

Primary Care's pivotal role regarding patients and their data

Britain Against Cancer
Tuesday, 05 December 2017

Summary

“We all need to be part of this discussion about consent to sharing our personal health data: to move on from a premise that risk, in relation to privacy, trumps its beneficial use in health care.”

Patient Advocate, use MY data

Contents	
Background to the session	Page 03
Aims of the session	Page 03
Chair's introduction	Page 04
The historical context of the current data opt-out situation	Page 04
Why patients opt-out of their data being used	Page 05
The crucial role that GPs play in helping patients decide about data options	Page 06
The proposed National Data Opt-out model and, how patients and the public can better work with GPs to achieve understanding of the rewards and risks of opting in and out of data sharing	Page 06
Discussion, questions and answers	Page 07
Biographies	Page 09
Useful links	Page 11

Background to the session

use MY data is a movement of patients, carers and relatives. Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

We provide learning resources for patient/carers advocates on patient data issues, including running workshops focussed on patient data issues. At our January 2017 workshop we held a session *Primary care & data collection: the impact on the GP & the patient* to examine the role of primary care with regard to the concerns of patients about data usage, sharing and options. We heard from GPs about the current situation and the ways in which conversations with patients are approached, or why they are not approached. GPs told us that they do not receive any formal training about data (the sharing and secondary use of data), and yet they are often the first port of call for patients with concerns about how their data are used. The GPs who took part in our session felt that a leaflet is not enough to explain data consent options and issues to a patient.

With clinical time constraints, is it actually possible to explain to a patient all of the potential rewards and risks of their data being used? If it is not possible to explain, how can a patient make a truly informed choice?

The Government's response to the National Data Guardian's recommendations about the new National Data Opt-out states "we will support professionals to implement the national opt-out successfully".

Ahead of the National Data Opt-out in March 2018, use MY data members want to focus on the challenges facing primary care. From our own straw polls up to December 2017, GPs did not seem to have been informed about the Opt-out and our members wish to do all they can to aid GPs in this area.

Given that the GP practice is one of the main places for patients to have conversations about their health and about the uses of their data, this session will discuss issues such as the lack of training and materials for GP staff and the risk to the continued use of data for analysis and research.

Aims of the session

Our aims for the session were for attendees to leave with an understanding of:

- the historical context of the current data opt-out situation
- why patients opt-out of their data being used
- the crucial role that GPs play in helping patients decide about data options
- the proposed National Data Opt-out and how patients and the public can better work with GPs to achieve understanding of the rewards and risks of opting in and out of data sharing.

Chair's introduction

Chris Carrigan, Expert Data Adviser, use MY data

Welcoming attendees, Chris gave a brief overview of the reasons for holding the session. When promoting the session use MY data received responses from several GPs who had picked up on the statement "GPs receive no formal training about data". GPs told us that they do indeed receive formal training and follow-up conversations ensued. These revealed that the GPs were referring to training about data protection and confidentiality, not training about the rewards and risks of sharing and using patient data for secondary purposes.

NHS England were invited to take part in the session, to reference communication plans in preparation for the implementation of the National Data Opt-out. However, it was not possible for NHS England to send a representative.

The historical context of the current data opt-out situation

Dr Alan Hassey, Member, National Data Guardian's Panel

Using patient data is fundamentally about trust. This was reflected in Dame Fiona Caldicott's 2016 'Review of Data Security, Consent and Opt-Outs' (which references trust 79 times).

Alan referenced the Care.data programme and associated opt-outs, for which concerns continue. Care.data gave rise to an increase in opt-outs:

- Type 1 opt-outs – prevents information being shared outside a GP practice for purposes other than direct care
- Type 2 opt-outs – prevents information being shared outside of NHS Digital (previously called the Health and Social Care Information Centre) for purposes beyond the individual's direct care.

In September 2015 the Secretary of State asked Dame Fiona to develop a single question consent model. Dame Fiona delivered her recommendations in February 2016, and they were published in July 2016. Responding in July 2017, the Government accepted all of the recommendations.

