Implementation and Engagement Lead, Data Standards & Products, Technology Office, Department of Health Informatics Directorate, explained at a recent BCS Health Northern Specialist Group event. Rita Arafa reports.

We need to code in healthcare for the following reasons:

- to record accurately, unambiguously, and consistently – GPs can thus add patient information to the record that another medical practitioner can understand unambiguously;
- for fast data entry – a GP has ten minutes with a patient and doesn’t want to use a time-consuming data-entry method;
- to facilitate features in the software e.g. decision support, clinical alerts – the use of code speeds the links between GP systems and other systems such as ‘Map of Medicine’;
- to retrieve records;
- to analyse data – secondary uses of data;
- to interoperate between systems – Leeds University Teaching Hospital has over 200 different patient-data-systems. It would not be appropriate to replace all of these with one central database.

The NHS codes for a huge number of many variable reasons. For example, Leeds Teaching Hospital is using SNOMED in their emergency department. Six months after introducing it, audits showed a massive reduction, from 30 per cent down to seven per cent, in the number of diagnoses that were not being recorded.

Charles Gutteridge, Medical Director of Bart’s Hospital and the London Hospital is quoted as saying: ‘...using SNOMED CT is starting to facilitate clinical benefits for us locally in that we can categorise and analyse our patient treatment direct from the patient record ...’

Information standard...for all the NHS

SNOMED CT is the ‘terminology of choice’ for the NHS, but it is necessary to go through a long process to test and ensure it is safe to use in a patient setting. Suppliers have been reluctant to be the ‘first one’ to go live. We now have a full fundamental standard approved by the Information Standards Board (ISB) for SNOMED CT, and a number of suppliers use SNOMED CT within their application to code the clinical data. The plan is to only maintain one terminology after 1 April.
2015, and suppliers have been notified of this intention. However, the NHS is undergoing a consultation and the response to this will have a bearing on this plan.

The current situation is that there are a variety of different coding schemes that are used across healthcare. Using different coding schemes means it is difficult to share information easily, or to ensure consistent interpretation-of-use of that information.

In secondary care, paper records have been the predominant recording method where information is taken from discharge summaries and coded using ICD-10 and OPCS4 to produce national returns and HRGs (health resource groups). Every episode-of-care that goes through a hospital has to be classified, recording what a patient came into the hospital for and what was done to them. This information is coded so that trusts can get paid.

In primary care, records are already predominantly electronic; however, they don’t all use the same coding scheme. READ v2 is used in some GP systems, but it is getting to the point that one cannot add any more to it. Workarounds are being used as some hierarchies are already full, but this does not provide a long-term solution. CTV3 (READ v3) is designed to cope with multiple hierarchies, but new terms are inserted manually: as the terminology becomes more comprehensive this is not a practical option. A lot of work has been done on CTV3, but there is still a significant amount missing compared with SNOMED CT, and CTV3 requires a lot of work to maintain.

The NHS needs to be able to pass information between primary and secondary care, and to be able to record outcomes; even more so when the new commissioning structure is introduced. With the support of software, we can semi-automate the classification of patient records in SNOMED to the secondary care classifications.

Using one terminology would make things more cost effective. The future plan is to have SNOMED CT as ‘the method of recording clinical data that needs to be coded’ and to use this to support effective identification of the appropriate classification codes.

**Challenges**

A lot of the nervousness around how to report using SNOMED CT starts with the observation that, unlike READ, the code itself doesn’t tell you what the ‘ancestor’ and ‘descendent’ codes are. In READ, getting everything that’s a descendent of H33 is as simple as a string comparison:-

```
SELECT patients WHERE INSTR (code,'H33') = 1;
```

This approach doesn’t work for SNOMED CT as the codes themselves do not carry meaning, but it doesn’t work consistently in CTV3 either – so this isn’t a new problem or one that’s unique to SNOMED CT.
Translating from ‘this coding system to that coding system’ overnight is impossible in health. The healthcare environment is the biggest industry in the UK. Moving from earlier to future coding requires a phase with a ‘mixed economy’ and a transition stage, which we are now in.

Questions from the floor

Into how many languages has SNOMED been translated and who has the responsibility of ensuring consistency of meaning?
SNOMED has been translated into Swedish, French, Spanish, and Danish, and currently it is being translated into Polish and Lithuanian. So far, 15 countries have bought in to SNOMED, but not everyone has put in the effort to translate it to their language.

Is there a reference site and what will be the effect of the UK Government’s decision to lower the NHS Funding?
NPfIT started with a small set of deliverables which has grown as the programme developed. Some of the original requirements are now felt to be inappropriate, such as a single large Patient-record database. The culture is changing. What will be delivered nationally has to be of value nationally: it therefore needs a sponsor nationally. Ongoing funding is expected to come from a commissioning board, with standards work being accountable to the commissioning board.

2015 is the deadline for SNOMED-CT to be in place. Is this realistic or merely hopeful?
The NHS is currently authoring three terminologies, including SNOMED-CT, so every new code request requires authoring three times. The work depends on funding sources. The NHS won’t always pay for three-times-the-work so the way forward is to focus on ONE terminology as standard. Therefore there are pressures to do it. The suppliers have been given eight years notice so it is expected to happen, but the NHS won’t/can’t retire READ codes if it is proved a risk to clinical safety.

The world’s first mother and baby database (produced by me) included coding in ICD for operations and drugs. The situation might arise on a death certificate where 1a was caused by 1b, which was caused by 1c. Does SNOMED-CT make it easy to code this?
Yes. Concepts make it easy to give causes via closed lists.

