



FRONTIERS MEETING

USE OF ELECTRONIC PATIENT RECORDS FOR RESEARCH AND HEALTH BENEFIT

24–25 May 2007



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UK Clinical Research Collaboration and the Wellcome Trust

**Frontiers meeting on the use of electronic patient records
for research and health benefit**

**24 and 25 May 2007
at the Wellcome Trust Conference Centre,
London, UK**

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*A video of this Frontiers meeting can be seen online at
www.flyonthewall.com/FlyBroadcast/wellcome.ac.uk/UKCRC_FrontiersMeeting/*

Introduction

Mark Walport

Director, The Wellcome Trust

The United Kingdom's long record of success in medical research and innovation has benefited the entire population. We now have the opportunity to enter a new phase in which clinical practice and research both gain from our emerging ability to gather and link information from a wide range of medical and non-medical sources.

The UK's key asset for making the most of this opportunity is the National Health Service, which can gather coherent data on nearly the whole population. The Frontiers meeting recorded in this report was held in London in May 2007 by the Wellcome Trust and the UK Clinical Research Collaboration (UKCRC) to discuss the potential to use electronic patient records in ways that will increase the health of the British people, in the short and long term. Those who attended were left in no doubt that the scope is immense. Existing patient data projects in areas such as Scotland, Wales and North-west England have already yielded health benefits and gained public support. With the introduction of the NHS National Programme for IT (within England) there is now an opportunity to realise this potential at a national level with 50 million users.

But we heard at the conference that the UK does not have this field to itself. Speakers from the USA and Scandinavia made it clear that the UK must learn from around the world, and move quickly to make the most of the strong position it has today in this area. Many of our speakers agreed that the UK has three to five years to set up a working system of linked medical records. If it takes any longer, we will have lost a crucial competitive advantage.

If we succeed in producing a national system of linked data, from medicine and from related areas such as the environment, it will be possible to improve patient treatment and safety, test approaches to health policy and expand research. But making the most of the opportunity will mean partnership between the NHS, government, industry and academe.

On behalf of both Wellcome and the UKCRC, I would like to thank the conference speakers, especially those who came long distances to give us their wisdom, and the organisers who made the event a success. Both Wellcome and the UKCRC are keen to follow this report with action as soon as possible.

The power of modern information technology to gain insights from large databases can be used to win substantial health gains for patients and the general public. The use of electronic patient records can ensure better treatments, improve patient safety and advance medical research. But these benefits will only be gained if large, coherent medical databases can be assembled on the largest possible scale.

At this meeting, delegates heard that the use of electronic patient records is already leading to better patient care in areas of the UK and around the world, for example in Scandinavia and parts of the USA. As well as patients, the UK pharmaceutical industry and the UK economy stand to gain from the integrated use of patient data.

In England the National Health Service alone has over 50 million patients in its records, potentially the largest coherent patient cohort in the world. This means that the UK is well placed to make the most of this new approach to healthcare. But if the potential is to be realised, it will be essential for every patient to be uniquely identified by a single number which is used every time they encounter the NHS or a private healthcare provider. Many people in Scotland and Denmark already know their number.

In addition, professionals and the public need to know about the big health gains that can flow from the use of electronic records. Experience in France, the USA and elsewhere shows that once they are aware of the potential gains, and reassured about privacy and anonymity issues, only a vanishingly small percentage of patients refuse to allow their records to be included in the appropriate database.

This report uses contributions at the Frontiers meeting to set the promise of electronic patient records in its societal and medical context. It then discusses the gains for patients, for medical research and for the UK economy which will flow from their use. Next, it looks at some aspects of the use of these records that we have to get right to ensure success. These include quality, scale, governance and public engagement. None of these issues are insoluble. But care is needed to ensure that we have the right approach, and we must make sure that public and professional audiences are fully aware of the health benefits of this new approach to medical information.

Report of the meeting

The meeting was held over one-and-a-half days at the Wellcome Trust's conference centre in London in May 2007.

It attracted over 80 delegates from government, industry, the health service and medical research. Speakers and delegates were drawn from the USA and Scandinavia, and all parts of the UK, including Wales, Scotland and Northern Ireland.

Professor Ian Diamond, chair of the UKCRC R&D Advisory Group to Connecting for Health, and Chief Executive of the Economic and Social Research Council, set the context by looking at the principal health challenges which the UK faces.

Life expectancy continues to rise, rising on a curve that has continued for about 120 years. But obesity is a growing epidemic that challenges this trend.

Households are getting smaller, continuing a trend that has been apparent since the 16th century. In 2021, an average household may contain 2.1 people, down from 4.5 in 1574. Fertility has fallen from about 4.9 children per woman in 1880 to 1.7 today, below the replacement rate.

Childlessness is becoming more common, and there will be more older people without children to support them. Over 80 per cent of people aged over 60 will have a living mother in the Britain of the future, meaning that people who may not be fully active themselves will be looking after others. At the same time, fewer than 80 per cent of women over 80 will have a living child by 2040. Moreover, an increasing number of these older people will be the 'oldest old'. There were 7000 centenarians in the UK in 2001. There were essentially none 100 years ago and only 1000 in 1968.

Taken together, these trends mean significant future growth in demand for social care and health services.

The problem is exacerbated because people have yet to realise the full extent of their increased life expectancy. Asked how likely they are to reach the age of 80, men and women both underestimate their true chances. So they may underestimate how much pension saving and other provision for the future they need to make. However, many of today's older people are living capable lives. Such conditions as incontinence, poor mobility, poor hearing and poor vision only apply to a minority.

Health inequalities still exist and by some measures have ceased their previous long-term decline. Those in the best health now have median wealth twice that of those with the poorest health indicators. The less prosperous are also systematically less able to provide for their future, because they tend to become economically inactive at an earlier age than the rest of the population.

Professor Diamond pointed to obesity as a vital current concern where electronic patient records might be of value. They could be used to investigate the effectiveness of interventions, perhaps in diet and exercise, in isolation or in combination. The UK has the highest percentage of obese adults (23 per cent) in Europe, and in 2003, 16 per cent of children from manual worker families and 12.4 per cent from non-manual worker families were obese. This means that a future epidemic is now beginning and we need evidence to design the correct interventions against it. Evidence is needed on steps that might be taken by individuals to change their behaviour, by communities, perhaps to encourage walking, and government, for example with tax policies to deter poor eating. Here, as in many other cases, the answers to health questions are not solely medical.

Patient data has been used for the first time to uncover a common genetic predisposition to obesity which, in turn, increases the likelihood of the development of diabetes in later life. It will be important to understand the mechanisms of genetic susceptibility to obesity in order to design optimal preventative strategies and interventions.

The meeting was set against a background of increasing awareness around the benefits that the use of electronic patient records can provide for patients and for medical research, and especially the opportunity that the NHS National Programme for IT (NPfIT) provides for the UK in this area. The benefits are increasingly appreciated within NPfIT and by Connecting for Health, the body in charge of the programme.

Today's NHS IT system already generates many worthwhile public and patient health benefits. It provides early warning of flu epidemics by setting off an alert if the diagnosis of flu is recorded for a significant number of cases.

Diabetes is increasing in prevalence across the developed and developing world. Many examples at the conference pointed to ways in which the use of patient data improves our understanding of the causes and its treatment. In the North-west of England, a system designed to integrate data on diabetes electronically combines primary and secondary data, from consultation notes to retinal photographs. Specialists from other fields such as heart and kidney disease have seen the advantages and want to participate. The system allows GPs to assess patient risk, and lowers costs for GPs and care trusts. The database is available for researchers. As well as making data available directly, it makes it simpler to recruit people for trials.

The meeting heard about the US Veterans' Health Administration data system, which has worthwhile care benefits, such as providing doctors with alerts of potential allergies when they are prescribing. The Administration has used IT to help deliver a significant improvement in its service quality, which formed part of a fundamental shift in its shape and mission. It has been named as a US exemplar for the use of electronic patient records. Its system started out as a series of databases on specific conditions, including some of military interest such as exposure to Agent Orange and artificial limbs. It now holds records on 7.7 million people. It is used by medical researchers outside the Veterans' Association, as it is the largest US patient database.

There can also be gains for industry and for the British economy from the use of electronic patient data. Richard Barker, Director General of the ABPI, told the conference that the pharmaceutical industry likes doing research in the UK. But it can be expensive and slow to do it here. The use of electronic patient records might allow both big breakthroughs and incremental improvements to be made more rapidly. But he warned that some US groups, such as the Veterans' Health Administration, are making progress in this field too.