Dame Fiona's recommended approach follows the "no surprises" principle for how patient data should be used. A key recommendation is that, whether patients opt-out or not, they should be reassured about the security of their data and that legal protections are in place. The Opt-out should apply beyond direct care. It should not apply to data anonymised within the Information Commissioner's Office (ICO) Code of Practice on Anonymisation.

The timescale for the National Data Opt-out, March 2017, ahead of the implementation of the General Data Protection Regulation in May 2017 is challenging.

Patients are often left confused about the best course of action. The more complex things are the harder for GPs to understand and discuss with their patients. It is a key role of primary care professionals to give reassurance to patients about the use of their data. Dame Fiona's 2016 Review focused on making data a more regular conversation. How do we take patients with us on the journey, so they can make informed choices about the use of their information? It is vital that there is consistency of message around what people's options are. The opportunity to use patient data to make improvements is immense.

Dame Fiona's National Data Guardian panel works hard to encourage a joined-up approach; at the end of the day it's about patients.

Why patients opt-out of their data being used

Paul Charlton, Patient advocate, use MY data

Paul does not usually reveal his own family's experience of ill health. However, he is angry about the risk to the use of patient data and he contextualised that anger by explaining some of his family's story.

Paul's oldest daughter was born in 1984 in August: her mother died 15 months later from lung cancer. Her cancer was of course a late diagnosis as an emergency presentation at hospital. Treatment was palliative radiotherapy at Barts Hospital in London – where their daughter had been born by elective Caesarean due to her mother's heart disease. At age five his daughter's Type 1 diabetes emerged. In 1994 Paul's youngest child was born. His son was five when his mother died of stomach cancer – her cancer of course was a late diagnosis as an emergency presentation at hospital. Another of Paul's daughters has myotonic dystrophy, the most common form of muscular dystrophy – diagnosed at age 23 early into her midwifery training, when she didn't have sufficient strength in her hands to hold the baby and also carry out another action. Consequently, Paul was drawn into health research in primary care to improve early cancer diagnosis and is now a National Institute for Health Research (NIHR) Patient Research Ambassador.

Personal privacy should not outweigh the potential health benefits to patients of increased data-sharing. The great majority of patients, who are informed about how personal health data is used or can be used, do not want to opt-out of that usage. We want our data used!

Why the anxiety about the beneficial use of patients' healthcare data? It's important to have a robust public conversation to be more communicative about the benefits of data sharing. Primary care is currently left to do its own thing in relation to data. It is difficult to understand how the NHS mandates data sharing for secondary health care, but just leaves primary care to do its own thing. It's important that patients who want to have their data shared have an advocate in their GP.

There is a narrative that there is risk to our privacy in the use of personally sensitive health data which constitutes a greater harm than the benefits using this data brings to our families and friends.

Paul highlighted a research initiative, VICORI, that has been bringing together the cancer and heart disease datasets; there are obvious advantages in being able to see crossovers. We can understand how these two diseases and their treatments interact – when cancer meets heart disease or when heart disease meets cancer – as with Paul's wife. As a patient member of the VICORI study management team Paul has unfortunately learned about the opposition within some of the medical community to connecting the data systems.

We are still battling to get linkage between the cancer and cardiovascular registries, let alone other key datasets (such as primary care prescribing data, Hospital Episode Statistics, Office for National Statistics). This is a tragic wasted opportunity and arises from an excessively zealous over-protection of data due to a misconception of the true risk of dissemination of patient sensitive information.

We all need to be part of this discussion about consent to sharing our personal health data: to move on from a premise that risk, in relation to privacy, trumps its beneficial use in health care.

There is a disparity between the public's expectations of accessing health data when compared to other things, such as financial data (e.g. online banking). Paul asked that, as with financial or other consumer information, to achieve his consent just let him know:

- firstly – what data about me do you have, and
- secondly – what you are doing with it.