It also covers social care terms. Has anywhere used this yet?
CTV3 (Clinical Terms Version 3) is being used in social care settings. SNOMED-CT is also being used in Birmingham re care-planning. People are looking at SNOMED terms for ‘end of life’ Care. Therefore there are current developments that use SNOMED CT in a social care setting.

Note: Some answers were from members of the audience
Some features of SNOWMED CT

SNOMED CT will support the ability to transfer information across different professions without the need to translate to a different coding system. SNOMED CT has already been translated into different languages meaning that, in the future, there is the possibility of transferring information internationally.

From a supplier's point of view, the fact that SNOMED CT is an international product means that systems they develop can be marketed in a number of countries that use SNOMED CT without having to redevelop them for different coding schemes, which is very cost effective. Also the different standards organisations can work collaboratively for their standards to be compatible, e.g. WHO and IHTSDO have a collaborative agreement to harmonise ICD and SNOMED CT.

Useful links:

UKTC website

Email for Data Standards help desk

NHS Networks – network name: SNOMED CT
Shorter waiting lists and raised productivity

The implementation of the SystmOne electronic patient record (EPR) system at NHS Rotherham was intended to make patient information available more easily to clinicians and carers, but created major challenges for some of the PCT’s community services organisation. Paul Chapman, Clinical Lead for Information Technology, The Rotherham NHS Foundation Trust explains how the Trust got around some of the problems by introducing digital pens.

The new system required all patient information to be entered via a keyboard, which was a fundamental change for services such as physiotherapy, where practitioners traditionally record a lot of information in drawings and diagrams. What Rotherham’s physiotherapists used to represent visually, for example in body charts, and with profession-specific notation symbols, now had to be described verbally (see figures 1 and 2).

As a result, they had to spend 40 minutes extra in administration time for each new patient they assessed. This was equivalent to two new patient appointments per day, resulting in fewer appointments, overrunning clinics and a rapidly growing waiting list.

The need for transcription and loss of profession-specific information also led to delays in data entry and a drop in the quality of information recorded, creating a source of clinical risk and potential litigation.

Finding a solution that works

To address these issues, the trust searched for a tool that would allow practitioners to capture the required information directly in electronic format, and ultimately help improve the process of entering physiotherapy data into the PCT’s shared database.

Having considered tablets, NHS Rotherham opted for a digital pen and paper solution from Ubisys, a specialist IT provider to the NHS. The technology, patented by Sweden’s Anoto Group, allowed them to write and draw as they had done previously without the need to then go and type up the information later.

The digital pens look and work like normal ballpoint pens. An infrared camera at the tip of the pen tracks its movements relative to a barely visible dot pattern on the patient form, recording and storing what is being written or drawn. After consultations, the pen data can be downloaded either via USB or, for field staff, via a mobile device. It is then sent to the Ubisys software, which immediately produces electronic versions of the documents in PDF, MS Word, XML and other formats. These can be added easily and quickly to the patient’s electronic record or used by other healthcare applications as required. The dot pattern can be printed on normal paper using a laser printer, along with the patient form itself.
This means physiotherapists can continue using the same forms and follow the same processes as before, with the benefit of an electronic version of their graphical notes being created at the same time as the paper version.

**Improved outcomes for all**

The digital pen and paper solution was quick to deliver benefits, enabling the physiotherapy service to meet its objectives for a more complete care record whilst increasing productivity and efficiency.

The physiotherapy service was able to recoup the 40 minutes per session lost through new patient administration after the introduction of the electronic patient record system. More importantly, using the digital pens has also helped increase consultation time with existing patients by 15 per cent.

Each clinician now has the capacity to see an additional three new patients and an extra five returning patients per week. Instead of having to wait six weeks for an appointment, patients can now be seen within three weeks.

Reduction in clinical administration allows practitioners to focus on the patient and quality of care, allowing more time for detailed subjective and objective examination. More time spent with patients means a reduction in the number of visits that need to be scheduled, as more can be achieved in a single session.

Overall, productivity gains of 35 per cent were achieved as a direct result of using the digital pen and paper system, with a return of investment in terms of increased clinic time within three weeks of its implementation.

In addition, the above outcomes have supported the physiotherapy service in meeting the requirements of the NHS QIPP (quality, innovation, productivity and prevention) agenda and the Commissioning for Quality and Innovation (CQUIN) framework.

**Reducing risk and stress**

The clinical information captured and stored provides an accurate and up to date record of history and treatment. The ability to add the information to the patient record immediately allows other clinicians to view clinically relevant information in real-time, ensuring patients are provided with the most appropriate care in a timely manner.

Thanks to improved record keeping the exposure of the service to clinical risk, and potential litigation, could be reduced significantly.

Beyond clinical and practical improvements, the introduction of the digital pens also had an impact on the clinicians’ working environment. While the physiotherapy team could see the benefits of electronic patient records, the complications associated with having to type up profession-specific information raised clinicians’
stress levels. As a result of working with the digital pens, staff now feel more in control of clinical time, less stressed, and have also highlighted the ability to return to a more personable approach in their work with patients.

**What next**

Following an initial pilot phase, the digital pen system was rolled out to the entire organisation, including clinic-based and domiciliary physiotherapists, at a cost of £14,000 for 25 pens and associated software.

In addition to 25 digital pen users in physiotherapy, another 150 pens have been introduced over the last two years to speech and language therapy, community elderly medicine, the Stop Smoking team, health visiting and school nursing. The organisations manage the system themselves in terms of designing dot pattern forms and providing ongoing technical support.

The digital pen and paper project at NHS Rotherham has shown that this type of technology can contribute significantly to enhancing staff productivity, financial savings and, ultimately, patient outcomes in the NHS.

