360° of Health Data:
Harnessing big data for better health

Preface

With the explosive growth in health and biomedical data, the 'big data' era has arrived in medicine. We are beginning a transformational change in which data analysis will assume central importance to healthcare and medicines development.

The potential benefits for health and wealth creation are significant, but to realise them will require effective partnerships between industry, academia and the health service, and with patients. The 2013 ABPI–NIHR R&D conference, '360° of Health Data: Harnessing big data for better health', brought together representatives from all these sectors to review the exciting work being undertaken to harness the UK's outstanding data resources, and to discuss how further progress can be made.

The conference also provided an opportunity for us to launch our big data road map, a report providing an industry perspective on big data and priorities for the next four years. This journey is one we need to make together, and it was profoundly satisfying to hear such unity of purpose among participants, with a shared commitment to use big data to achieve big solutions.

Stephen Whitehead
Chief Executive, ABPI

Executive summary

The Association of the British Pharmaceutical Industry (ABPI) in partnership with the National Institute for Health Research (NIHR) jointly held an R&D conference in November 2013 in central London on '360° of Health Data: Harnessing big data for better health'. What follows is a summary report of the proceedings.

The objectives of the conference were to hear about the evolving data boom and its impact on the biopharmaceutical industry and the NHS, highlight data needs and the opportunities to improve R&D productivity, and drive forward health research excellence through partnership working for patient benefit.

The explosive growth of big data is ushering in a new era likely to transform pharmaceutical development. Use of big data – 'real world' health data, captured in electronic health records and other datasets, plus deep genotypic and phenotypic data, for example from genome sequencing – has the potential to deliver great health and wealth benefits.

The most significant shift is towards stratified medicine, with patients receiving therapies more tailored to their likelihood of drug response – leading to safer and more effective use of medicines. This presents a challenge to conventional models of pharmaceutical development, but the strengths of the UK also make it an opportunity to pioneer new approaches.

The UK's competitive advantage reflects the value of the NHS, offering cradle-to-grave care for a population of more than 60 million, with developing electronic health record systems. Significant efforts are being made to link datasets and make them more accessible under strict governance. With the UK's strong biomedical and life science research base, in academia and industry, it is well placed to take advantage of these emerging resources.

Nevertheless, considerable challenges remain, both technical and infrastructural. As well as the technical challenges to extracting and linking data, there is a need to boost the health informatics skills base to support both data 'cleaning' and analysis. There are also challenges for regulatory authorities, with the drive to develop medicines targeting ever smaller numbers of patients and growing potential of real world data.

Throughout this period of change, it will be important to work with patients and the public – whose data will be essential for progress. The public is positively disposed to the use of their health data to benefit patients but governance and security issues must continue to be taken seriously.

To help guide the next steps in this journey, the ABPI has developed a big data road map outlining priority areas for the next four years. The road map calls for industry, academia and the NHS to work together to ensure the potential benefits of big data are realised for the UK and its citizens.

Introduction

It has been estimated that, every two days, more data are generated than were produced in the whole of human history up to 2003. Health and biomedical data are contributing to this data explosion. Although not at the scale of some other disciplines, health data sources are large, expanding and complex. It is widely recognised that they have the power to transform medicine, and that the UK is uniquely placed to play a leading role in this revolution.

These trends set the context for the 360° of Health Data conference. To open proceedings, **Lord Howe**, Parliamentary Under Secretary of State at the Department of Health, outlined a vision in which use of big data can drive both better health and economic growth.

The Government's Plan for Growth and Life Sciences Strategy illustrated its commitment to a strong commercial life sciences sector. This has led to substantial investment, for example in the Clinical Practice Research Datalink (CPRD), the Health and Social Care Information Centre (HSCIC), new E-Health Informatics Research Centres supported by the Medical Research Council (MRC), the National Institute for Health Research (NIHR) and other partners, the MRC-funded Farr Institute, and through an MRC call in medical bioinformatics. Sequencing of 100,000 genomes, coordinated through Genomics England Ltd, will put the UK in a leading position in the generation of whole genome data to support improved healthcare.

As well as skills development and capacity building, there is also a need to engage with patients and the public to ensure they have confidence in the practical issues of data management and governance.

Stephen Whitehead, Chief Executive of the ABPI, made the case that big data is driving a revolution in healthcare that will profoundly alter diagnosis, treatment and research.