Barker said that the industry needs a UK-wide system to provide as big a sample as possible for trial recruitment. A lifelong GP record will increasingly be essential for participation in a medical trial. Benefits could include more rapid drug approval, better knowledge of drug safety and unintended effects, and more detailed knowledge of treatment outcomes. Industry also wants to increase its ability to show that new treatments offer value for money. One pharmaceutical company, Wyeth, already works actively with patient data from Scotland and is using it in projects such as the development of biomarkers.

Electronic systems allow links between maternal and paternal conditions and the health of their adult offspring to be investigated rapidly. Separate studies in Scotland tracking diabetes and heart disease have the potential through linkage to grow into a Scotland-wide tracking system, which would include over 1000 GP practices and can be extended to cover other conditions such as asthma and cancer. It will allow studies, such as those on heart risk associated with diabetes and the connection between maternal pre-eclampsia and diabetes, to be carried out.

If we are to make the most of electronic patient records, the essential step is for a consistent patient identification number to be attached to every record of a patient encounter with the medical system. This number would accompany every person in the UK throughout life and should be used in transactions with private healthcare providers as well as the NHS. It is important that it is not confused in the public imagination with the controversial issue of UK identity cards.

In Scotland, a publicity campaign encourages people to know and use their CHI number. This ten-digit number has been growing in use since its introduction 30 years ago. Systems now in use allow a patient's CHI number to be looked up in an Accident and Emergency Department, so that their records can be accessed immediately.

Different approaches are taken in other countries. In Denmark, a single number is used for tax, health and other transactions with the state, and also for banking and other uses. This would require a level of trust between agencies and the public that does not exist in the UK.

Ideally the number should link relatives, especially mothers and children. Current NHS numbers are random, which makes it harder to track inherited disease or the effects of drugs taken in pregnancy.

The meeting heard about a number of issues that must be addressed if we are to use electronic patient records to best effect. One is quality. Data collected for research need to be accurate and meet professional standards. It also has to be as painless as possible for GPs and others to collect. Not all medical data are good enough to be used in research projects. There will have to be budgets for data to be improved for use by researchers. Another issue will be the use of data-matching technology to remove ambiguous or incorrect identifications of individuals. This should reduce the problem of patient medical histories becoming discontinuous when they change GPs.

Dr Dai Evans, a GP at a research practice, reminded the conference that GPs are business people and shape their IT systems to help their business. He described the PRIMIS+ database, derived from primary care data. It has to address issues of quality, vocabulary and consistency, and does not connect well with secondary care where very few comparable systems exist. The ways in which GPs code conditions vary, and alter as knowledge and practice change, although GPs can improve their coding consistency with training. Even imperfect GP data is better than self-reported patient data, especially from an older person whose memory may not be as sharp as it was. Data that provides good information on treatment history will grow in importance as the population ages.

The overall message is that electronic patient records can contain more data than older types of record, and can be corrected and updated more readily. This improves the quality of the record and subsequently improves patient safety and leads to better treatment for patients.

Another issue is size.

Can a system really be built that will hold and seamlessly transfer data on 50 million people? Experience in Denmark suggests that a group of perhaps five million may mark an upper limit of what is technically manageable. So it may be preferable to expand and link existing databases such as those in Manchester, Wirral and eastern Scotland, and create new ones, rather than attempting to build one repository for all of the UK's medical information. As Ian Diamond put it, the need is for an integrated system, not a single data set. This federated approach could in time embrace initiatives covering the whole UK. Professor Carol Dezateux, from the Institute of Child Health, who led one of the UKCRC research simulations, added that this approach would also give positive local ownership to NHS data. Steps are now being taken to ensure that data collected in Scotland and Wales is compatible and can be used in a consistent way.

Although the NHS provides most of the UK's healthcare, it does not have a monopoly. For example, about 70 per cent of assisted reproduction is carried out by the private sector. It will not be possible to collect information on the long-term effects of assisted reproduction for mothers and children unless the private sector participates in national data gathering.

In Denmark, with a population of 5.4 million, a register of prescriptions was the precursor of a national data linkage system which now has general support after significant public debate. As *Science* magazine put it in an article on Denmark in 2000, an entire country has become a cohort.¹

Dr John Parkinson, Director of the General Practice Research Database (GPRD), told the meeting that an effective database of medical records would have to link far more than reports from GP and hospital visits. The NHS IT programme is designed to cope with 1.8 million pathology results and 600 000 hospital discharge letters a month, and there are also images from a wide range of devices such as scanners and X-ray machines. The GPRD already covers 5 per cent of the UK population. The data it contains is comprehensive, but GPRD can lose people when they change GPs, and so fail to build up lifelong records of their health.

As well as medical records, an effective health database could also include disease registers, ONS data on deaths, data from the census, and information on environmental conditions such as pollution and weather, and economic data, for example incomes. This will inevitably vary in quality and format.

Electronic data can help overcome biases in self-reported medical histories. Studies examining associations between abortion and subsequent breast cancer tend to suggest that there is a link when based on a woman's own report of her previous abortions. But when medical records are used to determine whether she has had an abortion, it turns out that there is no positive link between the two. Medical records produce a more reliable source of information on abortions as it seems that women who have developed cancer are inclined to make a fuller disclosure of their medical history than those who are well at the time of enquiry.

¹ Lone F. When an entire country is a cohort. *Science* 2000;287(5462):2398–9.

The UK Clinical Research Collaboration, one of the organisers of this conference, has carried out a series of simulations to show the benefits that can flow from the use of patient records. Its report on the simulations stresses that a common patient identifier should be mandatory for all NHS activities. It also calls for existing databases to be federated, eventually covering the whole population, for data quality to be improved and assured, and for issues of governance and the role of research in the NHS to be emphasised. The full UKCRC report is available at www.ukcrc.org.

Several speakers told the conference that the potential gains from data linkage are so large that it would be unethical not to take advantage of them. But who would be in charge of a system of electronic patient records? Decisions on governance must ensure public trust and transparency as well as effective management.

Richard Barker of ABPI said that one possibility would be to create a trusted and independent service provider, which he termed the data guardian. Others were keener for the NHS label, which has enormous trust among the British public, to be applied to this growing database. These included conference speaker Denise Lievesley, Chief Executive of the (NHS) Information Centre. The Centre gathers data only on England. She made a clear distinction between the desirability of local data gathering and the necessity for it to be collected to a UK standard. Although much data gathering can and will be managed on a local basis, coherence will be lost if systems in the UK's four nations diverge. Much NHS data is gathered for management rather than clinical use, and there is a risk that the data gathered will diverge as management systems grow apart.

Professor Michael Thick of the NHS Programme for IT agreed that the programme, which is highly innovative, is driven mainly by clinical considerations. The Secondary Uses Service – covering all but immediate medical use – has come along later. Neither its technical structure nor its accountability and governance have yet been described completely.

Because a single national data system is unlikely to emerge, there need to be procedures and tools that promote local initiative, with governance systems to match. It is not possible to parachute an electronic records system into an unwilling NHS.

In Wales, where the government regards linked data as strategic national infrastructure, the many bodies that have agreed to provide data to it have been assured that it will not be used to develop league tables, addressing one of the main fears about the use of large datasets on medical outcomes.

Existing developments in IT for the NHS are certain to form the basic structure for the linked medical records system. But, as Ian Diamond pointed out, the research councils are investing heavily in e-science and grid computing. These already allow large research datasets to be handled flexibly and securely.

Patient data can be used to answer questions of acute public concern rapidly. In Sweden and Denmark, a 12-million person study linking blood donors and recipients showed that cancer was not transmitted through blood transfusion. Nor does all the data used have to be found in computer memories. A Danish study using a wide range of sources, including many years of old telephone directories, showed that workers in dry cleaning are not at extra risk of oesophageal cancer from the solvents they use. Previously incompatible systems in Nordic countries are now able to share data.

These proposals require public support, which means that public engagement is a priority. Professor Carol Dezateux told the conference that NHS patients should be made more familiar with the idea that research is a core function of the NHS, and that they may be asked routinely to take part in research studies. She regards them as being knowledge producers as well as patients.

Gatekeepers such as GPs are a key link to the public and need to be enthused about the potential of electronic records. So does the media. One suggestion at the meeting was for an Advocacy Pack, which could be distributed to help describe the benefits of novel uses of patient data in an accurate and reassuring way.