Since NHS Rotherham’s community services were integrated into The Rotherham NHS Foundation Trust (TRFT) earlier this year, TRFT has been investigating opportunities for extending the efficiencies generated by the digital pens into other organisations. These include podiatry and the wheelchair service, along with social care providers and GPs. The trust is also in the process of digitising the personal child health record (PCHR or Red Book).

Figure 1: Example of form and way of recording non-textual information traditionally (and with the digital pen)
Figure 2: Equivalent form on SystmOne
Creating leaders of the future

Dr Justin Whatling, Vice Chair of BCS Health strategy and policy, explains the work BCS are engaged in to create clinical informatics leaders of the future.

In the BCS response to the NHS Information Revolution consultation in 2011 we made a clear recommendation that 'the chief clinical information officer (CCIO) role be created in NHS organisations to ensure that clinicians lead the demand and use of better information and tools'.

Along with the Royal College of Physicians, BCS was a founding partner in the launch of the eHealth Insider's Chief Clinical Information Officer Campaign in 2011. The campaign called for each NHS organisation to put in place a CCIO role to provide leadership on using information to improve patient care and a vital bridge linking clinical and information technology expertise. With several successful CCIO appointments already under its belt the CCIO campaign is aiming to provide a CCIO Leaders Network, which is due to be launched on 8 March by the Secretary of State for Health.

It was obvious to me as a practicing clinician over ten years ago that the pursuit of a career in IT would be fundamentally important to the improvement of healthcare for patients. Yet, like many others clinicians, I could not choose clinical informatics as a career in the NHS, like I could neurology or public health. We have to change this for the next generation of clinicians. The CCIO role is central to the professionalism of informatics in clinical practice. People enter careers where there are paths to follow.

We have generally failed to fuse our IT profession with our clinical profession. Our cultural and social development up to now has not helped and has created a false divide between IT and its 'real' clinical application. This must change. Information and informatics are fundamental to driving improvement in the quality of patient care and how we engage patients as equal partners.

Increasingly, information systems play a role far beyond administration and efficiency – they are material to clinical safety and a failure to exploit them is a wasted opportunity for clinical improvement. As such informaticians must be recognised as having a shared responsibility for clinical outcomes and are not 'merely' implementers of IT systems. Yet, understanding and using information well, and effectively, are skills that take a lifetime to acquire.

The best people to take control of information and information technology are the people who best understand the business of healthcare and what it does. It is time for clinicians and the healthcare profession to take informatics seriously.

The size of the challenge was brought home to us in our recent BCS commissioned research ‘Preparing for information being mission critical to the NHS’. The research identified that the greatest challenges to making the health system information driven are more cultural, social and behavioural than technical. The top two
challenges were perceived to be the organisational culture in the NHS and the resistance to sharing information. Whereas challenges such as patient and public confidence in data and increased time demand on clinicians and patients were rated much lower.

The exposure and transparency of information offers the greatest opportunity for a care revolution but we must prepare for it. However, we must carefully prepare for it. Herbert Simon, an American political scientist, said back in 1971 ‘a wealth of information creates a poverty of attention and a need to allocate that attention efficiently among the overabundance of information sources that might consume it.’ Put simply the risk of exposing lots and lots of information is that it could generate a paucity of attention to deal with it and maximise the benefit.

Thus behaviour and confidence in how the NHS uses information needs fundamental modernisation and renewal. There is a significant risk that both the NHS and the public will lack the capacity to process and make optimal use of information about health services.

So we must now develop our maturity, acting courageously to develop the informatics profession; nurture and grow skills and capability across the entire workforce; share existing good practice; and take a sensible, appropriate and realistic approach to the application of standards. It is in this context that the CCIO role is vital.

The issue of clinical engagement and leadership was highlighted by Frank Burns in Information for Health in 1998. Ten years later the Health Informatics Review again referred to the need for strong clinical and management engagement, and the development of informatics capacity and capability within the NHS workforce. We haven’t made enough progress.

In some countries such as the US, the concept of a chief clinical or medical information officer is common, generally reporting to the medical director, though sometimes to the CIO, giving a senior, credible clinician with responsibility for the success in the use of information and IT.

In healthcare IT deployments where success has been demonstrated, analysis shows that clinical staff have had process and financial incentives to become involved in informatics. There are positive drivers, too, to support the case for introducing CCIOs. In the US, the role has developed over the past two decades. One study found CCIOs had been able to set project expectations, support the selection of vendors, recruit other champions for IT-enabled clinical projects, contribute to design meetings and training programmes and direct go-live and support.

Successes are associated with strong clinical leaders, performing the CCIO role, who can engage with both clinical and non-clinical staff to show them the full benefits landscape, igniting enthusiasm for transformation, yet imparting a common-sense approach to problem solving.
Accountability is central - CCIO accountability becomes a lever and an authority to demand from others that they listen and respond - and in the case of other professionals a recognition that their judgement is on the same level.

Recognising clinical informaticians as professionals means they can be personally held to account for their practice outside of their employer/employee relationship. To support a just and fair accountability, they need to be capable, and supported by the infrastructure of a profession that enables them to live up to the responsibility.

It is the role of the BCS and the royal colleges to provide this environment. BCS has already created a draft job description which is being introduced into the NHS Careers Framework and is currently compiling example careers pathways to help clinicians understand how to get started developing skills and how to shape a career pathway in informatics.

If the right clinicians are to be attracted into the CCIO role, the NHS must now support a career pathway for clinicians interested in informatics and develop opportunities for clinically trained health informaticians to help harness the power of informatics to modernise the NHS.

