Exploring the benefits and challenges from sharing patient data

Wednesday 14th September 2016
Royal College of Physicians, London
I am pleased to welcome you to the Royal College of Physicians for the third annual Sowerby Symposium. In 2011, the Peter Sowerby Foundation was established as a charitable trust to direct funds towards Peter Sowerby’s charitable objectives, and those of his late wife Ann. The Foundation’s principal aim is to have a lasting impact through supporting well researched initiatives that can make positive changes in aspects of primary healthcare. In March 2013, the Institute of Global Health Innovation became one of the charity’s first grantees.

Peter Sowerby was a GP and entrepreneur who helped pioneer the use of electronic records in patient care at his surgery in north Yorkshire, and in 1987 founded the company now known as EMIS. It was an important milestone in the early phases of what we now know as the eHealth movement, which embraces information technology in patient care.

Electronic health records like those held in EMIS can provide valuable data sets that, when integrated, have far-reaching potential to dramatically improve patient care. At this year’s conference, we will hear from a diverse range of speakers, including researchers, doctors, and government advisers, about the potential ways that data sharing could improve patient care. We will hear examples where health data has produced tangible improvements to patient care, and discuss how the benefits of data initiatives can best be communicated to the public.

Thank you for joining us for what promises to be a very interesting discussion - taking stock of progress made since last year, and debating where we can all most helpfully apply our energies in the coming year.

Note that the event will host a live Twitter feed and you are encouraged to join the debate using the hashtag #Sowerby2016 in your tweets.

Professor the Lord Ara Darzi
Director, Institute of Global Health Innovation, Imperial College London
Conference Agenda

8:30 - 9:00  Registration and breakfast

9:00 - 9:10  Introduction and welcome
Professor the Lord Darzi, Director, Institute of Global Health Innovation, Imperial College London

9:10 - 9:30  Keynote – Effective data sharing to transform care delivery
Mustafa Suleyman, Co-founder, Google DeepMind

9:30 - 9:55  Panel discussion: How to make data sharing policy work
• Katie Farrington, Director of Digital and Data, Department of Health
• Brian Fisher, Director of PAERs Ltd
• Sharmila Nebhrajani, Director of External Affairs, Medical Research Council and Chair, Human Tissue Authority
• Nigel Mathers, Honorary Secretary of the Royal College of General Practitioners
• Fran Husson, Patient Representative
• Roger Taylor, Moderator

9:55 - 10:25  Tea / coffee break

10:25 - 10:45  Understanding ‘real life’ patient benefits in dementia research
Hilary Doxford, Vice-Chair of the European Working Group of People with Dementia & Dementia Research Champion

10:45 - 11:10  Panel discussion: From Predictive Modelling to Population Health: Applications of data sharing
• Chris Laing, Consultant Nephrologist at the Royal Free London NHS Foundation Trust, Associate Medical Director for Patient Safety
• Paul Elliot, Chair in Epidemiology and Public Health Medicine, Imperial College London
• Irina Bolychevsky, Open data consultant, Director of Shevski Ltd
• Jen Hyatt, Founder, Big White Wall
• Roger Taylor, Moderator

11:10 - 11:30  Sowerby presentation: Research findings from the Institute of Global Health Innovation Sowerby e-health forum
Erik Mayer, Dilkushi Poovendran, Rhia Roy
Sowerby e-health Forum, Imperial College London

11:30 - 11:50  Physiological monitoring in citizens’ homes within a new care model for people living with dementia
Des Holden, Medical Director, Surrey and Sussex Healthcare NHS Trust

11:50 - 12:00  Conclusions
Roger Taylor

12:00 - 13:00  Lunch and poster viewing
Professor the Lord Darzi of Denham
PC KBE FRS FMedSci HonFREng
Director, Institute of Global Health Innovation

Professor Darzi holds the Paul Hamlyn Chair of Surgery at Imperial College London, the Royal Marsden Hospital and the Institute of Cancer Research. He is Director of the Institute of Global Health Innovation at Imperial College London and an Honorary Consultant Surgeon at Imperial College Hospital NHS Trust.

Research led by Professor Darzi is directed towards achieving best surgical practice through innovation in surgery and enhancing patient safety and the quality of healthcare through global health policy. His contribution within these research elds has been outstanding, publishing over 950 peer-reviewed research papers to date. In recognition of his achievements in the research and development of surgical technology and healthcare innovation, Professor Darzi has been elected as an Honorary Fellow of the Royal Academy of Engineering, a Fellow of the Academy of Medical Sciences and a Fellow of the Royal Society. In 2013 he was elected a foreign associate of the Institute of Medicine.