Some conference speakers referred to past problems that better analysis of patient records might have helped prevent. It has been shown that analysis of electronic patient data might have allowed the high mortality rates following children's heart surgery at Bristol Royal Infirmary in the 1980s and 1990s to be spotted more rapidly.

Privacy is the key to establishing public trust in electronic health records. Most research projects that make use of these records will be using data on large numbers of patients and will never involve a researcher knowing the identity of a specific individual. In a drug trial, a researcher might know the identification number of an individual, but not his or her name. The public needs to be assured that only their GP or some other medical professional with responsibility for them will be able to connect a medical record to a named person.

Privacy and security will be vital concerns in the future development of electronic patient records. Research on privacy-enhancing technology may be needed. It may draw on IT security work beyond the field of medical records.

Research projects using patient records will need ethical approval in the same way as any other research proposal. Trust is also helped by the fact that substantial datasets such as GPRD and the Tayside database have had no breaches of confidentiality in many years of use. However, this suggests substantial reputation risk if things go wrong. In Scotland, hundreds of thousands of people have been told about the use of electronic patient records, both to keep them informed and to persuade them to use and know their identifier number.

Electronic patient data is already used around the world in research projects. Some speakers at the meeting suggested that the NHS should make it clear that research is a key part of what it does when the use of patient records is explained to the public. However, three speakers who described the US experience of patient data linkage – Dr Lawrence Deyton of the Veterans' Health Administration, Dr Henry Chueh of Massachusetts General Hospital and Dr Mark Dente of GE Healthcare – said that they had found it important to illustrate to patients that the use of their data could lead directly to improvements in their own treatment.

They added that better IT systems have advantages for GPs, which makes data gathering more acceptable. It can enhance patient safety, increase treatment quality and, in the US system, make it easier to get paid. This helps enlist doctors as advocates for electronic systems.

Pharmacovigilance is one of the main concerns which electronic patient records can help address. This means that it is attractive to patients' groups and to politicians. Both can be recruited as supporters for data linkage. GSK's Safety Works system, described at the conference by Dr Phil Burstein, merges computer and paper records to provide information

on the safety of medicines, especially those entering general use. Like other US speakers at the conference, Dr Burstein stressed the enviable scale of the data which the NHS makes available. He made it clear that this is a significant competitive advantage for the UK.

Statins are taken regularly by millions of people across the world who are at risk of heart disease. In the west of Scotland, a randomised trial demonstrated a reduction in coronary risk in the five years after starting treatment with statins. By using data linkage it was possible to show that these health gains for individuals persisted over a 15-year time span. This ability to carry out long-term follow up in clinical trials through electronic patient records is enhancing Scotland's claim to be a top venue for biomedical research. Mental health, drug response and osteoporosis are among topics now being investigated with the same database.

The overall message is that the use of electronic patient records has advantages for organisations and individuals involved in providing medical care, as well as for patient groups, politicians, researchers and the pharmaceutical industry. They are all potential supporters of these developments.

This report was written by Martin Ince: martin@martinince.com

Further information on this meeting can be obtained from Robert Terry, Wellcome Trust: r.terry@wellcome.ac.uk

Appendix 1: Agenda of the meeting

UKCRC–WELLCOME TRUST FRONTIERS MEETING

The use of electronic patient records for research and health benefit

Thursday 24 May 2007

08.30	Registration and refreshments	<i>Williams Lounge</i>
09.00	Introduction and welcome: aims of the meeting <i>Dr Mark Walport, Director, Wellcome Trust</i>	<i>Auditorium</i>

Session 1: The vision and the benefits

Chair – Dr Mark Walport, Director, Wellcome Trust

The potential benefits for patient health and safety of electronic records
Professor Ian Diamond, Chair, UKCRC Connecting for Health Advisory Group, Chief Executive Economic and Social Research Council

Enhancing research through record linkage: the benefits for patients and the public's health
Dr Carol Dezateux, Director, MRC Centre of Epidemiology for Child Health and UKCRC Research Simulation Lead

The UK, an international centre for medical industry (clinical trial identification and drug safety)
Dr Richard Barker, Director General ABPI

	Refreshment	<i>Williams Lounge</i>
	Panel discussion	<i>Auditorium</i>
12.00	Lunch	<i>Williams Lounge</i>

Session 2: Use of electronic patient records in the USA

Auditorium

Chair – Iain Buchan, Director of NIBHI & Senior Lecturer in Public Health Informatics, University of Manchester

US Department Of Veterans' Affairs electronic medical record: health benefits, quality improvement and research
Dr Lawrence (Bopper) Deyton, Chief Public Health & Environmental Hazards Officer, US Department of Veterans' Affairs

Leveraging electronic health records for research and public health at Massachusetts General Hospital
Dr Henry Chueh, Director, Laboratory of Computer Science; Chief, Division of Biomedical Informatics; and Director, Clinical Research Program IT, Massachusetts General Hospital

Role of GE Healthcare in information technology: clinical trial recruitment using electronic medical records

Dr Mark Dente, Vice President, GE Healthcare

Panel discussion

Session 3: Building on what is already there – how to handle data, protect and benefit patients

Chair – Dr Liam O’Toole, Chief Executive UKCRC

Auditorium

Research using primary care data

Dr John Parkinson, Director, The General Practice Research Database Division, The Medicines and Healthcare Products Regulatory Agency

Health protection: towards real-time surveillance

Professor Mike Catchpole, Health Protection Agency

Panel discussion

16.20

Refreshment

Williams Lounge

Providing an integrated electronic healthcare record for long-term conditions

Dr John New, Department of Diabetes, Hope Hospital, Salford Auditorium

UK primary care data: realities and problems of data quality

Dr Dai Evans, Clinical Adviser, University of Nottingham PRIMIS+

Panel discussion

18.30

Drinks followed by buffet dinner

Williams Lounge

Friday 25 May 2007

Session 4: What can be done

Auditorium

Chair – Professor Thorkild Sørensen, Institute Director and Professor of Clinical Epidemiology, Institute of Preventative Medicine, Denmark

Record linkage in Scotland: options and opportunities for post-genomic research

Professor Andrew Morris, University of Dundee

Development of a health and environment information research platform

Professor Ronan Lyons, University of Swansea

Register-based health research in Denmark

Professor Elsebeth Lynge, Institute of Public Health, University of Copenhagen, Denmark

Panel discussion

11.00 Tea and coffee break *Williams Lounge*

Session 5: Models for the future *Auditorium*

Chair – Dr Mark Walport, Director, Wellcome Trust

New developments in pharmacovigilance: perspectives from the USA
Dr Philip Burstein, GlaxoSmithKline

Unlocking the potential of health data
Dr Denise Lievesley, Chief Executive, The Information Centre

The role of NPfIT in a programme of e-health research
Professor Michael Thick, Chief Clinical Officer, CfH team

13.00 Open discussion

13.30 Sandwich lunch *Williams Lounge*

14.30 Meeting closes

Appendix 2: Speaker biographies

Richard W Barker

Richard is Director General of the Association of the British Pharmaceutical Industry (ABPI). In this capacity, he is also a board member of EFPIA (the European Industry association) and a council member of IFPMA (the international equivalent). His priorities include boosting the UK and Europe as a global leader in pharmaceutical innovation, strengthening the partnership between the industry and the Health Service, increasing patient engagement and access to new medicines in the UK and globally, and ensuring that the industry's external image reflects its major contribution to health and economic prosperity.

He is a member of the NHS National Leadership Network, the NHS Stakeholder Forum, and also the UKCRC and its Advisory Board on Connecting for Health.

He is a stakeholder in the TB Alliance, developing new medicines for the devastating condition. He is also active in the biotechnology sector, as a board member of Adlyfe, developing detection technology for diseases involving protein misfolding, and of iCoTherapeutics, an early stage company developing ocular therapies.

He is a board member of Datapharm Communications, a company bringing online medicines information to UK prescribers and patients.

Prior to joining the ABPI, Richard was Chairman of Molecular Staging, a biotechnology company focused on whole-genome amplification and protein biomarker development. He was also founder of New Medicine Partners, an advisory firm focused on biopharmaceuticals and molecular diagnostics. His past operating roles include CEO of iKnowMed, a clinical decision support and pharmaceutical services business in oncology, Chief Executive of Chiron Diagnostics, a global diagnostics company, and General Manager of IBM's Worldwide Healthcare Solutions business. He also led McKinsey's European pharmaceuticals and healthcare practice.