References


About the author

Dr Justin Whatling is vice chair strategy and policy, BCS Health. Justin is also Chief Clinical Officer for BT Health and a visiting professor in health informatics at UCL.
Interview with Paul Woolman

Paul Woolman, who currently works for Scottish government in the eHealth Enterprise Architecture Team and is Chair of the BCS Health Scotland Group, recently spoke to Justin Richards about the BCS Health Scotland Conference he helps to organise, the state of health informatics today and the three biggest challenges health informaticians currently face.

Why do you think conferences like this one are important to health informatics?
Well, three years ago, when I took over chairing the group - because of my work in the NHS in Scotland and from reading a report about professionalism in health care IT and also from talking to heads of health care IT - I realised that they largely didn’t know about BCS at all. So the purpose of the conference is to really publicise the Chartered Institute and get the people on the ground, working in the NHS and in the IT arena, familiar with BCS, as an organisation, and then, hopefully, we can get them considering themselves as members and signing up for membership. And, along with that, we also want to promote the concept of professionalism within health care IT.

So what do you think of the state of health informatics at the moment in the UK – is it healthy – is morale good amongst health informaticians at the moment?
Health informatics is a wide branch combining health care in IT and health care information and also it combines the roles that individuals have. There are a lot of clinicians - doctors, nurses and allied health professionals - who are interested in information and what we call ehealth, which is the general applications of IT and information systems in patient care. There’s also the community of technologists – people who work in IT and the NHS and people who work in research. There’s a healthy academic community out there doing research into healthcare, information and IT. And then there’s a big supplier market. And what the conference does is to bring together the academics, the clinicians, the technologists and the suppliers and it creates a buzzing lively community.

What’s your own take on BCS’s Professionalism in IT programme and how it might impact the health sector?
Sadly I think people working in the health sector, like many other sectors, don’t necessarily have to have particular competencies in order to be employed. I think the concept of promoting professional qualifications and promoting professional courses that BCS is doing, and aspiring towards being a chartered IT professional, are all good things and ought to be there within the NHS in all the home countries in the UK. Sadly it’s not there yet and we need to create an environment and create relationships within the NHS, with their professionals, so that they actually want to have both BCS membership, but also the qualifications that you can get from BCS. We’re not there yet.
It’s a long path and, in the current climate (Sept 2011) of financial stringencies, savings, cost cuttings and head count reduction that the NHS is going through, it’s going to be more challenging to promote the idea of paying for qualifications. And, actually, I think it’s something that BCS could contribute to through its charitable status – one of its charitable aims is promoting professional development – it could do that more cheaply and easily for public sector workers.

**What are the top three biggest challenges facing health informaticians at the moment?**
The number one challenge is going to be cost cutting and trying to deliver at least the same level of services with fewer resources, and that’s very often reduced staff.

The second challenge is the continuing escalation of aspirations amongst clinicians and managers for new applications, for new clinical information systems and management information systems and that comes from both local managers, but also is directed by central government because they need management information. Delivering those new requirements in the face of diminished resources is another big challenge, as is trying to reduce those requirements.

And I finally I think managing with existing resources when those existing resources perhaps need to be retrained or need to be trained in new technologies and you can’t recruit because recruitment is almost non-existent in the public sector at this time. So trying to get people who’ve got skills in new technologies when you can’t recruit and you can’t train, those are the real challenging things.

One of the things that BCS Health Scotland is working on is delivering some training packages, some interesting lecture series, through remote technology like the webcasting technology we’ve used for this conference; so remote delegates can access lectures and training courses, almost for free, without having to travel. So the kind of lectures that BCS branches might put on at a local branch; we want to try and deliver those to remote delegates over the web.

**What are, in your opinion, the highlights of this conference?**
Well, we’ve just had the morning session so far – I think it was really great that the director general of the NHS in Scotland was able to open the event, (Derek Feeley was there), and I’m really looking forward to Professor James Barlow talking about the current activities in telehealth and telecare – I think that’s going to be good. But I think we’ve also got some really good speakers coming on tomorrow including a very interesting international speaker, coming from Estonia, to talk about health information technologies they use in Estonia and some other European projects that he works on. We try to mix European speakers with international speakers, with the local speakers here.

But we do the lighter side of things as well – we have a nice, fun reception event this evening and a conference dinner that a lot of people are going to enjoy, I hope; so I’m looking forward to the lighter side of the event as well.
So if you were trying to encourage someone to come to the event next year how would you ‘sell’ the event to them?
Well, this year and last year, we used an online social networking tool to help people to get a flavour of what the event is like and who’s attending. So we use a social networking tool for that called Videowiki. So I’d urge people to look out for that and I’d also urge them to sign up to the BCS Health Scotland mailing list and to join the specialist group, if they’re already a member of BCS. You can go to our website and join for free. And you will hear about the event and receive all the emails I send to people about the evening lecture series and everything else.

I would encourage you to register early as we’ve sold out delegate places two months before the event and, if any supplier wants to exhibit, they need to be in touch six months before the event because we sell out exhibition spaces that early. So the key thing I’d say to people is to book early!
A real rollercoaster ride

Dr Julie Greensmith is part of the Intelligent Modelling and Analysis Group in the School of Computer Science at the University of Nottingham. Here she talks to Justin Richards about her work and why computer science is such an exciting subject to research at the moment.

Can you provide some background on yourself (college years to present).
I started out as a pharmacology student at the University of Leeds. I was really interested in how drugs interacted with the body and the creative aspect of it – developing new cures for stuff. But I found the lab work was really quite repetitive and I wasn’t really very good at it. I was a bit fingers and thumbs and I wasn’t very good at following someone else’s procedure. I was quite good at coming up with my own processes, but when I had to follow other people’s procedures I was less adept at it.