With deep phenotyping, every disease is now a rare disease with huge implications for the development of medicines and regulatory processes. The NHS provides

a unique opportunity but faces numerous challenges, while the industry must maintain its commitment to data transparency. With its information resources and strong R&D base, the UK is in a unique position to lead this revolution, the first steps of which are outlined in the ABPI's newly published big data road map (see later).

Dr Ruth McKernan, Senior Vice-President at Pfizer and Chief Scientific Officer of Neusentis, touched upon some of the ways in which big data is affecting pharmaceutical research. She suggested there were three main categories of health-relevant data:

- 'Real world' data: Health data in medical records or other sources.

- Phenotypic information: More complex, less structured data in scans, blood biomarker measures, 'omics' and in biobanks.

- Genetic data: Genomic data from initiatives such as the 100k Genome Project.

These all feed into the three key decision stages of pharmaceutical development: picking the right target, creating the right molecule, and selecting the right patient.

In terms of target identification, genetic approaches have already assumed a key role. Leads have been identified through work on single-gene conditions, revealing genes involved in disease processes, and through genome-wide association studies, which identify alleles affecting the risk of disease. An area of growing interest is the territory between these two extremes, characterised by low-frequency alleles of intermediate effect size.

Genetics is also revealing considerable complexity that raises significant challenges for medicine development. Many different mutations affect the CFTR gene, for example, causing cystic fibrosis through different mechanisms. Genetic variation also affects drug responses – the classic example being metabolism of warfarin, influenced by the CYP2C9 genotype, which may ultimately lead to dosing algorithms based on patient genotype. But genetic variation in a drug target can also affect drug responses by altering the target's affinity for a drug. Genetic variation leading to just two amino acid differences in the P2X7 ion channel protein, for example, underlies a tenfold difference in a drug's binding affinity.

Medicines may also have unanticipated effects, some of which may be captured in health record data. Uric acid levels, for example, have been found to drop in response not just to cardiovascular medicines but also to other

classes of medicines, such as anti-psychotics, while some types of medicine have the opposite effect.

One of the most eagerly anticipated uses of health data is to support personalised or stratified medicine. Cancer is the most advanced area in stratified medicine, with some therapeutics targeted to specific molecular changes and used in concert with companion diagnostics. Other possible applications include genetic tests to guide treatment of patients with inflammatory diseases, as an alternative to the sequential use of agents.

Integrating multiple forms of data, and potentially data collected from people in their daily lives, will be a major challenge. It will also be important to raise patient awareness of the importance of health data analysis. Finally, all work is ultimately dependent on an environment supporting the development of new medical innovations and uptake by the NHS.

Transforming the development of business models using big data

Peter Knight from the Department of Health described the policy context for big data health research in the UK, and recent changes made to promote use of health data. The UK Government's Life Sciences Strategy, published in 2011, outlined a vision to bring the NHS and science base closer together to make the UK the best location in the world to carry out pharmaceutical R&D. At the same time, the 2011 Department of Health report 'Innovation Health and Wealth: Accelerating adoption and diffusion in the NHS' outlined a strategy to enhance the uptake of innovation.

Information is central to this vision, and measures are being put in place to harness the UK's unique set of circumstances. These include investment in the CPRD (as well as development of the Secure Anonymised Information Linkage (SAIL) Databank in Wales and the Scottish Informatics Programme (SHIP) in Scotland), launch of the Farr Institute to promote capacity building, establishment of the HSCIC, and funding from both the MRC and the NIHR. The academic sector is making key contributions, through ehealth research centres and initiatives such as the Oxford Big Data Institute. As well as health data, other sources of information, such as education or other social data, may also be useful in understanding patterns of disease and healthcare usage.

Professor Sir Rory Collins from the University of Oxford outlined some of the opportunities offered by big data, as well as obstacles limiting its use. One powerful application is the use of electronic health records to accelerate recruitment of patients into clinical trials, either large numbers of patients

with common conditions or smaller numbers of geographically dispersed patients with rare diseases.

Centralised systems can both speed up and reduce the cost of recruitment. A US clinical trial team, for example, planned to recruit 7000 patients through 400 sites over 15 months. Through a centralised system using electronic health records, recruitment targets were achieved in just seven months at half the number of sites.

Health data also provides additional methods to assess longer-term health outcomes of trials. Follow up of patients in a statin trial, for example, was able to confirm that health benefits were maintained.