Paul asked: "Stop preventing the use of my personal health information because of privacy: just get on with letting me know". In parallel to Public Health England's 'Be Clear on Cancer' campaign, we need a 'Be Clear on Data' campaign. We need to inform the public of the consequences of not sharing data.

The crucial role that GPs play in helping patients decide about data options

Dr Arjun Dhillon, GP & Deputy Caldicott Guardian for NHS Digital

The culture of confidentiality is embedded in healthcare professionals, on top of which is the Data Protection Act. Individual patients will opt-out and opt-in on various issues which often conflict with one another. Day to day, data requests come in many forms. This can highlight conflicts e.g. a patient opting out of their Summary Care Record or making a Type 2 objection, but consenting to take part in a clinical trial. Without patients seeing their own records/audit trail, how can they consent/make informed choices?

Primary Care is under an increased burden. Many GPs are already struggling to balance everything legally required of them. Data protection legislation is ever-evolving and complex. There is a collective responsibility to train GPs and ensure consistency about information. This hasn't been good enough in the past. GPs are generally quite reactive about data sharing and struggle to be proactive, often relying on patient proactivity and understanding.

The reaction from society and GPs is distorted by a lack of trust. About 2% of patients in Arjun's practice have opted out. They don't trust the system and there is a need to make clear the benefits of patient data sharing. There is an element where it is easier not to share and increasing shades of gray, where those at the coalface may not be best placed to answer patients' questions. Where patients have opted-out, they are typically those who are well-informed, fit a specific demographic and usually have been supported to be able to opt-out.

We also need to get the health workforce up to standard on transparency and the importance of sharing information. The current system doesn't share the data it already has in an efficient way. The Cancer Dashboard for example, already contains a great range of useful information but this is often overlooked or not integrated properly. Supporting patients to make good data decisions is part of providing good care. NHS Digital is committed to sharing data in a safe and transparent way.

The proposed National Data Opt-out model and, how patients and the public can better work with GPs to achieve understanding of the rewards and risks of opting in and out of data sharing

Dr Richard Roope, RCGP / Cancer Research UK Clinical Champion for Cancer

Richard began by stating that data is vital to everything GPs do, and at the heart of the interface between GPs and patients. GPs know a lot about data, but don't know much about the National Data Opt-out. The role of GPs in relation to the Opt-out is pivotal. We need to increase awareness across primary care: GPs, nurses etc.

The Royal College of General Practitioners (RCGP) has set up the Patient Data Choices Project in response to the Opt-out. There is a lot of myth-busting to do. A programme manager within the Clinical Innovation and Research Centre (CIRC) has been appointed, as well as a new clinical champion for the Project; Dr Geoff Schrecker.

The Project will have e-learning modules, webinars, train the trainers pack, case studies. As an education event for GPs ahead of the Opt-out, a national conference is planned for March 2018, alongside six regional workshops. GPs need to be trained and equipped. The RCGP is committed to informing all GPs – 50,000. The willingness of GPs to engage is essential.

The overwhelming views from patients and carers is that others should benefit from the patient's data. Yet, there is a lack of understanding amongst politicians, policy makers and media professionals about the importance of data. There is therefore a huge role for better educating these different audiences.

Without data you change nothing. You cannot address inequalities unless you have data to demonstrate inequalities. Everyone is instantly aware of the risks of data sharing. The greater risk is not releasing data; the next generation cannot benefit from your data. Opting-out may seriously damage your health.

Panel discussion / Q&A

Opting out - why did some GPs opt their practices out?