His academic research was in biological magnetic resonance at Oxford, Leeds and Munich.

Iain Buchan

Iain Buchan is Director of the Northwest Institute for BioHealth Informatics (NIBHI), Clinical Senior Lecturer in Public Health Informatics at the University of Manchester, and Honorary Consultant in Public Health in the English National Health Service.

Originally from Liverpool, UK, Iain studied medicine and pharmacology there in the late 1980s. While an undergraduate, he developed a strong interest in medical statistics and wrote statistical software for clinical researchers – this grew into www.statsdirect.com, with around 10 000 users worldwide. He also developed an interest in clinical information systems and the coordination of healthcare for populations, particularly across the primary–secondary care interface. In the mid-1990s Iain moved his developing health informatics research to the University of Cambridge at the same time as undertaking Public Health Consultant training in the Eastern Region. In 2003 he returned to the Northwest of England, to focus his public health and informatics work into one research role at the University of Manchester.

Iain's core research interests are 'e-epidemiology' and obesity. 'E-epidemiology' is the fusion of statistical, social, biomedical, economic and computational thinking for studying

public health problems in the e-record epoch. This requires a transdisciplinary team approach, which is being taken in NIBHI. The outputs are not only research papers but also technical developments towards 'real-time' public health decision-making and the development of 'Social BioHealth E-Laboratories' (E-Labs). E-Labs target gaps in understanding: first, diseases with complex determinants; second, population-level health interventions; and, third, the potential for early (personalised) intervention and prevention.

See www.nibhi.org.uk/people/iain.aspx for more information.

Philip Burstein

Dr Burstein received his medical degree and internal medicine training from the Medical College of Virginia. After completing a fellowship in endocrinology at the University of Colorado Health Sciences Center, he practised endocrinology for ten years before becoming Vice President of Medical Affairs at Lutheran Medical Center in Wheatridge, Colorado. In 1998 he joined SmithKline Beecham, Healthcare Services, as Director of Clinical Content for their Disease Management programmes. In 1999 he was appointed Director of Disease Modeling supporting research and development within Biostatistics and Data Sciences. Following the formation of GSK, Dr Burstein led a group called Data Exploration Sciences, a diverse group of project leaders and scientists dedicated to advanced data mining of varied, complex data sources both internal and external to GSK. Currently he is leading a team dedicated to the optimisation of observational data as well as the re-use of clinical trials data to enhance drug discovery and development. Dr Burstein is a member of the UKCRC Research Advisory Group for CfH.

Mike Catchpole

Professor Mike Catchpole is the Deputy Director (Public Health) of the Health Protection Agency's Centre for Infections. He has worked in infectious disease epidemiology and response at the national and international level since 1991.

He has over ten years' experience of management of national communicable disease surveillance systems, and was responsible for developing the unlinked anonymous HIV prevalence monitoring programme in genitourinary medicine clinics. His main research interests have been in the fields of HIV and sexually transmitted infections.

Mike has a special interest in issues of data protection and confidentiality as they relate to public health and surveillance, and is a member of the Patient Information Advisory Group.

Henry C Chueh

Dr Chueh is the Director of the Laboratory of Computer Science (LCS) and Chief of the Division of Biomedical Informatics at Massachusetts General Hospital (MGH), and an Assistant Professor of Medicine at Harvard Medical School. He is also the Director of Information Technology for the MGH Clinical Research Program and the Director of Applied Informatics within the MGH Center for Quality and Safety. Dr Chueh has extensive experience with research in patient-oriented clinical systems and has established novel informatics architectures in systems that are used in clinical practice at MGH. Over 2500 clinicians spanning dozens of MGH departments and divisions utilise web-based clinical systems designed by Dr Chueh and the LCS. The LCS has also designed numerous research registries and the Partners Healthcare's terabyte-sized research repository. Dr Chueh has published extensively on informatics technology approaches and architectures as well as informatics intervention studies, and has been an elected fellow of the American College of Medical Informatics for many years. He lives in Cambridge, Massachusetts, with his wife and two sons.

Mark Dente

Dr Dente started his informatics career over 16 years ago after graduating Boston University School of Medicine, focusing on new approaches to increase patient safety, drive physician adoption of technology, and create new methods to implement evidence-based medicine.

As Vice President of Healthcare Solutions for GE Healthcare Integrated Information Technology, Dr Dente's responsibilities include strategic evaluation of emerging technologies. He also leads 'knowledge management – clinical content strategy' for GE, including such areas as evidence-based medicine and clinical decision support.

As a physician executive, Dr Dente continues to maintain close academic and industry contacts and is passionate about driving GE's 'Early Health – Personalized Medicine' initiative at the national and international level.

For more information about GE Healthcare IITS, visit www.gehealthcare.com/usen/hit.

Lawrence Deyton

Dr Deyton is Chief Public Health and Environmental Hazards Officer for the US Department of Veterans' Affairs (VA) and is Clinical Professor of Medicine and of Health Policy, George Washington University School of Medicine and Health Sciences. He has responsibility for VA's policies and programmes relating to veterans' environmental health, public health, women veterans' health and VA's emergency preparations, management and responses as well as VA employees' work-related health. Dr Deyton is an active clinician and holds a weekly clinic at the Washington DC VA Medical Center caring for veterans with HIV, infectious diseases and hepatitis C. Dr Deyton joined VA's national leadership team in 1998, serving as director of the AIDS Service, and in 2002 established VA's Public Health Strategic Health Care Group which encompassed responsibilities for HIV, hepatitis C, smoking, bioterrorism, and issues such as SARS, pandemic influenza and other emerging public health threats. He became Chief Officer in January 2006.

Dr Deyton served for 11 years in leadership positions in the National Institute of Allergy and Infectious Diseases (NIAID) at the National Institutes of Health, for six years in the Office of the Assistant Secretary for Health of the Department of Health and Human Services, and as a legislative aide with the House of Representatives Subcommittee on Health and the Environment.

Dr Deyton has extensive experience in public health, HIV clinical medicine and clinical research. From 1988 to 1994, he was the Assistant Director for Community Clinical Research in AIDS for NIAID and Chief of the Community Clinical Research Branch, Division of AIDS (NIAID). In this position, he established the Terry Beirn Community Programs for Clinical Research on AIDS and led that programme until he became chief of the HIV Research Branch, DAIDS, in 1994. In this capacity, Dr Deyton was responsible for scientific oversight of HIV clinical research supported by DAIDS, including all HIV therapeutic research of the AIDS Clinical Trials Group, CPCRA and other clinical trials programmes. Dr Deyton has developed, reviewed and supervised the conduct of over 200 trials of HIV therapeutics. Between 1996 and 1998, he was the acting director of NIAID's Division of Extramural Activities where he was responsible for the scientific review and management of the Institute's entire scientific portfolio, including all research grants and contracts in allergy, immunology, HIV/AIDS, infectious diseases, transplantation, and asthma. This portfolio had an annual research budget of approximately US\$1.4 billion.

Dr Deyton was the convener of and served on the Executive Committee of the Forum for Collaborative HIV Research – a public/private collaboration between government and industry, and has served on the scientific advisory committee for the American Foundation for AIDS Research, and as a consultant to the FDA Antiviral Drug Advisory Committee. He serves several advisory boards related to hepatitis C, including the American Liver Foundation's Veterans' Hepatitis C Council. In addition, Dr Deyton serves as VA representative on many government and private advisory groups, boards and committees, including the NIH Office of AIDS Research Advisory Committee, the NIAID National Council, the Division of AIDS' AIDS Advisory Committee, the National Vaccine Advisory Committee, and co-chairs the Federal Health Architecture Workgroup on Public Health Surveillance. He is a founder of the Whitman Walker Clinic, a community-based AIDS service organisation in Washington DC. In 2002, Dr Deyton received the Legion of Honor Award by the Chapel of the Four Chaplains, a non-denominational veterans' service organisation dedicated to 'service to all people regardless of race or faith'.

Dr Deyton is a graduate of Kansas University, the Harvard School of Public Health and the George Washington University School of Medicine. His postdoctorate medical training was at the University of Southern California/Los Angeles County Medical Center. He is board-certified in internal medicine and received his infectious disease specialty training at the National Institutes of Health with Dr Anthony Fauci. Dr Deyton has over 100 publications in peer-reviewed journals on AIDS clinical trials, clinical trials methodology, and public health aspects of HIV, and is a frequent reviewer for numerous peer-reviewed medical and public health journals.