During that time we had to use a lot of analysis software, which I found really frustrating and it didn’t work. My ex-boyfriend, who was doing a computer science degree, got fed up with me winging about the software and chucked his textbook at me and said ‘right, make one yourself, if it’s that bad!’ I did; I wrote my own analysis software for my own experiments in the lab. I could do all the maths so it was just a case of learning how to program, which I did - it was a hell of a lot easier than I thought, but because I’d never done it before I didn’t know that I could do it.

So I decided to take modules in computer science in the second and third year, which I did much better in than the pharmacology modules. I was in the top ten of the year for those modules that I took, which was really cool. I decided at the end of it that it was obvious that I should be doing computer science and not do pharmacology; hence I did a Masters in multidisciplinary informatics, which is a pain to write on every application form I have to do! It roughly translates as funky applied computing – it’s the application of computing to lots of different types of stuff. You view computing and computer science as a tool and then get your teeth into what the domain actually requires and match the two up. So it’s not being a bit of a mongrel, where a biologist is a bit of a computer scientist or vice versa, it’s learning to marry the two disciplines up. You actually do bridge the two and I learned the skills to do that.

Then for my PhD I studied biologically inspired computing. That involved the development of artificial immune systems. I worked with practical immunologists at the University of the West of England, in Bristol, and would build some models of how a particular cell in the immune system works and go down and get them to verify, experimentally, if the model was valid or not. If there were any questions, they would ask me, we’d discuss it until we got a good enough model, then I’d make an algorithm from that model and apply it to computer security; so using an artificial immune system to detect artificial pathogens, effectively. And that’s where the bulk of my research has been.
So you’re modelling the potential problems and also the potential solutions? Yes, that’s right. At the same time, because that’s what you need to do to develop anything that complex.

How would you describe an artificial immune system? There’s not just one artificial immune system – it’s not like a genetic algorithm – with an artificial neural network. There’s an archetypal one and then you have variations within that. Artificial immune systems aim to use metaphors of components of the actual immune system to perform computation, to solve problems in the engineering domain (it’s like a ‘double hot process’). However, the immune system is not just made up of a single immune cell. An immune system is a complex collection of what they call heterogeneous cell types – it’s got loads of different cells with lots of different properties solving lots of different problems in parallel, which gives you protection against pathogens. So there’s not an artificial immune system because there’s not an immune cell. So, therefore, what artificial immune systems are is a collection of algorithms, each one picking out the different properties of computation inherent in the different types of cell, which collectively form the immune system.

So could systems like this help to cure certain diseases? They are applied back to biology, but that’s just one of the applications that they are used for. They’re mostly used for applications that are ‘noisy, real-world apps that require error tolerance, require decision making and require adaptivity’ in their function. So, basically, any kind of complex, real-world, 21st century problem is where they’re coming in. Data is getting bigger, it’s getting messy, it requires correlation, it requires fault tolerance in our systems, because the systems are getting too big to monitor, so that’s where these kinds of algorithms come in, not for solving little toy problems in optimisation anymore.

Is that where your dendritic cell algorithm comes in? It’s one of them. It’s what we call the second generation.

Is that ‘dendritic’ in the old sense of the word – with different strands branching off? Yes, it’s an immune cell, which has an up-regulated surface area when it sees damage. It up-regulates its surface area for lots of reasons. Dendritic cells, to put it nicely, are the policemen of the body; they run around the tissue collecting evidence regarding the health of that particular tissue. And they also hoover up, through a process called phagocytoses, loads of protein molecules. So they’re checking if everything is kosher and then ‘eating’ all this other stuff and, if they see enough damage, they mature and go to a lymph-node where all the other immune cells hang out. They communicate with them, telling them where the damage is and what proteins they found nearby the damaged area, as one of those proteins has to belong to something that actually caused the damage.
So how do you actually model for that – without getting too technical?
Well, you stay awake for many, many nights…! You spend a lot of time on a train visiting immunologists, you look in the lab, you poke these cells, you see what happens, you hypothesise various ‘what if’ scenarios. It’s a really iterative process; it’s not a case of ‘you finding out some information and then making a model from it’. You start off with pen and paper, or as I did with bits of string, sellotape, bluetac and bits of coloured paper on a big sheet of A0 paper and then you put the different characters down and you make different components of your paper for different analysis and that’s how you generate the conceptual model, or that’s how I do it because I’m from the Blue Peter age!

Because you’ve got someone from the computer security domain trying to understand the usefulness of this model and you’ve got an immunologist sat next to you – how are you going to make these people talk together? You can’t really do it by showing the biologist an algorithm and you can’t really do it by showing some experimental results to a computer security guy so you’ve got to resort to basics. Everyone’s kind of done the old Blue Peter thing. So that was basically my role, to get feedback from these very different sets of people at the same time. Because of my history I spoke both languages.

It must be useful for you coming from a biological background, but also understanding the IT side of things too…?
Oh yes. Communication is the key part of any interdisciplinary stuff; if you don’t have someone who speaks both languages it must be really, really difficult.

Tell us a bit about your work on emotion discrimination for the entertainment industry?
It’s basically the incorporation of bio-sensing technology into computer interfaces; that’s where the proper, serious facing research is.

And how is it progressing?
It’s really coming to the fore. So what we do is to put people into different scenarios and see if we can physiologically measure their emotional state. Whether we can actually determine emotion or not, I’m not entirely convinced, but we can certainly discriminate between fear and enjoyment.