Mustafa Suleyman
Keynote speaker
Co-founder, Google DeepMind

Mustafa is a co-founder & Chief Product Officer of DeepMind Technologies, a leading AI company backed by Founders Fund, Li Ka-Shing, Elon Musk, and David Bonderman amongst others, which was bought by Google in 2014 in their largest European acquisition to date. He is now Head of Applied AI at Google DeepMind, responsible for integrating the company’s technology across a wide range of Google products. He launched DeepMind Health, the company’s big effort in building clinician-led technology in the NHS. At 19, he dropped out of Oxford University to help set up a telephone counselling service, building it to become one of the largest mental health support services of its kind in the UK. He then worked as a policy officer for the Mayor of London Ken Livingstone. Mustafa went on to help start Reos Partners, a boutique consultancy with eight offices across four continents specializing in designing and facilitating large scale multi-stakeholder ‘Change-Labs’ aimed at navigating complex problems. As a skilled negotiator and facilitator, Mustafa has worked all over the world for a wide range of clients such as The UN, The Dutch Government and WWF.

Roger Taylor (Moderator)
Writer and entrepreneur

Roger is founder and chair of the Open Public Services Network at the Royal Society of Arts. He co-founded Dr Foster, the healthcare information business that has pioneered transparency in healthcare and was one of the UK’s fastest growing start-ups. His first book God Bless the NHS was published by Faber and Faber and was a Guardian best-seller. His second book, Transparency and the Open Society co-authored with Tim Kelsey, was published by Policy Press in June 2016.

He is a board member of Ofqual, the exam regulator in the UK and a trustee of SafeLives, the domestic abuse charity. He has worked with governments, NGOs and leading media organisations globally on the use of open data and public reporting. He is a strong advocate for the role of greater transparency as a mechanism for improved public services and consumer protection.
Irina Bolychevsky
Open data consultant, Director of Shevski Ltd

Irina is a globally recognised expert on open data, data platforms, data standards and decentralised technology.

From 2011 to 2014, she led the ckan open source open data platform project, which powers the official national data portals of over 20 countries and numerous local and community installations. She defined the product, strategy and brand for ckan, while winning and delivering key contracts with the UK, US governments and European Commission. In 2014 she joined Open Knowledge’s senior management team as Commercial Director, leading on commercial and technical consultancy work.

She has since worked as a consultant for multiple organisations and governments, including the W3C and Open Data Institute, and is the founder of redecentralize.org — a project to promote and bring together people who are working or interested in decentralised digital technologies.

Hilary Doxford
Vice-Chair of the European Working Group of People with Dementia & Dementia Research Champion

Hilary is the representative for England on Alzheimer Europe's, European Working Group of People with Dementia and a member of the World Dementia Council. She participates in research trials and projects and is a champion for ‘Join Dementia Research’. In December 2012, at the age of 53 Hilary was diagnosed with early onset Alzheimer’s Disease. She is keen to do all she can to assist in finding a cure for dementia and volunteers for the Alzheimer’s Society in England as part of their research network and user involvement programme and is also an Ambassador for the Society.

Paul Elliot
Chair in Epidemiology and Public Health Medicine, Imperial College London

Dr Elliott is a Professor of Epidemiology and Public Health Medicine at Imperial College London and Director of the MRC-PHE Centre for Environment and Health. He is academic theme leader for the Informatics and Biobanking research theme of Imperial’s Biomedical Research Centre. His research interests include environmental and genetic risk factors for non-communicable diseases, cardiovascular epidemiology and biobanking.

He is a founding member of the UK Biobank Steering Committee and currently chairs the Enhancements Working Group and a member of the NIHR BioResource Steering Committee. He is leading the UK MED-BIO project that is developing high powered computing resources for handling “big” data. He is the Imperial College AHSC Director of Information Governance with responsibility for ensuring compliance with current data and ethical regulations and development of joint initiatives with NHS colleagues to improve data quality and security for clinical and translational research.
Des Holden
Medical Director, Surrey and Sussex Healthcare NHS Trust

Des was appointed as a consultant in Obstetrics and Gynaecology at Royal Sussex County Hospital in 2000 after a role at St George’s Hospital Medical School where he was the Lecturer in Fetal Medicine. He became an Honorary Clinical Senior Lecturer at the Brighton and Sussex Medical School in 2003. Des held various managerial posts at Brighton and Sussex University Hospitals (BSUH), going on to become Medical Director. After leading on the redesign of the safety and quality strategy at BSUH, he was appointed as the Clinical Director of the Enhancing Quality Programme, reducing variations in the management of several common clinical diagnoses across all acute trusts in Kent, Surrey and Sussex.

He is currently Medical Director at Surrey and Sussex Healthcare NHS Trust (SASH) and joined the SASH board in June 2011. He is a regional expert and advisor to APEC, the national charity supporting action against pre-eclampsia.