- Data (unpublished at the date of the session) shows opt-out by practice and it seems that this tended to happen where GPs have personally had a bad experience.
- Where professionals are uncertain/confused the default position is not to share data. This is reinforced by fear; many health professionals are worried about potential ramifications e.g. from the General Medical Council (GMC) rather than the Information Commissioner's Office (ICO).
- It is important that positive ways of promoting data usage also happen more regularly. The whole narrative context of data is negative. Public engagement on this is important – signposting people to good practice and guidance.
- Patient Participation Groups (PPG) within practices have also been influential in encouraging a practice to opt-out. A GP in the audience gave the example of her practice where the PPG encouraged the opt-out, driven by fear. Now there is recognition that the data is needed and the practice is moving towards opting back in.
- Another GP noted that Care.data means a lot of work needs to be done in terms of trust and reassurance. Key conversations will be between care professionals and patients. There is a fear that the more you tell people the more you risk them opting out. Dame Fiona's position is that people need to know what is happening with their data.
- How to get patients who opted out under Care.data (which is around 1-2% across GPs surgeries) to opt back in? The National Data Guardian's perspective is not to *persuade* people to opt back in, but to give them all the information necessary to make a fully informed decision.
- GP websites can be a wonderful resource for information about data sharing and consent. Of course they cost money to update, but data is worth money.

Data sharing and security

- We need to get to the state where we share patients' existing records with them. This would mean openness, transparency and the possibility of challenging the records. It is about the journey of trust in a wider sense, beyond data.
- It was noted that we are at the beginning of an Artificial Intelligence (AI) data revolution.
- We need to collect data to drive early diagnosis. The opposition to using data and changing things is immense. We have to find a way to communicate potential benefits when it's unknown.
- The importance of talking about the risks of not sharing data was emphasized. If data are withheld, we can't advance treatments or analyse patient experience. The risks of not sharing are greater than sharing.
- We can make the case that by sharing data it can be linked/have correlations. Fear is always strong than altruism. This is not a medical problem, but is impacting on the medical profession. Public engagement is key and use MY data, Understanding Patient Data, The Farr Institute are all working in this area – we need more open conversations about what interconnectivity means.

- Security is every bit as important. While the WannaCry attack did not cause a data breach, it was effectively a denial of service. Although the system can never be 100% secure, we need to have the infrastructure that enables us to feel reasonably confident.
- Encryption of NHS data is robust and we can be confident in promoting this to patients. It is important to develop more robust industry standards so that health professionals can feel more confident in relation to data issues. This leads to transparency and results.
- Data consent/sharing outside of the UK was touched upon, briefly. The General Data Practice Regulation (GDPR) will align the UK with Europe. There is a fundamental clash between the National Data Opt-out and GDPR.

Communications – the importance and difficulties

- Many problems around the sharing of data have arisen from poor communications and communications are still not as connected as they could be. We have still not seen enough of the detail on the National Data Opt-out to know what's happening, and the GDPR guidance is not yet out.
- The next substantial step will be translating the usage from primary care environment into secondary care decisions.
- Primary Care has a huge challenge to get the message to 50,000 GPs by March 2018. Consistency of message is essential.
- A Suffolk CCG has commissioned a local Learning Disability charity to produce an easy read leaflet on consent opt in / out.
- It is really important that everyone is engaged.
- The message is not neutral; there is an unconscious bias working all the time. Care.data sits in the consciousness. The very use of the word 'Opt-out' is biased towards opting out.
- There are a lot more patients than there are professionals – we need patient power to communicate the rewards of sharing and using patient data.

Biographies

Chris Carrigan

Chris Carrigan is a specialist in cancer data and information, but with a particular focus on patient involvement and patient power, based from the University of Leeds MRC Bioinformatics Centre.

Chris has a range of interests around patient involvement and the uses of patient data and is Expert Data Advisor to use MY data, which he has done since leaving Public Health England in June 2016.

Previously, Chris was a founding member of the National Cancer Intelligence Network (NCIN), a partnership putting patients at the heart of how their data is used funded by a range of bodies, including the public sector and leading cancer charities, tasked with providing new insights and intelligence into cancer inequalities, diagnosis, care, outcomes and experience.

In 2014 he was named as one of the Health Service Journal's Top 50 Innovators in the NHS for his innovative and collaborative approach to patient empowerment, and also featured on BBC Radio 4's Networking Nation series, where the NCIN was highlighted as a leading example of how best a network can operate.