I suppose in the case of fear you can measure aspects of physiological change by monitoring how much sweat they produce and so on…
It’s not quite that simple – I wish it was. If you look at the characteristics of the GSR (Galavanic Skin Response), you can tell what a person is thinking from that – or at least how stressed out a person is. It’s never that simple – you need more data. This is where the artificial immune systems come in because they can process multiple streams of complex data that occur asynchronously. So you’ve got someone’s heart rate, you can stick a hat on them, (a bio-sensing kit, to measure their EEG and measure their brainwaves as well), which is pretty weird to look at, you can measure their breathing rate, you can measure how often they’re blinking, how often certain muscles are being activated – the smiley ones or the frowny ones, so you can tell the difference between that. Just looking at any one of those data streams in
isolation you can’t tell what the person is doing - just one of those standard time series statistical techniques is insufficient.

However, you can also measure the productivity of people; you can measure workplace stress of people. Products like this are already on the market and can be given to people. For example, to help those with bipolar disorder, to give them the ability to monitor whether or not they’re about to have an upper or a downer, then they can interface with the computer, which can then give them a program to calm them down, to cheer them up or just to bring them back to a more appealing state.

I like to use it in entertainment because, well, it’s fun and it gets me out of the office! Seriously though, rollercoasters were used, initially, to collect data since people thought that it was a constrained extreme response, because you need extreme responses, not just to test out an idea. So, for example, you can do sensory deprivation where someone just sits there in a room with ambient lighting, controlled temperatures, no windows, no sound, the room is soundproofed, and you can give them no stimulation and then you need something at the other end. But you need it to be reproducible – so just giving someone a shock isn’t really very good.

We didn’t like the idea of electroshock therapy in this case because that would affect the equipment. It’s all transmitted via Bluetooth and stuff, so it’s not cool. By sticking them on rollercoasters we thought it might generate a large enough effect for us to be able to see what’s happening. Plus it’s reproducible because rollercoasters are inherently temnistic, with the exception of one in the UK – Spinball Whizzer at Alton Towers, which is now called Sonic Spinball. They’re recently repainted it. It’s a Maurer Sohne construction one, like the rollercoasters at Blackpool pleasure beach in the late 60s, with the sharp turns, but the rollercoaster carriages are on a rotating base so you’ve got four people in the carriage and, depending on the weight distribution, that will determine how many times carriages spin at the different corners, and it also depends on who you’ve got in with you and how wet the track is and how hot the ambient temperature - you can a different ride every time. By carefully monitoring people on these rides, watching if they’re about to be sick and so on, you could lock down the degrees of freedom, as long as it’s suitably easy to replicate.

Who's funding this work?
The Engineering and Physical Sciences Research Council (EPSRC), primarily. They funded a feasibility study in order to monitor people on various different rollercoasters off the back of an initial event and now this work takes place under the blanket of Horizon Research and Digital Economy of which Nottingham is a hub. I think we’ve got something ridiculous like £18 million over the next five years. So we can apply for money and researchers through that and because this strand was central to securing the grant, they’re generally quite open to suggestion.

So are you funded by grants or are you funded by the university as a lecturer?
I’m funded by the university as a lecturer, which is nice – it takes the pressure off.
How long have you been lecturing for?
I’ve been two years in post – I’ve just had my two year party.

What aspects of the job do you enjoy the most and what parts are more difficult?
That’s a difficult question, but I really enjoy finding new ways of doing stuff. For example, developing complex analysis tools and thinking about how complexity can actually be applied. I think that’s pretty awesome because it’s hard. If you read some of the old complexity sites, which are full of abstract maths and physics, and then you look at something elegant like a bunch of starlings swarming off Aberystwyth pier and you think how amazing that is – we should really be able to fathom this activity using computational systems. I really enjoy thinking about that sort of stuff and then actually doing it.

Are your sponsors happy with the way things are going – do they set you goals to do?
You have deliverables and I generally deliver twice as many papers as I’m supposed to. I do enjoy writing – if I ever get bored of university I’ll have your job off you!

On your website it mentions danger theory. Can you explain danger theory?
Danger theory is the core theory of immunology from which we build our models, dating from a couple of years back. The classical theory of immunology is a bit like a lock and key scenario – in that the immune system is trained to respond to proteins which are defined as non-self; so you have this classical view of immunology which is the ‘self – non-self’ theory, which is very discriminatory. This theory stipulates that the human immune system is tuned and developed to mount responses against anything that are not belonging to self. The theory was that while you’re in embryonic development you sample enough proteins from your own body to build up a representative picture of self so the immune system is tuned by the deletion of anything that matched self to produce the detectors which would then go out into the body to detect anything that was non-self. And this theory stood for about 70 years as the central dogma of immunology.

But there are loads of problems with that theory because what is known as self changes over time and friendly bacteria in your gut are not part of self and yet co-exist there. Also, why do we get auto-immune diseases, which a lot of people have got, for example, rheumatoid arthritis, where the immune system attacks itself. So if it’s trained not to do that, why is it doing it? There are a lot of things the classical self – non-self theory can’t explain.

So in 1994 this rather wayward immunologist Polly Matzinger came along and said the immune system doesn’t respond to self and non-self, it responds to whether it’s in danger or not and the self – non-self thing is just another filter. So what it says is that you have an initial self – non-self path and then you have additional signals, which come potentially from things like bacterial sugars – so if you encounter these you pretty much can be sure it’s a bacterium, which is signal-based. Then you’ve got the danger-based model, which says if this protein is around when there’s
danger, then you should really respond to it because where there’s danger there’s often damage. So danger signals are generated when cells undergo necrosis as opposed to signals of tolerance that occur when cells undergo apoptosis, which is controlled cell death. If you’ve got a greater level of necrosis as opposed to apoptosis, then the immune system should either take a closer look or sort it out and send the boys in really! It’s the dendritic cells that relay the information ‘danger’ back to the central processors of the immune system in the lymph nodes.