Carol Dezateux

Carol Dezateux is a Clinical Professor of Paediatric Epidemiology, Director of the MRC Centre of Epidemiology for Child Health at the University College London Institute of Child Health, London, Honorary Consultant Epidemiologist at Great Ormond Street Hospital for Sick Children NHS Trust, and co-directs the UK Newborn Screening Programme Centre. Her research addresses early life influences on child health and the effectiveness of screening and other clinical and public health strategies to improve the health of children. She has led initiatives to ensure the wider research use of newborn biobanks in the UK, the collection of biomarkers and biomedical data within the UK Millennium Cohort Study and the enhancement of these data using record linkage. She is a member of the Birth Cohort Studies Scientific Committee, the MRC Data Sharing and Preservation Steering Group, the MRC Ethics and Policy Advisory Committee, and is Deputy Chair of the Cohort Studies Working Group on Record Linkage. She led the simulation on retrospective epidemiological studies for the UKCRC Research Advisory Group to Connecting for Health.

Ian Diamond

Professor Diamond joined the Economic and Social Research Council (ESRC) in January 2003 on an initial four-year appointment. He came from the University of Southampton where he was Deputy Vice-Chancellor. He had been at Southampton since 1980 as Lecturer, Senior Lecturer and Professor. He is a social statistician, and his work has crossed many disciplinary boundaries, most notably working in the area of population but also in health, both in the developed and developing world, in environmental noise and with local authorities.

Ian Diamond's research has involved collaboration with many government departments, including the Office for National Statistics, the Department for International Development, the Department of Transport, and the Department for Work and Pensions.

Dai Evans

Apart from being a practising GP in the Peak District, Dai is a Clinical Advisor for PRIMIS+ at Nottingham University. PRIMIS+ is the lead organisation working in health informatics training and comparative data analysis within primary care in the NHS. Dai's particular interests lie in medical audit and data quality, and led him to help set up Keele's General Practice Research Network. He also sits on QResearch's Board and is the lead technical advisor on data quality for the NHS' General Practice Data Quality Accreditation Programme.

Denise Lievesley

Professor Denise Lievesley, a social statistician by training, is Chief Executive of the English Information Centre for Health and Social Care which is based in Leeds. Formerly, she was Director of Statistics at UNESCO, where she established its new Institute for Statistics. The Institute was relocated from Paris to Montreal in 2001 and so Denise lived in Montreal for four years before returning to the UK.

Denise began her career as an official statistician specialising in survey sampling. She went on to become the Director of the International Statistical Institute and then the Director of the UK Data Archive as well as Professor of Research Methods in the Mathematics Department at Essex University.

She has an honorary doctorate from City University in London and is a fellow of University College London. She was President of the Royal Statistical Society from 1999 to 2001 and will be President of the International Statistical Institute from 2007 to 2009, the first woman to hold this office. She is currently the international representative on the board of the American Statistical Association.

Elsebeth Lyng

Elsebeth Lyng has been Professor of Epidemiology at the University of Copenhagen since 1998. Before this, she was head of the research unit at the Danish Cancer Society. Her research interests include screening and cancer epidemiology, and she is author/co-author of 319 publications.

Professor Lyng is a member of the Danish Strategic Research Council, Programme Committee on Food and Health, and was previously a member of the Danish National Research Foundation and Danish Medical Research Council.

Ronan Lyons

Ronan Lyons is Professor of Public Health at the School of Medicine, Swansea University. He also holds honorary consultant appointments with the National Public Health Service for Wales and Swansea NHS Trust. His main research interests are in the use of health information to support health research, and injury epidemiology and prevention.

He jointly leads the Health Information Research Unit (HIRU), which carries out research into methodologies to support research using routine and non-routine sources of health data, the analysis of large and complex datasets, and the application of GIS technology to the study of public health and health services research.

Andrew Morris

Andrew Morris is Professor of Diabetic Medicine at the University of Dundee and leads a translational research team that focuses on the informatics, epidemiology and molecular basis of diabetes complications. He also has a major interest in how managed clinical

networks can improve patient care across geographical boundaries. He coordinates the DARTS research study, has published over 160 original papers, and has attracted over £15 million in peer-reviewed grant funding. He was awarded the RD Lawrence lecture by Diabetes UK in 2003 and the Saltire Society/Royal Society of Edinburgh Scottish Science Award in 2005. Andrew was Chair of the Scottish Diabetes Group and Lead Clinician for Diabetes in Scotland (2002–2006), and is a Fellow of the Royal Society of Edinburgh. Andrew chairs the Generation Scotland Committee, the Translational Medicine Research Collaboration Steering Group, and is principal investigator of Generation Scotland: the Scottish Family Health Study.

John New

John New is a diabetologist at Hope Hospital Salford. His interest in medical informatics developed from the need for easy access to information while caring for people with diabetes.

Since arriving in Salford he has been involved with many projects aimed at improving healthcare delivery by more effective use of existing information using IT. These have included developing secure internet access to healthcare records; developing a care call service to improve glucose levels for patients with diabetes and using the data collected through healthcare provision for epidemiological studies.

Liam O'Toole

Dr Liam O'Toole is Chief Executive of the UK Clinical Research Collaboration (UKCRC). The UKCRC is a partnership of organisations delivering a broad programme of work to transform the environment for clinical research in the UK and establish the UK as a world leader in clinical research. Through coordinated working, the UKCRC Partners are building up the infrastructure for clinical research in the NHS, developing an expert research workforce, streamlining the regulatory and governance environment, coordinating research funding and building incentives for research in the NHS. The partnership includes the main UK funding bodies, academia, the NHS, regulators, industry and patients.

Before taking on his current role with the UKCRC, Liam was the first Administrative Director of the National Cancer Research Institute (NCRI), which is a partnership of the main funders of cancer research in the UK. The NCRI has been instrumental in facilitating a number of high-profile joint initiatives to enhance cancer research in the UK and is regarded as a successful and dynamic partnership organisation. This model of partnership working was used as a model for the establishment of the UKCRC.

Prior to working with the UKCRC and NCRI Liam had 16 years' experience of research management in the public and charity sectors.

Liam is also Interim Director of the Office for Strategic Coordination of Health Research (OSCHR).

John Parkinson

John Parkinson gained his PhD in Biochemistry from the University of Liverpool and then worked both within the pharmaceutical industry and as a consultant to it. In 1995 he joined Professor Tom MacDonald's pharmacoepidemiology/database group, MEMO, at the University of Dundee, where he managed the relationship with study sponsors and users of data, ensured the governance aspects of the operation were leading edge and improved the methodology for data capture. He has lectured widely on many aspects of

pharmacoepidemiology and on record linkage and issues of confidentiality of data/privacy-enhancing technologies. He joined the Medicines and Healthcare Products Regulatory Agency in September 2005 as Group Manager of the General Practice Research Database Division. He sits on a number of high-level working groups concerned with maximising the research utility of data from the NHS in England, and has recently been the lead on a UKCRC–CfH simulation concerning surveillance uses of health data.

Thorkild Sørensen

Thorkild I A Sørensen, born in 1945, gained his MD in 1971 and achieved his doctoral degree (Dr Med Sci) in 1983 at the University of Copenhagen. He received his clinical training at several university hospitals in Copenhagen, and became Chairman of the Department of Emergency Admissions and Chief Physician at the Department of Hepatology at Hvidovre University Hospital in 1988. In 1989, he received a five-year position as MRC Professor of Clinical Epidemiology and, in 1994, at the end of this period, was appointed as full Professor of Clinical Epidemiology at the University of Copenhagen in combination with a position as Chief Physician in Clinical Epidemiology at the Copenhagen Hospital Corporation. In 1993, he became Director of the Institute of Preventive Medicine. He was Dean of the Faculty from 1995 to 1996.

Professor Sørensen has published more than 300 papers in international peer-reviewed journals, with several papers in high-impact journals (see PubMed 'Sorensen TI'). The main topics of his research have been various aspects of obesity, alcohol drinking, liver and gastrointestinal disorders, addressed by methods in clinical, genetic and general epidemiology. He is coordinator of several national and international research projects and networks. He has been, and is, adviser, supervisor or reviewer of multiple doctoral and PhD dissertations, and has been involved in establishing a graduate school in public health sciences. He has served as scientific adviser or reviewer for many different national and international institutions, organisations and journals.

