Building trust in the use of personal data for medical research

Tuesday 1 April 2014

Summary report of roundtable discussion

On 1 April 2014, the All-Party Parliamentary Group on Medical Research, the Association of the British Pharmaceutical Industry (ABPI) and Genomics England jointly hosted a breakfast roundtable discussion, 'Building trust in the use of personal data for medical research', to discuss ways to foster greater trust in care.data and other initiatives using personal medical data. Please note that the views reflected in this summary note do not directly reflect the views of the hosting organisations.

Chaired by Lord Turnberg, the discussion touched upon a number of key points:

The sharing of patient data and building trust

- In March 2014, NHS England announced that the launch of care.data programme would be delayed in the face of concerns raised by both healthcare professionals and the public.
- Linkage of primary health care data to additional data sets is widely seen as being beneficial, with the potential to improve medical practice, the development and use of medicines, and the allocation of NHS resources.
- It is acknowledged that care.data did not fully gain the support of general practitioners, and did not communicate effectively with public audiences, particularly hard-to-reach ones. The six-month delay was put in place in part to address these issues.
- Nevertheless, there is evidence that the public is generally supportive of the use of personal medical data, with important caveats around data privacy, the nature of the organisations allowed access to data, and the purposes for which the data might be used.
- Concerns were raised about non-inclusion of primary care data relating to conditions such as arthritis in the first potential wave of data included in the care. data programme. A timetable for how to address their inclusion will be agreed shortly.
- It is important to recognise that many of the concerns raised were valid and need to be addressed; the response needs to be substantive, constructive and not simply a more carefully orchestrated PR campaign.
- The key principles underpinning care.data will be confidentiality, transparency, and use of data only with the aim of generating health benefits.
- Legislation is one route by which safeguards are being strengthened; amendments to the Care Bill will restrict access only to projects with the potential to generate health benefits.
- The proposed wording of amendments to the Care Bill may need to be modified to capture appropriate access and usage intentions more accurately.
- Concern has been raised about sharing of sensitive personal information between Government departments. The new legislation should prevent such sharing, unless a clear health benefit can be demonstrated.
- In public communication, it will be important to stress that health and research are not different domains, and that the two naturally go together and are not independent of each other.

The value of personal data in research

- It may be helpful to 're-normalise' the public perception of medical data analysis, emphasising that it has always been a routine part of healthcare planning and research, and is essential for understanding the effectiveness and safety of medicines and planning efficient health services.
- One important benefit of care.data will be in preventing harm, such as by providing valuable information about medicines' side-effects and risk factors for adverse events. It would be helpful to have specific examples of beneficial use of data to clearly communicate its purpose.
- The nature of data to be gathered is under discussion, particularly use of individual identifiers. De-identified data protect privacy but restrict linkage to other data sets. 'Pseudonymised at source' approaches are an option but could be hard to implement widely.
- Many GPs raised concerns about potential conflicts between original care.data requirements and data protection legislation, which need to be ironed out.
- GPs were also concerned that particularly sensitive information in free text fields of medical records would be shared. There are currently no plans to gather free text information, although this is something that may be considered in the future.

The use of health records in medicine development

- Although industry has a vital role to play in delivering new medicines, its involvement is seen by the public as contentious. In part, this reflects low levels of public trust in industry, which needs to continue demonstrating its commitment to ethical practices and transparency, for example by improving access to clinical trial data for research.
- Industry is increasingly working with academia, blurring the boundaries between 'commercial' and 'non-commercial' sectors. It also has an interest in data for activities such as economic modelling to support pricing decision making. Ongoing dialogue would be helpful to clarify industry's role in accessing electronic health data.

The need for robust safeguards and controls

- Many examples exist where patient data have been used for research without raising public concern or data security issues. Examples include the Clinical Practice Research Datalink (CPRD), the Secure Anonymised Information Linkage (SAIL) in Wales, and the Clinical Record Interactive Search (CRIS) system, which draws on anonymised information held in the South London and Maudsley NHS Foundation Trust's electronic clinical records.
- Patients with rare and life-limiting conditions expect medical data to be shared to accelerate the development of new therapies. Confidentially is generally not a major concern to these patients, as long as the data is treated with respect, not shared indiscriminately, and, most importantly, not in ways that might disadvantage them.
- The Genomics England initiative, a pioneering programme to sequence the genomes of patients with cancer and rare diseases, has, to date, encountered few problems with recruitment or patients' willingness to share genetic and clinical information. Data analysis will be carried out in its own secure environment rather than being released to third parties.
- Data security is of paramount importance. However, it should also be acknowledged that no system can guarantee absolute security.
- Security could be enhanced by requiring researchers to work within the Health and Social Care Information Centre's IT environment, though this would have drawbacks. Organisations working outside this environment would be required to have a strong corporate responsibility to maintain data security, and there was also discussion about a 'one strike and you're out' policy for any breaches of security. It may also be necessary to consider criminal sanctions for serious or deliberate transgressions.

Attendee list

Charlotte Augst	Richmond Group Partnerships Manager	Macmillan
Mark Bale	Deputy Director of Health Science and Bioethics	Department of Health
Phil Booth	Coordinator	MedConfidential
Professor Mark Caulfield	Chief Scientist	Genomics England
Sir John Chisholm	Executive Chair	Genomics England
Professor Dame Sally Davies	Chief Medical Officer	Department of Health
Professor Carol Dezateux	Council Member	Academy of Medical Sciences
Dr Catherine Elliott	Director, Clinical Research Interests	Medical Research Council
Dr Jon Fistein	Clinical Programme Manager	Medical Research Council
Dr Robert Frost	Policy Director, Medical Policy	GlaxoSmithKline
Emma Greenwood	Head of Policy Development	Cancer Research UK
Tim Kelsey	National Director for Patients and Information	NHS England
Alastair Kent	Director	Genetic Alliance UK
Giselle Kerry	Data Access and Regulatory Support Officer	Wellcome Trust Sanger Institute
Professor Jonathan Montgomery	Chair	Health Research Authority
Baroness O'Neill of Bengarve		Parliament
John Parkinson	Director	Clinical Practice Research Datalink
Sir Nick Partridge	Non-Executive Director	The Health and Social Care Information Centre
Nicola Perrin	Head of Policy	Wellcome Trust
Dr Bina Rawal	Research, Medical and Innovation Director	Association of British Pharmaceutical Industry
Professor Alan Silman	Medical Director	Arthritis Research UK
Professor Liam Smeeth	Head of Department, Non-Communicable Disease Epidemiology	London School of Hygiene and Tropical Medicine
Richard Stephens	Chair	NCRI Consumer Liaison Group
Lord Turnberg	Chair	APPG on Medical Research
Dr Hasib Ur-Rub	Co-Chair	EMIS National User Group
Professor Peter Weissberg	Medical Director	British Heart Foundation
Professor Sir Simon Wessely	Vice Dean, Institute of Psychiatry and President Elect Royal College of Psychiatrists	King's College London
Lord Willis of Knaresborough	Chair	Association of Medical Research Charities
Dr Sarah Wollaston MP		Parliament