The immune system gets it wrong from time to time though…and detects danger where there isn’t danger?
Yes, or it’s marginal…or the threshold on the direct current (DC) was too small or you get the ‘bystander effect’, which is how they think MS happens - which is where a person gets an infection, too much cell protein is taken in, the damage is seen at the same time as an invader, so the cells are presenting the two proteins. Both sets of protein are then responded against by the immune system. However, one was from a minor infection and one is yourself, therefore the ‘danger’ persists and the immune system keeps attacking it.

So the danger theory is not saying immune systems are brilliant, it says immune systems are flawed but they’re much more sophisticated than the classical ‘you’re either in or you’re out’ sort of ‘bouncer with a blacklist’ approach to immunology.

It’s still very controversial – the receptor for the detection of danger signals was only found about 18 months ago, so that’s about 14 years after the theory was first proposed. That’s why we like to try and model it because there’s a lot of work now being done in that area. Initially it was to try and disprove this lady’s theory, but now it’s a case of ‘oh, she’s kind of right, we were all kind of right, so now we need the evidence to back it up’. It’s a really interesting time to be working on IAS because immunology is changing really rapidly.

Was this what you were talking to the Bristol Branch of BCS about recently?
No, I was talking about the rollercoaster stuff because that lends itself much better to public engagement. Public engagement is what I’m supposed to do – it’s my admin role within the School of Computer Science and I’m school liaison for our department so I do a lot of stuff for school kids, but I somehow got involved in a lot of women’s groups, which gave me the opportunity to give a lot of talks on it and people have met me through that. They either ask me to talk about the role of women in computer science or they ask me to talk about the rollercoaster stuff. Because I’m trying to attract people into computer science or to say ‘look at the diverse array of applications, look at all the different things you can do with it’, I tend not to talk about the core research outside of academic circles.

I guess for a lot of people it goes over their heads fairly quickly…
It would take me half an hour just to put the background down. However, the majority of people, including the man in the pub, understand the basic concept of what we do, namely designing computer immune systems to help fight against computer viruses.
Do you think the IT profession’s reputation of being full of nerds and geeks is deserved and do you think anything can be done to improve this stereotypical image?
I think it was true initially, but it’s a very different world now. I’ve got this photo that I show in my slides, of Microsoft in 1979 and you should see the quality of the beards, they’re unbelievable! I saw it and thought, this is what people think we’re all like! But we’re really not. This is a difficult one – there’s no easy answer because there’s a number of factors.

So do you think this bearded, weirdy image still persists with young girls?
Yes. But I think it’s also a lack of confidence. If you watch boys and girls playing with computers, the boys will nearly always try and wrest the controls off them. I think most people still think that most of the people in IT still look like this (points to a photo full of blokes who look like George Lucas wearing sandals) – even the women look like they should have beards!

They’re like escapees from a hippy commune…
This is the fault of the industry attached to it. Obviously people have got a lot smarter and more professional looking.

You’re out there liaising with schools, which is obviously a good thing, but do you think the government should be doing more?
Yes, I think so, because computer science isn’t on the national curriculum. I do taster days for year 10 to year 13 kids, who come into our department and they learn some programming through Scratch, which is really visual, and graphic, nice and friendly and happy. They know how to do it, (it’s applied problem solving), but show me a class in school which has that… maths is really prescriptive now, technology is really vague and IT lessons are all Excel spreadsheets and Access databases and if you’re lucky, you get to do a webpage. But that’s not problem solving, using algorithms or even thinking about how you’d go about solving a problem. It’s either very subtle or it’s just not there.

We’re starting to get more girls taking IT ‘A’ levels, but the general numbers of students taking up IT are going down. It’s looking pretty bleak at school level, so I think the government really needs to step in if they want us to push forward in this sector in this country. And we’re actually pretty damn good at it, to be honest. They’ve got to start introducing IT somewhere in the national curriculum.

Do you think what puts some girls off is that they don’t want to be the only girl in the class?
They feel intimidated, yes. It’s really intimidating. I had that in my electronics class at school. But when you get to university level, it’s an advantage; everyone knows you and you get treated a bit nicer because you’re the girl. People actually remember your name and you actually get the personal touch at university. That’s what I found anyway, although it might have been due to the fact that I had pink hair!
It does shock me though, when I talk to these kids and ask them if they like computing and they say 'I like putting numbers into a spreadsheet' and I say 'really? I don’t!' That’s not what computer science is about! The problem with that is we have quite a high drop-out rate as a result, because you get students turning up thinking it’s going to be that and they get a bit of a shock when they find out it’s quite maths-intensive and it’s quite a lot of programming, as it needs to be in order to be a software developer.

It’s the same with the gaming industry – people don’t seem to realise that it involves a lot of programming and maths…it’s not just about pretty pictures.

**Going back to the issue of women in the IT industry – do you think the glass ceiling still exists?**

Sadly, yes. I like to get out of bed and believe that it doesn’t, but I know it does.

**Do you think that might change over the coming years?**

Yes, I hope so, but it won’t if there are not enough girls coming up from school level. If there’s not enough mass of girls, if there’s not a loud enough voice, then it won’t change. Unfortunately, I think the time at which career women reach the upper levels it’s right about the same time as that their biological clock has to tick, because you’re kind of running out of time. Many reach senior management level about 35. I personally have been too busy studying to do anything about that. But at the age of 35 you are faced with that choice – are you going to go into the boardroom or are you going to have a family? They say they’re increasing support for maternity leave and this, that and the other, but it’s all on paper.