Professor Michael Thick

Michael Thick qualified as a doctor in 1976 from the University of Cambridge, and trained as a junior doctor in London. He was then made Senior Registrar to Professor Sir Roy Calne in Cambridge, and has set up several transplant units. Until recently he was the Director of Liver and Renal Transplantation at the Freeman Hospital in Newcastle, and was also Chair of the Information Management and Technology Strategy Committee for the city's hospitals. Throughout his career he has been active in health informatics, having a particular interest in theoretical modelling as a means of understanding and then designing systems to support clinical activity. He was recently seconded to the NHS Information Authority for two years, where he was the Caldicott Guardian, and helped develop the infrastructure required by Caldicott Guardians to implement access control and information governance within their organisations. He was also Chair of the Clinical Communications Programme Board.

Until September 2006 he was Senior Medical Advisor to the Choose and Book and PACS Programmes, and was then appointed as Chief Clinical Officer to Connecting for Health. His principal roles are to ensure that patient safety and clinical governance are core values within the National Programme for Information Technology, and to ensure that all clinical disciplines are represented and valued within it.

He maintains his clinical interests by researching 'bench to bedside' technologies at the National Heart and Lung Institute, Imperial College, in particular the use of genomic technology for the prediction of diseases.

Mark Walport

Mark Walport was appointed as Director of the Wellcome Trust in June 2003. He heads one of the world's largest biomedical research charities, which spends some £400 million a year in pursuit of its mission to foster and promote research with the aim of improving human and animal health. Before joining the Trust, he was Professor of Medicine and Head of the Division of Medicine at Imperial College London where he led a research team that focused on the immunology and genetics of rheumatic diseases. He was appointed a member of the Council for Science and Technology in 2004.

Appendix 3: Synopses of presentations

Session 1: The vision and the benefits

The potential benefits for patient health and safety of electronic records

Professor Ian Diamond, Chair, UKCRC Connecting for Health Advisory Group, Chief Executive Economic and Social Research Council (ESRC), Polaris House, North Star Avenue, Swindon SN2 1UJ, UK

- Highlight the importance of research for the advancement of healthcare and modern health services
- The opportunities lie in accessing the core information about patients and individuals that exists within various data systems and structures
- By establishing connections between databases such as those holding primary care patient records and cancer registry records, trends and associations can be explored which may have huge potential impact on patient outcomes
- In order to achieve such data linkage, there is a need to address a range of capability and governance issues.

Potential gains for UK healthcare

Making the health service safer

Access to electronic healthcare records will enable early detection and therefore more timely response to adverse events, including drug reactions.

Reliable assessment of different causes of disease

Scientists have known for many years that the risk of developing different diseases is caused by the complex interplay of factors such as lifestyle and environment, susceptibility (genes) and the play of chance (luck). However, despite this long-standing awareness, a clear picture of the combined effects of different factors on the risks of different diseases in different circumstances is yet to emerge.

Identifying effective treatments more rapidly

The UK has a significant opportunity to increase clinical trial activity through the successful development of electronic patient records with research-focused national programmes for IT in place. Clinical trials are one of the most reliable methods for establishing whether a treatment works and whether it is safe.

Answering public health concerns

Linkage of routine health service data, environmental, fiscal and educational data, and data on vital events such as births and deaths can all enhance our understanding. It can also strengthen the scientific basis of strategies to maintain the health and wellbeing of the population, and can prevent and control disease.

International learning

A number of countries have established authoritative and planned linked systems which utilise a single NHS number or its equivalent in all settings.

The UK experience base

The existing systems in the UK have already been used to good effect, and the UK has a strong track record and tradition of excellence on which to build. For example, the links

between vital statistics data and cancer registers are relatively well developed, allowing individuals to be traced.

Enhancing research through record linkage: the benefits for patients and the public's health

Professor Carol Dezateux, MRC Centre of Epidemiology for Child Health, Centre for Paediatric Epidemiology and Biostatistics, UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH, UK. E c.dezateux@ich.ucl.ac.uk

Research is a fundamental activity in delivering effective health and public health services. There is considerable experience of using record linkage for research in the UK, including in epidemiological studies of causation, natural history and outcome, for the follow up of clinical trials and for pharmacovigilance. It is now timely to revisit the strengths and weaknesses of these existing systems for research and to learn from approaches in other countries to ensure that the opportunities afforded by the emergence of the electronic patient record in the UK are fully exploited. These new opportunities include the planning of clinical trials, as well as the recruitment and follow up of trial participants, and linkage of routine data to biobanks.

The findings of research based on linked records have made significant contributions to the advancement of the health of patients and the public both in the UK and internationally. Linked data provide an essential infrastructure for research and for studies to improve patient safety, to identify effective treatments more cost-effectively, and to assess different causes of disease, disability and death reliably. They are, in addition, a powerful means of responding rapidly to public health concerns. It is vital to promulgate wider awareness of these benefits in debates on linking and sharing data for research.

The findings from the simulations undertaken for the UKCRC R&D Advisory Group tConnecting for Health support the need for an integrated system of person-based, rich, real-time and reliably coded data sources linked by a unique identifier to deliver effective healthcare and high-quality research. Linkage to the full range of datasets within the NHS is needed, together with functionality to link externally to a range of routine data sources (including primary care and pathology), as well as to special cohorts, registers and surveys.

Examples of research from the UK and internationally will be used to illustrate the range of benefits of record linkage for healthcare and the health of the public. They will also be used to highlight the methodological, structural and other challenges to be addressed in enhancing opportunities for research using record linkage.

The UK, an international centre for medical industry (clinical trial identification and drug safety)

Dr Richard Barker, Director General ABPI, 12 Whitehall, London SW1A 2DY, UK

Following the publication of the Cooksey report last year and the UKCRC simulations report on the use of the NHS CRS for research, the UK government has shown strong commitment to implement the National Programme for IT through Connecting for Health in a way that will enable research to be carried out in the UK in a more efficient way. The UK clinical research is placed into a global perspective, and the findings of the clinical trials recruitment simulation and the medicines' surveillance simulation are presented. The key criteria from these simulations are highlighted. If these criteria are fully implemented in collaboration with industry, the UK could become a leading place for industry to invest in,

enabling patients to access innovation whilst protecting their privacy by keeping their medical records confidential.

Session 2: Use of electronic patient records in the USA

US Department of Veterans' Affairs electronic medical record: health benefits, quality improvement and research

Dr Lawrence Deyton, Chief Public Health & Environmental Hazards Officer, US Department of Veterans' Affairs, Washington DC, USA

The US Department of Veterans' Affairs (VA) operates the largest integrated health system in the USA, serving over 5.4 million patients in FY2005 at over 1000 sites of care (hospitals, community clinics, long-term care, counselling programmes, etc.) in nearly every community in the country. The VA has developed and, for nearly ten years, fully deployed a system-wide electronic medical record. This asset is the foundation upon which medical care, services, administrative functioning and performance assessment is based.

The presentation will give the relevant background of the VA healthcare system and review the development of VA's electronic medical records (EMR). It will provide a survey of the major current elements of EMR as used for clinical care at the VA, and also offer examples of applications of the VA EMR for:

- individual patient management tools
- patient population management tools
- patient safety
- medical error reduction
- clinician decision support applications
- applications for system-wide quality and performance monitoring
- uses of the VA EMR for research endeavours.

The presentation will also review the limitations of the VA EMR.

Leveraging electronic health records for research and public health at Massachusetts General Hospital

Dr Henry Chueh, Director, Laboratory of Computer Science; Chief, Division of Biomedical Informatics; and Director, Clinical Research Program IT, Massachusetts General Hospital, 50 Stanford Street, 5th Floor, Boston, MA 02114, USA

The demand for high-quality clinical data for research and public health is increasing dramatically. A combination of factors is driving this demand: these factors include the need for public health reporting and transparency, phenotypes in clinical genomics research, and clinical outcomes for quality improvement. Without a predetermined strategy, raw clinical data is typically usable only for direct clinical care. Methods are needed to harness research to the clinical documentation process effectively.

Massachusetts General Hospital has taken multiple approaches to solving this problem. Three categorical methods are in use today: first, collection of available discrete data from information systems into large-scale research repositories; second, performance of manual or automated chart review to update disease-oriented research registries; and, third, creation of electronic health record systems that generate research quality data as a by-product of clinical care. This presentation will discuss the advantages and disadvantages

of these approaches, as well as touch on the need for inter-institutional models for aggregating clinical data for research and public health.