Fran Husson
Patient Representative

Fran is a Patient Representative who uses her own experience of acute illness and long term conditions to actively support initiatives and interventions designed to spread and quicken the implementation of digitisation across all health and social care settings. This lay partnership with professionals covers different fields and topics such as patient assessment of recent Patient Online implementation in primary care, patient-held information about medication and implications for the development of EPRs and EHRs, impact of electronic prescribing for both patients and inpatients and technology-supported medicine optimisation. Her outreach work to raise awareness of all the benefits of sharing data to achieve truly integrated medical records is titled “I share because I care”.

Brian Fisher
Director of PAERs Ltd

Dr. Fisher has been a GP in SE London for 35 years and is involved with the Lewisham Clinical Commissioning Group in various projects. For many years, he has been interested in user involvement in the NHS, including community development (for which he was awarded an MBE), Patients as Teachers, patient access to their health records and working with colleagues to ensure that lay people’s views are incorporated in the daily work of CCGs.

He is Vice-Chair of the New NHS Alliance and chair a national group that brings together key organisations and individuals who are passionate and well-informed and active in community development and health. He has championed patient record access, and is now the director of a company called PAERS Ltd that is on the government Framework to offer Patient-Facing Services to England. This includes free, secure, online access to your own GP electronic health record. He has published research in the field.

Katie Farrington
Director of Digital and Data, Department of Health

Katie is the Director for Digital and Data in the Department of Health, responsible for data security and data sharing; information and transparency, including business sponsorship for the Health and Social Care Information Centre; and digital strategy. Katie led Dame Fiona Caldicott’s review team for her review of data security and consents / opt-outs, published on 6 July. She has worked in Cabinet Office, as the head of the public services team in the Economic and Domestic Affairs Secretariat, and in the Department for Education, on early years education and school standards including Ofsted, testing and the teaching of English, mathematics and science and technology.

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**Nigel Mathers**
Honorary Secretary of the Royal College of General Practitioners

As Honorary Secretary of the RCGP, Professor Mathers has responsibility for governance of the RCGP and leads on all College consultations, also hosting the College’s leadership and workforce portfolios. Professor Mathers qualified as MB ChB in 1979. The run-down, single person inner-city Sheffield practice he took over in 1989 has now grown to a four-partner teaching practice providing clinical placements for medical, nursing and counselling students as well as two GP Registrars. He led the development of RCGP’s Clinical Innovation and Research Centre (CIRC) and was appointed to the NHS Evidence Advisory Board in 2008.

He has been an expert witness to the House of Lords, and a member of the Advisory Group on Welfare Reform for the DWP. He has also been Chair of the Trent RDSU, Trent Focus and the Sheffield Health and Social Research Consortium on behalf of the NHS.

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**Jen Hyatt**
Founder, Big White Wall

Widely recognised for her achievements in the fields of social entrepreneurship and digital technology Jen has founded or co-created over 30 organisations worldwide. In 2007 Jen founded Big White Wall (www.bigwhitewall.com) as she recognised that stigma and poor access were preventing millions from getting mental health support. Using digital technology and data analytics, Big White Wall has transformed the mental health journey into one of personalised support and recovery that is available immediately and anonymously 24/7. In 2013, Jen also created the Collaborative on Health and Technology (ChaT) to help evidence-based digital healthcare companies achieve scale in the UK (chat-healthtech.com).

Jen has won multiple awards for her work, including 2016’s Women in IT’s Innovator of the Year. She was also invited to be a fellow of the Royal Society of Arts and to sit on the Strategy Committee of the Guy’s and St Thomas Charity. Currently, Jen is launching ‘Troo’, a new enterprise focused on developing a digital approach to the improved social, physical and psychological health of teenagers.

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**Chris Laing**
Consultant Nephrologist at the Royal Free London NHS Foundation Trust

Dr Laing is a consultant nephrologist at the Royal Free London NHS Foundation Trust and is associate medical director for patient safety. He trained in nephrology and internal medicine in north London and undertook advanced training in critical care in the Thames region. He undertook research training at University College London under the supervision of Professor Robert Unwin, including a secondment to INSERM PARIS, achieving MD(Res) UCL.

Dr Laing is also currently associate medical director for patient safety. In this role he provides senior clinical leadership on matters relating to patient safety. This includes oversight of the investigation and learning from safety incidents as well as providing clinical leadership to the trust’s patient safety programme. The latter is a large cross-trust quality improvement programme aiming at reduction in avoidable harm. This is the largest cross-trust patient safety improvement programme in UCL Partners.

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**Sharmila Nebhrajani**  
**Director of External Affairs, Medical Research Council and Chair, Human Tissue Authority**

Sharmila is the Chair of the Human Tissue Authority, and has been in this role since April 2014. She is also Director of External Affairs for the Medical Research Council. Sharmila was previously Chief Executive of the Association of Medical Research Charities (AMRC) after a varied career spanning business, media, technology and health. She spent 12 years at the BBC latterly as Chief Operating Officer of BBC Future Media and Technology, managing the business functions of bbc.co.uk including the launch of the iPlayer. She also served for two years as Executive Director of Finance and Performance for NHS Sussex.