Health data are increasingly being used to understand disease biology, categorise disease, and target treatment. The oestrogen receptor status of breast cancers, for example, is central to treatment response. Novel ways to analyse complex datasets will increasingly reveal biologically relevant associations. One promising approach is network analysis being used to identify clusters of interacting genes affecting specific biological systems. Genomic approaches are also revealing numerous potential disease targets. In the case of PCSK9, just a decade has passed between its implication in control of cholesterol levels and coronary heart disease risk and the testing of medicines in clinical trials.

Additional opportunities are emerging from the increasing availability of high-throughput assays and large-scale data analysis. As well as 'omics', other technologies such as brain and heart scans and forms of imaging also provide growing sources of data.

The pharmaceutical industry is showing a growing interest in the use of 'real world' data, some advantages and disadvantages of which were described by **Chris Chinn** of GSK. Broadly speaking, real world data are those captured during routine or near-routine use of medicines by doctors.

Given their strict inclusion/exclusion criteria and careful oversight, randomised controlled trials leave many questions unanswered about effectiveness in the real world. Observational studies and 'pragmatic' trials can address some of these issues, as may use of real world data. Post-launch analyses may provide supplementary information, and a way to examine use of medicines in the context of care pathways, potentially providing scope to modify such pathways and to consider patient preferences. The European Medicines Agency (EMA) is moving into this space, with its powers to request post-authorisation efficacy studies.

Another novel approach, exemplified by the Salford Lung Study, is the pre-launch pragmatic study. In this study the effectiveness of GSK's Relovair treatment is being assessed, before licensing, in a real world setting. The study required considerable coordination in data collection in order to capture information from GPs, hospitals and pharmacies.

Such studies are taking place in an environment of considerable uncertainty. There is strategic uncertainty – how will this kind of study connect to regulatory processes, how will the data be assessed in other countries? There is operational uncertainty, as the study is breaking new ground in trial management and data collection. And there is analytic uncertainty, with doubt about transferability and integration of data from other studies. These are among the issues being addressed in the 'GetReal' initiative organised by the EU's Innovative Medicines Initiative (IMI).

The panel discussion highlighted other key issues, including data quality. Much data is 'dirty', requiring clean up before it can be analysed – a currently neglected area with a significant skills shortage. Thought could be given to how 'data cleansers' could be attracted into the field, and whether more could be learned from companies already routinely handling and manipulating big data.

A related issue is the profusion of data standards. Much work is underway to standardise data sources throughout the health service, while bodies such as the Global Alliance – representing more than 70 medical and research centres – are attempting to establish common standards for genetic and medical information. Conversely, advances in computational science may offer new methodological approaches to dirty data, and there is a risk that standardisation may become an end in itself. Disease definitions, for example, can become highly contentious. Data may ultimately provide the most biologically informative approach to define standards.

Potential obstacles to efficient health data sharing include the processes adopted by oversight bodies and the attitudes of health professionals such as GPs. Recent European Parliament proposals on data protection legislation are a potentially serious challenge to data sharing. A decision on these proposals has been put back to 2015, providing an opportunity to address their potentially damaging impact.

Sharing of trial results by the pharmaceutical industry itself is also under scrutiny. The industry is committed to being more open about clinical trials, and to make clinical trial data available to further analysis, while

protecting patient confidentiality and commercially sensitive information. Recent ABPI commissioned research has found that, for more than three-quarters of EMA-approved medicines, trial results are being made publicly available within a year.

Industry's data needs: 2020 vision

The ABPI used this session to launch its big data road map. The genesis of the road map was described by Rob Thwaites of Evidera and Professor Hilary Thomas of KPMG.

The UK is Europe's top location for pharmaceutical R&D. To maintain this position, suggested Mr Thwaites, the UK will need to harness its unique health data resources. This data infrastructure has been developing over the past two decades, with the beginnings of computerisation in the 1990s, a recognition of the importance of electronic health records in the 2000s, and the development of data linkages and data services in the 2010s.

Big data is a game-changer, suggested Professor Thomas, signifying a major shift in industry towards data-driven organisations. The big data road map, produced following consultation with more than 70 stakeholders in industry, the NHS and academia, was developed to raise awareness of this profound change but also to identify practical steps that could be taken to deliver economic benefits to the UK and health benefits to patients.

Professor Thomas painted a picture of big data as a 'black box', with a widespread lack of awareness of what is available. Moreover, the black box is getting bigger, faster, with a particular growth in 'dark data' – data not known to be available.