I know from a personal perspective you’ve got to make a choice. So that’s possibly why there’s not so many female professors or so many women in the boardroom because, if you do go down the traditional career path, your chance to get into the boardroom will often coincide with that last chance to start a family. If you leave it any later, it gets more difficult – maybe the best way is to start a family at 17 and then get a good run at a career later on in life? I don’t know, that’s just one hypothesis. Another one is that women just don’t ask for promotion as much, they just don’t go knocking on the boss’s door as heavily as men do.

**What are your thoughts on professionalism in IT – do you think the government should get more involved or do you think industry should regulate itself?**

I’m averse to doing more exams – I think there are too many exams as it is! I think it should be experience-based – I think there should be some sort of points system where you get points for completing a really good project. I think the industry needs to self regulate, whereby the industry awards some sort of standards to completed projects – a bit like LinkedIn lets you recommend the work of other people – some sort of network like that, which enables you to recommend other people, would be far more useful than someone passing an exam.

I know some of the students that I’ve got can pass a programming exam, but can’t programme for toffee! I know some of my doctor friends have to keep studying in
order to become registrars, but I think, can't the assessors just follow you around and see how you are with patients and see if you're actually good enough. I think that would be a better approach. I know that lawyers and doctors have to do more exams to get chartered, but I don't necessarily feel that that's the right way.

I think there are some things, especially in IT, where it just come down to practical problem solving, which you can't really solve by taking exams, if you know what I mean?

I think it's a good idea to regulate – I think there are a lot of shysters out there – a lot of money for old rope, but at the same time I wouldn't like to see a situation where you had to pass one exam to be able to do this and another to perform another task. I just think that's a nice money-making enterprise for someone to run those courses.

Who were your role models that inspired you to get involved in IT?
I was quite gender-blind until quite recently – so it wasn't really a case of female role models. I was so stubborn about it, I didn't think my gender would mean anything. I just thought I don't need a female role model. I think, to be honest, I could have done with one looking back on it. But I'm trying to engage a bit better now.

So are there any male role models you aspire to be like?
Yes, there's a professor in Bristol, Dave Cliff, who's awesome. He hired me for Hewlett Packard and I worked with him for nine months. He was amazing – he just can't sit still, it's unbelievable. I like the way in which he can get on and do some really good stuff, but the way in which he can present it as well and the way in which he interacts with people and comes up with really original stuff and keeps coming out with more original stuff, and has a family, and goes running and all the rest of the stuff he does, it's really amazing.

Does he sleep?
I'm not convinced of it! I've seen him on Facebook at 2am, so I'm not sure.

What would you say have been the most exciting, most groundbreaking, changes in the IT industry over the last five or six years?
Mobile computing. It's completely changed society. It's introduced people to computing in a way in which they're not even aware that it's computing. I think that's awesome, because that's a revolutionary thing to do. To get people involved in something they're not even aware of and then it just becomes part of the language.

I mean my mum looks at my Twitter to see what I'm up to; if she can't reach me on the phone, she looks for me on the internet. It's so different from how it used to be. So I would say mobile computing and social networking via mobile computing have changed everything. I wasn't expecting it to be that big. I mean when you first got a camera on your mobile you thought it was such a white elephant, but now it's a staple ingredient. When the first Nokias came out with WAP on them, or something like that, and the internet took forever to open, we thought internet on phones would never work.
When I get into a school, as part of my talk about ‘computing is everywhere’, I get the kids to put their hands up if they’ve got a mobile and pretty much everyone puts their hand up. Then I say ‘keep your hand up if you’ve got a Smartphone’, and about a third keep their hands up, and these are 14-year-olds! There not like my lot, who you’d expect to have one – I don’t personally. So I think that is impacting the entire spectrum, that’s massive, and the development of apps for that has changed the business model for IT.

**What are the biggest challenges in your own sphere of study that you see will need to be cracked over, say, the next decade?**
Maintaining the security of these networks and devices is going to be a problem. Nobody has really gone to town so far on mobile or cloud security and this is where I see these complex analysis tools coming in.

**Quick questions**

**Open source or proprietary?**
Open source all the way. It’s also bogus when people, (like me a few years’ ago), say that proprietary is the only way to make money out of software. It’s not true – a friend of mine has done really well out of open source.

**Apple or PC?**
Apple, because they work. When I go home I don’t have to be a system administrator, but yet I can still tinker using my XLM terminal. But I don’t like their aggressive marketing policy.

**Wii, Xbox or Playstation?**
I love my Wii – I’m currently losing weight just by doing Just Dance 2 thirty five minutes a day; it’s brilliant. The interface is so innovative and I know that Xbox Connect is out and iMove Playstation is out, but Wii were there first. The iMove isn’t so good. I’m getting a Connect because somebody’s hacked it so you can now plug it via the USB connection, into the Xbox and you can now write your own open source tools with it, which is really exciting.

**Blackberry or Smartphone?**
Neither, get a life! Talk to somebody. If you’re sat on the train try talking to the person sitting next to you. I once had an Android for two weeks that I borrowed and when I checked my Twitter on the toilet I realised I really shouldn’t have a Smartphone!

**Geek or nerd?**
Geek, but chic.

**Do you think there’s a difference between a geek and a nerd?**
Yes, there is. There’s a much better culture associated with geeks than there is with nerddom, which is more focused, I think. I think geeks are generally aware of their geekiness, whereas nerds have got a few too many personal issues!
If you were going to give a piece of advice to someone who was thinking about getting into IT, what would it be?
Just try it, you'll get addicted. Programming and stuff is really addictive – there’s a lot of instant gratification. Don't be afraid to just try it.