Sharmila is currently Board Member of the BMJ, the Pension Protection Fund and the General Council of University of Sussex as well as Independent Trustee-director of LifeSight, a pension Master Trust. Her previous non-executive roles encompass a broad range of sectors including deputy chair of the Human Fertilisation and Embryology Authority, the body that regulates all embryo research and licences assisted reproduction clinics in the UK and six years as a Charity Commissioner. In addition to her non-executive work, she was a World Fellow at Yale University in 2007/08 where she lectured on both media policy and practical cases in medical ethics.

**Erik Mayer**  
**Clinical Senior Lecturer at Imperial College London**

Erik is an Honorary Consultant Surgeon at Imperial College Hospital NHS Trust and The Royal Marsden Hospital. He completed a PhD thesis evaluating aspects of the Quality of Care in Surgery with emphasis on improved techniques for appraising surgical performance and outcomes. Continued research in this area is undertaken in the Centre for Health Policy (Institute for Global Health Innovation) and includes evaluating metrics that encompass the entire patient pathway and novel assessment tools for capturing the quality of the patient experience during treatment episodes. His health services research routinely uses big data analytical techniques for evaluating quality and safety in healthcare. Combined with qualitative data, this mixed methods approach provides an ideal platform for policy evaluation and translation of evidence-base to the real world healthcare setting, focusing on the intersection of healthcare policy and practice.

**Dilkushi Poovendran**  
**Research Fellow, Sowerby eHealth Forum**

Dilkushi is a researcher funded by the Sowerby e-Health Forum at Imperial College, leading on a programme of work that focuses on communicating healthcare data sharing schemes to the public. She has a background of using mixed methods approaches to conduct process evaluations of randomised controlled trials in order to understand how and why clinical outcomes are achieved. Prior to joining the Centre for Health Policy, she was a clinically-based health services researcher in mental health and addiction treatment settings, investigating evidence-based approaches in the treatment of opioid dependency. She is a PhD candidate with an interest in the development of evidence based mental health policy, with a dissertation focussing on the process of recruiting treatment providers, clinicians, and patient participants into randomised controlled trials in community drug treatment services.

**Rhia Roy**  
**Research Fellow, Sowerby eHealth Forum**

Rhia is a researcher on the Sowerby e-Health forum at Imperial College, investigating whether patient-held records can be a cost effective method of improving shared decision between patients and doctors. She is completing her MSc in Health Policy, Planning, and Financing at the London School of Economics and the London School of Hygiene and Tropical Medicine. She is currently on secondment from the Department of Health, where she was Private Secretary to health ministers covering a broad portfolio of areas including workforce and medical education policy.
Poster sessions

Estimating under-diagnosis of rheumatoid arthritis in primary care data from the UK Clinical Practice Research Datalink
Michael Soljak

Palliative Care in the Digital Age: Identifying the need for patient-held, shared electronic care plans in patients aged 70 years+ admitted as an emergency
AM Bielinska

Better Use of routine Data to improve Satisfaction - BUDS
Susanna Sakonidou

e-iatrogenesis, eHealth and the role of regulation: what is the status quo?
Guy Martin

Public involvement in connected healthcare for greater Manchester
Sarah Thew

Advanced analytics on joined-up datasets
Sarah Jasim

Making electronic interventions engaging: Development of a smartphone app targeting harmful drinking in adults
Joanna Milward

How Well are Digital Technologies Working for Patients? A Patient-Centred Framework for Evaluating Digital Maturity
Kelsey Flott

Enhancing Recovery after Surgery: Wearable technology and the future'
Aliza Abeles

Quantified self for obesity: Physical activity behaviour sensing to improve health outcomes
Dave Taylor and Ahmad Mian

Primary and secondary care doctors’ views of the benefits of patient-accessible electronic health records
Dilkushi Poovendran

Patient access to medical records: a longitudinal evaluation of care information exchange in north west London
Sagar Jilka
Exploring the benefits and challenges from sharing patient data

The Institute of Global Health Innovation works to improve global healthcare through evidence based innovation.

This conference is made possible by the support of the Peter Sowerby Foundation, whose grant to the Institute of Global Health Innovation supports a programme of research and development in this area. The Peter Sowerby Foundation was established in 2011, to direct the personal wealth of Dr Peter Sowerby as grants to organisations that meet the charitable objectives of Dr Peter Sowerby and his late wife, Ann.

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Get in touch

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Join the debate
Follow the event on Twitter using the hashtag #Sowerby2016