The shifting landscape presents other challenges. Some data may make for uncomfortable reading, for example, on the real world effectiveness or safety of medicines. Industry also has to deal with complexity – the reality is not one black box but many.

What practical steps can be taken to extract more value from this critical resource? One step forward would be to make it easier to identify what information is available, by improving metadata labelling and development of a comprehensive metadata platform encompassing the diversity of data sources.

Use of big data also needs to be considered within a sustainable data ecosystem, linking data, insight and value in a virtuous circle. This will depend on skills development and capacity building (topic of discussions between the Farr Institute and the ABPI), and better engagement between industry and the NHS, with a stronger focus on value rather than volume. 'Demonstrator projects' could illustrate the power of data-driven innovation in areas such as pharmacovigilance and stratified medicine for chronic, complex diseases.

In the future, competitive advantage needs to be derived not from preferential access to data but in being the most effective in analysing, understanding and utilising data. Ultimately, stressed Mr Thwaites in conclusion, this new model will depend on partnerships working together towards shared goals.

Breakout sessions

Workshop 1: Stratified medicine

Dr Jeremy Haigh of Amgen suggested that the current model of drug discovery is unsustainable. With the 'fragmentation' of disease, current systems of drug development, regulation and reimbursement are no longer fit for purpose and require radical overhaul.

The key shift is the move towards stratified medicine, with therapeutics targeted at smaller patient populations. Yet drug development still relies mainly on large randomised controlled trials to demonstrate safety and efficacy, followed by interactions with national and international regulators and pricing negotiations. The process is long, slow and inefficient, limiting patients' access to innovative medicines.

Significant changes to existing processes can be envisaged. More flexible and adaptive trial design may be needed, and more use made of post-authorisation safety data. Approaches to medicines pricing may also need to be more flexible and adaptive, with more thought put into assessment of value.

Stratified medicine is based on the detailed characterisation of patient groups. The NIHR BioResource, described by **Nathalie Kingston**, is a resource that can be used to generate phenotypic data to support targeted drug development.

The NIHR BioResource grew out of the Cambridge BioResource, a panel of some 13,000 volunteers and patients who each provided a blood sample for DNA analysis, completed a health and lifestyle questionnaire, and agreed to be contacted to take part in research. It is not a tissue bank, but enables patients to be recruited on the basis of genotype or phenotype. It is open to both academic and commercial use. Following the success of the Cambridge BioResource, it is being developed into a national resource, drawing on NIHR Biomedical Research Centres and Units in London, Oxford and Leicester.

Professor Adrian Towse of the Office of Health Economics outlined some of the experiences of other countries wrestling with the challenges of stratified medicine. France, for example, has made considerable progress in introducing stratified treatments for cancer, driven primarily by anticipated cost savings. In Australia and the UK, the changing model is leading to joint assessment of therapies and diagnostics.

In the USA, while physicians recognise the importance of genetics to drug responses, only around one in

ten feel well informed about pharmacogenomic testing, limiting its practical application. Clinical guidelines are being developed by the US Clinical Pharmacogenetics Implementation Consortium to support pharmacogenomically informed prescribing practice.

Although not the only way to stratify patients, genetic make up will increasingly be used to guide therapy development and use. A major resource will be the 100k Genomes Project, described by **Professor Mark Caulfield** of Genomics England. The project is generating whole genome data with a focus on rare inherited diseases, cancer and infectious disease, and is committed to working in collaboration with the NHS and industry as well as academia.

Workshop 2: Harnessing data in the UK – innovations driving research in the UK

Sir Alex Markham, Professor of Medicine at the University of Leeds, warned of the dangers of raising expectations too high when progress was likely to be slow. He argued that change should be incremental, building on the existing foundations provided by infrastructure such as the CPRD and HSCIC. It is also likely that substantial investment will be required if the full value of health data is to be realised in the UK.

John Parkinson, Director of the CPRD, ran through some of its key features. Designed as the NHS observational data and interventional research service, it provides regulated and simplified access to ehealth data. It covers a complex set of 50 datasets, encompassing 1.4bn consultations, 1.2bn clinical instances and 5.3bn primary care events, with robust systems to manage ethics, linkage and security.

Among its applications are 'TrialViz', a tool for rapidly searching records to identify potential recruits to clinical trials given specific inclusion/exclusion criteria. It has also developed a patient journey visualisation tool incorporating primary care and Hospital Episode Statistics (HES) data.