Chris is also Chair of an advisory group for NHS Digital, IGARD - the Independent Group Advising on the Release of Data.

Paul Charlton

Paul has significant family experience of cancer, including early cancer death, as well as with a number of other metabolic and neurological conditions. He spent six years on the National Cancer Research Institute's Primary Care Clinical Studies Group, with a specific interest in early cancer diagnosis and GP decision making support tools.

His current research involvement includes study advisory group membership for a cancer and heart disease data linkage analysis as well as:

- Patient Research Ambassador for the National Institute of Health Research
- Lay member of the Cancer and Nutrition Research Collaborative
- Lay advocate with the National Cancer Research and Analysis Service
- Lay member of the Health Technology Assessment Commissioning Board.

Paul's current work is in supporting adults with learning disability. He has recently published an anthology of poetry *Love's Music* exploring the emergence, experience, loss and remembrance of love.

Dr Arjun Dhillon

Arjun supports the Caldicott Guardian and Senior Information Risk Owner (SIRO) to ensure they are meeting their obligations and support the implementation of the new General Data Protection Regulation (GDPR) regulations. He also provides clinical support to the Information Governance teams and works closely with the Independent Group Advising on the Release of Data (IGARD) team.

Arjun's aspiration is to promote transparent data usage to improve our system for the benefit of our patients and has a keen interest in elderly care.

Previously, he was Director of a Primary Care Web Tool and was a GB Member of Ealing CCG. He was also Chair of the Royal College of General Practitioners Health Informatics Group (RCGP HIG) and Joint GP IT Committee (JGPITC) and was Managing Partner and Trainer at The Argyle Surgery.

Dr Alan Hassey

Dr Alan Hassey MSc MB BS DRCOG FRCGP was a GP in Skipton, North Yorkshire until retiring from general practice in June 2013.

Alan is a member of Dame Fiona Caldicott's National Data Guardian Panel and is the HSCIC IG Clinical Lead & Deputy Caldicott Guardian.

He is a member of the RCGP Health Informatics Group (HIG), past chair of HIG and the Joint GP IT Committee of the BMA & RCGP and in October 2017 became one of the Founding Fellows of the UK Faculty of Clinical Informatics.

Dr Richard Roope

Richard is a Portfolio GP working in Primary Care and Cancer Management. Richard studied at Gonville & Caius College, Cambridge and The Royal London Hospital, qualifying in 1987. He did a Masters in Occupational Medicine in Manchester. He started working within cancer services in Hampshire and Wessex in 2002.

In 2014 he was appointed as the RCGP and Cancer Research UK Cancer Champion and, in 2015, as one of the Senior Clinical Advisors for Cancer Research UK. He is a member of several national steering committees, including the National Cancer Advisory Group and England's Be Clear on Cancer Steering Group.

In 2015, he was elected to Fellowship of the RCGP for contributions to Cancer Management. In his leisure time, he sings in a choir, and cycles, sometimes raising money for Cancer Research UK.

MA, MBBS, MSc, FRCGP, AFOM, MFMLM

Useful links	
Royal College of General Practitioners - Patient Data Choices Project	http://www.rcgp.org.uk/clinical-and-research/our-programmes/innovation/patient-choices.aspx
The Farr Institute	http://www.farrinstitute.org/
General Data Protection Regulation (GDPR)	https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/
General Medical Council (GMC)	https://www.gmc-uk.org/
Information Commissioner's Office (ICO)	https://ico.org.uk/
National Data Guardian	https://www.gov.uk/government/organisations/national-data-guardian
National Data Opt-out	https://digital.nhs.uk/national-data-opt-out
NHS Digital	https://digital.nhs.uk/
Patient Participation Groups	https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2016/09/ppg-introduction.pdf
Understanding Patient Data	https://understandingpatientdata.org.uk/

www.useMYdata.org.uk

getinvolved@useMYdata.org.uk

[@useMYdata](#)