Role of GE Healthcare in information technology: clinical trial recruitment using electronic medical records

Dr Mark Dente, Vice President, GE Healthcare

GE Healthcare provides transformational medical technologies and services that are shaping a new age of patient care. Our expertise in medical imaging and information technologies, medical diagnostics, patient monitoring systems, performance improvement, drug discovery and biopharmaceutical manufacturing technologies is helping clinicians around the world re-imagine new ways to predict, diagnose, inform, treat and monitor disease so patients can live their lives to the fullest.

The electronic medical record (EMR) has been widely touted as an essential tool to improve the quality of medical care. The way in which the EMR can be used to support the clinical trial process, streamline work flow and increase efficiency is explored.

Specifically, the EMR and associated clinical data warehouse's potential to identify qualified sites for participation, ensuring adequate numbers of potential subjects, is described. Also discussed are new work flows for identifying and screening of potential candidates at the time of treatment visits and, finally, how 'coordinator follow up' can be facilitated.

An example of using the EMR for clinical trial recruitment is described in the context of a diabetes study example. This opportunity utilises a network of physicians who are using a specific EMR system, Centricity®, and who have agreed to pool their clinical data into a data warehouse called the 'Medical Quality Improvement Consortium' (MQIC).

Session 3: Building on what is already there – how to handle data, protect and benefit patients

Research using primary care data

Dr John Parkinson, Director, The General Practice Research Database Division, The Medicines and Healthcare Products Regulatory Agency

The UK is blessed with having a healthcare system in which primary care is the gatekeeper to most aspects of NHS care, with the consequence that a lifelong record of care is maintained. Additionally, primary care IT systems have been in use for about 20 years, enabling the General Practice Research Database (GPRD) to make available over 40 million patient years of well-validated, anonymised person level, research quality, data. Add to this the recent major NHS IT changes that have already happened, are ongoing and will continue to happen in the future, and the prospects for extending the research capabilities are hugely exciting. The presentation will be based around research in the context of medicine and device safety; it will cover capabilities that are just becoming available and look ahead a little to what might/will/should be possible.

Health protection: towards real-time surveillance

Professor Mike Catchpole, Health Protection Agency, 61 Colindale Avenue, London NW9 5EQ, UK

It is the nature of health protection threats and events that they may occur in a rapid or explosive way, and that new threats may arise without warning. Surveillance for health protection must therefore not only deliver the necessary information to inform the action required to control or prevent the spread of infection or exposure to environmental hazards, but it must deliver this information in a timely and continuous manner. The detection of outbreaks, at an early enough point in their evolution to interrupt transmission, has always been a unique requirement of communicable disease surveillance, as compared to chronic disease surveillance. This need to detect clusters of cases at an early stage has shaped many communicable disease surveillance systems, which often share common features of frequent reporting, rapid analysis, and reporting of cases on the basis of suspicion or incomplete diagnostic work-up. However, at the point of analysis, the data collected and collated through many long-established surveillance systems relate to exposures, or disease events, that occurred days, or even weeks, in the past. These analyses may be adequate for monitoring medium- and longer-term trends in disease, and for documenting the distribution of disease within the population, but they rarely detect outbreaks that have not already been identified by alert clinicians or that are at an early stage in their evolution.

Over the past ten years the Health Protection Agency (HPA), and its predecessor organisations, has worked closely with NHS laboratories to develop electronic capture systems that improve the timeliness of reporting and the quality of surveillance data, thus reducing the effort required by laboratory staff in reporting to the HPA. The HPA also uses data from primary care and independent service providers to support its surveillance function, and more recently has developed systems for the reporting of data by clinical staff working in infection control.

The HPA believes that the NHS National Programme for Information Technology provides a major opportunity to strengthen surveillance of infectious disease and events or exposures owing to other environmental threats to health, particularly through the potential to capture data on a near real-time basis. HPA is therefore working with Connecting for Health (CfH) to define the requirements that the HPA has for data to be captured and reported through the systems that NHS CfH are deploying. This project is aiming to meet three key objectives:

1. To document the detailed data requirements of the HPA for the surveillance, control and prevention of infections as well as any associated business rules for when and for whom those data should be collected and/or reported.
2. To document the full functional requirements of systems relevant to the capture of data that may be used for public health purposes, e.g. prompts for clinical or risk factor information that might be built into electronic test requesting systems.
3. To determine internal HPA development needs, in terms of both process and information systems, to take full advantage of the opportunities offered by NHS CfH.

Providing an integrated electronic healthcare record for long-term conditions

Dr John New, Department of Diabetes, Hope Hospital, Stott Lane, Salford M6 8HD, UK

Diabetes is a classic example of a long-term condition where care is provided by multiple providers throughout primary and secondary care. We will describe how Salford developed an electronic patient record that integrated information from primary and secondary care sources into a combined diabetes record. This shared record is used to support healthcare delivery, the National Service Frameworks and the Quality Outcomes Framework. The system has now been extended to include multiple long-term conditions, showing how this can simultaneously increase efficiency and reduce costs by decreasing duplication of effort and patient investigation.

Salford has 60 primary care centres using both EMIS and Vision systems, and a hospital utilising iSOFT Clinical Manager. In 2004 Hope Hospital worked with the middleware provider Graphnet to facilitate and integrate data export from these different sources to form a centralised information repository to support the management of long-term conditions. The Graphnet solution uses the same standards for message export as Connecting for Health.

Using this extended system, information is now captured and combined for all individuals with a diagnosis of diabetes, cardiovascular disease, stroke and chronic kidney disease. All data relating to the management of these conditions are exported to a centralised data repository within the Primary Care Trust (PCT). These data relate to investigations (e.g. biochemical tests), comorbidities (myocardial infarction, stroke, etc.), lifestyle (smoking and exercise) and all current medications. The repository is linked to the master patient index in Exeter to ensure that any changes of address or GP, as well as deaths, are captured. The PCT also receives information relating to cause of death from the Office of National Statistics, and this information is then linked to produce a comprehensive electronic patient record that includes mortality data.

Access to individual records is closely regulated. General practitioners and secondary care clinicians can only access information for the people for whom they provide direct care. Access is controlled depending on clinical role. GPs can access information on patients in their practice, while secondary care physicians have access only to their patient's records. All access rights are managed by the PCT.

A pseudoanonymised copy of the information is available for research. This greatly facilitates the planning of clinical studies, epidemiological research and public health information. Feasibility for clinical trials is made straightforward, and the development of realistic study protocols is far easier when accurate real-time data that will influence proposed inclusion/exclusion criteria are available. These data are a major resource for epidemiological research and can demonstrate the translation of research into clinical practice (e.g. changes in antihypertensive prescribing) or measure clinical effectiveness (e.g. reduction in myocardial infarction rates with cholesterol lowering therapy). Further examples will be provided during the presentation.

Salford is now expanding the potential of this information system by integrating data for all people within the city. This will significantly increase the clinical utility provided by the system and markedly expand uses of the data for epidemiological research, public health research and service planning. This presentation will demonstrate how improved information, as will be provided by Connecting for Health, can be used to improve clinical care and enable population-based health services research.

UK primary care data: realities and problems of data quality

Dr Dai Evans, PRIMIS+, University of Nottingham, 15th Floor, Tower Building, University Park, Nottingham NG7 2RD, UK

This talk will look at the structure and development of primary care IT in Britain and how this influences the current content of information recorded in general practice IT systems. It will look at some of the problems encountered in setting up a primary care research network and the solutions employed. It will also cover current and likely future data extraction systems, as well as the current assessments of data quality in primary care information systems.

Session 4: What can be done

Record linkage in Scotland: options and opportunities for post-genomic research

Professor Andrew Morris, Division of Medicine & Therapeutics, Ninewells Hospital and Medical School, Dundee DD1 9SY, UK

Overview: the Universities of Aberdeen, Dundee, Edinburgh and Glasgow, in collaboration with the National Health Service in Scotland and Scottish Enterprise, have embarked upon an ambitious nationwide research development programme that aims to position Scotland at the forefront of record linkage internationally to support biomedical research. This talk discusses:

- how the size of Scotland (5 million residents), allied to a stable and homogeneous population, facilitates nationwide epidemiology
- how integrated, population-based National Health Service datasets and disease registries facilitate recruitment into clinical trials and allow automated, efficient follow up of clinical events and treatment response
- the rationale behind a national informatics platform that will provide a web-based pharmacovigilance reporting, electronic trial monitoring, and the conduct of large-scale genetic case control, pharmacogenetic and family-based studies.