Another key national resource is the Health and Social Care Information Centre (HSCIC), described by **Dr Mark Davies**, its Director of Clinical and Public Assurance. The HSCIC is the UK's national centre for real world health and social care data, responsible for information management and underlying technology.

It has an important role in collecting and making available the data required for measuring quality of care across the NHS. Uniquely, it can request information from NHS bodies and require that they provide it. It also aims to provide access to integrated primary and

secondary care data, anonymised, pseudonymised or with individual identifiers (subject to patient consent). Although at an early stage, this promises to be an important resource for the life science industry complementary to the CPRD offerings.

Recent years have seen spectacular growth in the use of social media. According to **Peter Knight** at the Department of Health, these new tools provide an important opportunity for public and patient engagement. Opportunities exist to engage in discussion and dialogue to generate interest in clinical research, and perhaps to promote recruitment into trials. It might also be possible in future to run trials through social media.

Professor Harry Hemingway, Director of CHAPTER (the Centre for Health Service and Academic Partnership in Translational E-Health Research) at UCL, outlined the Farr Institute's plans to address the shortage of skills in health informatics. The Farr Institute unites four ehealth research centres across the UK. While islands of expertise exist in different sectors, there is an overall skills shortage and no established career path for 'data scientists'. Similarly, various modules and short courses do exist, but there is no integrated masters course in the UK.

Professor Hemingway suggested that a national strategy was needed to develop capacity in health informatics research, to address the issues outlined in the ABPI's big data road map.

Professor John Williams of the Swansea Farr Institute developed the Royal College of Physicians' data standards recommendations. He argued that higher quality health data are required, based on agreed and widely implemented data standards.

Workshop 3: Data integration and linkage – value to the NHS

Tim Jones from University Hospitals Birmingham NHS Foundation Trust described how the hospital had developed new digitally driven systems, enabling the hospital to introduce a range of innovations to its clinical decision support system. The hospital is one of the biggest in the UK, with some 8000 staff and an annual budget of around £640m. Hospital facilities have recently been rebuilt, providing an opportunity to integrate new IT systems.

One important application has been in error management, with systems intervening to prevent sloppy errors. Prescribing practice has also been enhanced; the numbers of prescriptions that are not

actually given has been significantly reduced, while audit trails enable people to be held accountable for their actions. Monitoring of junior doctor decision-making has identified problematic areas thereby informing education activities.

The system also supports automation. Detection of MRSA, for example, generates an antibiotic prescription within seconds, contributing to improved infection control. It has also been linked to the HES database, to support benchmarking. The Birmingham system is being made available to other centres through commercial partners.

As discussed by **Richard Corbridge**, Chief Information Officer at the NIHR Clinical Research Network (CRN), efforts are being made to integrate data across the Network and make information more widely available, initially to NIHR users. Some 10,000 people in the NHS are funded by the CRN to deliver clinical research, supporting the recruitment of some 630,000 people into research in 2012. The structure of the Network is evolving, with 15 regional networks to be put in place by April 2014.

By linkage to HES data, an app has been developed to compare proposed sites of research activity with locations of patient treatment, helping to identify appropriate sites for research. Another app, Map My Study, will enable patients to discover what research is being carried out locally. The Network has also developed a Reference Data Service, a metadata system mapping NHS structures, to enhance data compatibility.

John Parkinson, Director of the CPRD, described some of its clinical uses. The CPRD has primarily been used for research, but with issues of consent, security and linkage comprehensively addressed, it has potential applications in real-time decision-making.

An analysis of benefits and risks is one area where it could have significant impact, helping to identify low-benefit, high-risk patients who could be taken off a medication (providing important data for value-based assessment).

The 'Flu CAT' research project is testing the potential use of real-time data feeds to support triage of patients during a flu pandemic. The 'TrialViz' application, developed to identify patients suitable for clinical trials, could also be used as an alternative to modelling of cardiovascular risk. The system can extract historical data on patients matching the profile of a specific current patient, generating information on their health outcomes.

Patients harnessing big data

Patients and citizens are the source of most data, and need to be engaged in conversations about the use of health and other data. The public are in general strong supporters of the use of health data, with understandable concerns around data privacy and misuse.

Digital engagement may be a way in which health data can be generated or dialogue established. **Dr Matt Jameson Evans** of HealthUnlocked described his organisation's experience of organising the EU's largest social network for patients.

The HealthUnlocked strategy is to provide a social media platform for use by patient groups. They have developed relationships with more than 2,000 health organisations and has some 170,000 members. Patients have been keen to contribute, generating more than two million pieces of information.

However, most contributions are unstructured comments, which raises challenges for information management and analysis. Inspired by the approaches taken by Facebook and other social media, HealthUnlocked has developed tools to analyse contributions and extract relationships as a way to identify connected content or point users towards relevant third-party content.

Quintiles, a contract research organisation, is using digital tools to engage with some three million patients, said **Chris Kula-Przezwanski**, to streamline development, demonstrate value and increase treatment adherence. It has established a range of online communities, including MediGuard, a forum for sharing information about medications and their side-effects, ClinicalResearch.com, which enables patients to identify clinical trials they could participate in, and Facebook communities.

Communication with such communities can help shape the practicalities of trial design. By connecting real world data to electronic health records, as in 'WASPS' (Wales SAIL + Patient Reported Outcomes Study), the organisation has gathered additional information on value, identifying limited understanding among patients of their medication and low levels of adherence. One way to tackle adherence is to enable patients to customise health programmes they sign up to online.

Clinical practice in the UK is heavily influenced by the National Institute for Health and Care Excellence (NICE), particularly its clinical guidelines. As **Professor Mark Baker** explained, NICE attempts to base its judgements on the best available evidence, while recognising that most sources of information are imperfect.

The strongest forms of evidence are randomised controlled trials which typically try to eliminate potentially confounding factors. In real life, however, patients generally suffer a range of health problems and may be taking multiple medications. Patient profiles in trials may also be different, further skewing cost-effectiveness analyses. Wider societal benefits have also not been taken into account, although technology assessment criteria are now being amended.

NICE has no formal hierarchy for different kinds of evidence, explained Professor Baker, and there is scope for real world observational data to feed into its decision-making. However, he argued, observational data rarely test hypotheses, limiting their usefulness.

Simon Denegri, chair of INVOLVE, emphasised that patients are very willing to participate in clinical trials and support the use of health data in research to improve patient care. Indeed, the full potential of patient participation has yet to be achieved, and it remains a challenge to enable and empower people so they can contribute fully.

More thought needs to be given to public engagement, with a lack of coordination across different bodies. He suggested a more strategic, coordinated and large-scale approach to public engagement was now needed.

The panel discussion focused on the possible impact of a 'digital divide', with so much emphasis on web-based approaches. Might groups such as older people or the socially disadvantaged be less able to contribute? While a potential issue, older people are adopting digital technology in growing numbers, while social structures such as libraries or GPs' surgeries provide sites of access to online services.

There was also some interest in 'everyday data', such as exercise or dietary logs. While initiatives such as UK Biobank do routinely capture such information in a structured form, there is probably limited scope at present to make use of self-reported information.

Conclusions

Summing up, Professor **Dame Sally C Davies**, Chief Medical Officer for England, reviewed some of the features that position the UK as a leader in the use of big data in medicine. Central to this vision is the cradle-to-grave care provided by the NHS, generating a wealth of data available through resources such as the CPRD and HSCIC (and SAIL in Wales and SHIP in Scotland).

Considerable investment have been made in these initiatives, and in the Farr Institute and Genomics England – where the UK is leading the world in generating genomic data to support the future of healthcare. NIHR Biomedical Research Centres are being encouraged to enhance their data sharing and analysis, while projects such as CRIS (Clinical Record Interactive Search), developed by South London and Maudsley NHS Foundation Trust, are showing how psychiatric service delivery can be informed by large psychiatric datasets. The MRC and the NIHR are working together to promote big data analysis in medicine and to build capacity, and charities such as the Wellcome Trust have similar interests. Other important players include Health Education England, which is working to build clinical bioinformatics skills, and the Royal College of Physicians, undertaking vital work on records standards.

In all these endeavours, people and patients remain essential partners. The public shows a strong willingness to contribute to this healthcare transformation, and will be critical to its success.

Summing up on behalf of the ABPI, **Dr Bina Rawal** described how the topic of the conference grew out of a theme emerging from the 2012 event, leading to the big data road map and the framework for the 2013 conference. The data revolution has only just begun to impinge on healthcare and pharmaceutical development, and like all disruptive changes, it offers both challenges and opportunities. The UK is uniquely placed to address the challenges and harness the opportunities to deliver economic and health benefits. Although the future is uncertain, initiatives such as the road map's first demonstrator projects may begin to illuminate the road ahead.