Examples from two large-scale research programmes will be used: the Wellcome Trust United Kingdom Case Control collection for Type 2 diabetes, and Generation Scotland: the Scottish Family Health Study.² Generation Scotland complements UK Biobank and aims to deliver:

- a large family-based intensively phenotyped cohort recruited from across Scotland as a resource for both the genetics of quantitative traits of common complex diseases and pharmacogenetics
- a multi-institutional and NHS collaboration that will share knowledge and best practice in human genetics research
- an engagement programme to understand and explain the public reaction to genetics in healthcare
- computer-delivered education on genetics for healthcare professionals in Scotland
- a collaboration with NHS Scotland, the Information and Statistics Division, and the National eScience Centre to create a research platform in emerging technologies of health informatics in genetic research.

²Smith BH et al. Generation Scotland: the Scottish Family Health Study; a new resource for researching genes and heritability. *BMC Med Genet* 2006;7:74.

This approach to developing a secure, resilient, integrated information environment aims to provide a nationwide resource for clinical translational research.

Development of a health and environment information research platform

Professor Ronan Lyons, Professor of Public Health (CHIRAL), University of Swansea, Singleton Park, Swansea SA2 8PP, UK

The need to utilise the enormous amount of electronic health data held on individuals for research has been recognised by the UK Clinical Research Collaboration. The Wales Office of Research and Development has pump-primed the Health Information Research Unit (HIRU) to develop this field. Data relevant to the health of individuals is held in large numbers of databases held by many different organisations, not all within the National Health Service. HIRU's funded programme of research includes four strands:

1. Developing new methodologies for accessing and combining routine data in ways that do not breach data confidentiality rules and regulations, but that still permit the use of data for a wide range of research purposes
2. Exploring how to use routinely collected data to support large-scale multi-site intervention, cohort studies and policy evaluation studies
3. Developing innovative analyses of large and combined datasets
4. Developing methods for data capture to common standards and definitions in multiple and remote locations.

There are four steps required to utilise routine data to support research:

1. Development of anonymisation and linkage techniques
2. Building partnerships and collaboration
3. Quality assessment and appraisal of datasets
4. Use of datasets in research.

HIRU has largely completed the first two tasks. The development of anonymisation and linkage techniques involving the creation of two-staged encrypted anonymised linking fields (ALFs) supports individual level data linkage with data flows from multiple sources. All data held by HIRU are anonymised. Work is progressing on the development of ALFs for individual buildings to support research into the built environment and health, and also for family relationships (mother–child). Trust is essential before anonymised datasets can be shared for research. HIRU has developed partnerships with many NHS and non-NHS bodies (primarily departments of local government), utilising a process of collaborative involvement in research and data utilisation agreements that specify that information is for learning, not blaming. A pilot study of data access in a health community has been very successful, with 34 out of 35 general practices in the local health board, the social services department and NHS hospitals providing multiple datasets. This is now being rolled out to other health communities. Access to national level datasets has been agreed (or is in the process of agreement), covering: emergency department attendances, outpatients, inpatients, out of hours services, births, deaths, migration, community child health dataset, cancer and neonatal screening, cancer incidence, congenital anomalies. Linkage is being undertaken to existing and developing clinical datasets: myocardial infarction (MINAP), arthropathies, diabetes, stroke and others. Linking individual health and environmental exposure data at an ecological small area level (lower super output areas) is progressing with the use of geographic information systems (GIS) and non-GIS datasets from the Census, Ordnance Survey, and datasets from central and local government departments and other agencies.

Considerable research time is required to interpret the meaning of discordant findings from individual and combined datasets. The next step is to utilise the data to support a wide variety of research methodologies, including individual and cluster randomised trials, electronically enhanced cohorts, and interrupted time series analyses to support clinical, public health and policy-relevant research.

Register-based health research in Denmark

Professor Elsebeth Lyng, Department of Epidemiology, Institute of Public Health, University of Copenhagen, Oster Farimagsgade 5, opg.B 1001 Copenhagen, Denmark

In Denmark, cause of death and cancer registers date back to 1943. Personal identification numbers were introduced in 1968, and a national hospital discharge register was started in 1977. Denmark therefore has an excellent infrastructure for register-based research, where the 'cohort' can be the entire population. The registers have formed the basis for studies on: first, socioeconomic determinants of health; second, associations between diseases/treatment and other diseases; and, third, evaluation of screening programmes. Register data are now being linked with biobanks. A challenge today is to maintain quality of registration under new management structures in the healthcare system.

Session 5: Models for the future

New developments in pharmacovigilance: perspectives from the USA

Dr Philip Burstein, Vice President, Healthcare Data Optimization, Drug Development Sciences, Medicines Development, R&D, GlaxoSmithKline.

Drug safety is of the utmost importance to everyone who is currently taking a medication, or will be in the future. Currently the industry and regulators depend on the outcome of clinical trials and spontaneous reporting of adverse events to guide them. Researchers can do better, but need to be informed by better information. Electronic health record data can be the cornerstone for improved safety surveillance. GlaxoSmithKline (GSK) is committed to enhanced pharmacovigilance and is at the forefront in the development and application of new processes in this field. GSK has developed a new in-house system called 'Safety Works' (SW) to leverage and enhance significantly observational data on the use of our medicines. Disparate data sources are concurrently analysed using ontologies, hierarchically structured sets of categories for a particular domain. SW applies multiple analytical methodologies and creates detailed full context drug/condition information for subpopulations of patients. Manual processes are augmented with sophisticated data exploration, data mining and data visualisation tools. SW enhances and supports the expertise of drug safety scientists to make decisions based on the 'preponderance of the evidence'. To make this happen, SW must be able to focus on the period of uncertainty, be capable of finding classic 'drug list' events, drug- or class-specific suspected events, increases in events with large public health consequences as well as unsuspected events. It must also be able to assay benefits and be a source for validating signals through hypothesis testing on observational data. Operating characteristics must be quantitative, longitudinal and near real-time.

GSK is committed to improving pharmacovigilance within the organisation and is equally focused on collaborating with the rest of the pharmaceutical industry in similar efforts. In the USA the industry association, PhRMA, is working very closely with the Food and Drug Administration (FDA), which is now also committed to changing its approach to safety

surveillance. Much is happening in the USA of which the UK needs to be aware. Through a series of workshops and seminars, organised jointly by industry and the regulators, new approaches are being explored. There has been a significant increase in the publication of consultation papers and in enquiries on potential future scenarios. Anticipated new legislation will also drive a sense of urgency as well as funding.

As we go forward, access to data is fundamental. Electronic health record data will be the information to drive change. Challenges that must be addressed include: accessing the most relevant sources of data, language, semantics, completeness, quality, continuity and duration as well as analytical methodologies and, very importantly, governance and the protection of patient confidentiality.

Whether it is in the USA or the UK, the industry must take a leadership role in ensuring that systems being developed are fit for purpose and will lead to a step change in drug safety monitoring. The healthcare community expects this kind of diligence and it will happen with or without us. Eventually this must be a global effort, with the public and private sector collaborating more closely than previously. New partnerships must be developed, with industry, academia, research funders, regulators, patients and physicians all working together.

Every effort must be made to assure access to data: patient confidentiality must be addressed. Public trust must be earned.

If the appropriate mechanisms can be put in place in a timely manner, the UK is in a unique position to set a high standard for safety.

Unlocking the potential of health data

Dr Denise Lievesley, Chief Executive, The Information Centre

The Information Centre for Health and Social Care collects and distributes a wide range of data from surveys, clinical audits and administrative sources. The organisation exists to promote and support the informed use of these data while ensuring that their use is appropriately governed with respect to protecting the confidentiality of the data subjects. These data resources will be discussed, noting especially the developments in building the secondary use of data from the national patient care record.

The role of NPfIT in a programme of e-health research

Professor Michael Thick, Chief Clinical Officer, CfH team

Better, safer patient care: The NHS touches people's lives at critical times. Information available at the point of need is crucial to patient safety. NPfIT will radically reduce drug prescribing errors, diagnostic waiting times and empower patients through access to their personal medical record through Healthspace (web portal). Research using patient records is integral to patient benefit and makes an important contribution to the completeness and quality of data. Existing strengths in the use of data for research can be built upon rather than being replaced, while ensuring patient confidentiality is critical.

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