

The patient voice – who is listening?

**use MY data workshop
Summary**

26 January 2017

**Lift, 45 White Lion Street
London, N1 9PW**

Session 1 – Can patients control how their data are used?

This session examined existing initiatives where patients lead on the use of their data and the impact of this. It also looked at potential initiatives where patients want to lead on the use of their data & the possible impact for research and outcomes.

Andy Smith, Patient advocate, use MY data presented his own cancer record, drawn largely but not exclusively from the National Cancer Registration and Analysis Service (NCRAS), analysing what is there, what's missing and why. Andy had found that the information recorded was accurate but incomplete in some areas. There was much detailed data about diagnosis and treatment. Andy emphasized that his healthcare data (and therefore NCRAS) describes the treatments he was given, but doesn't hold anything about him as a person e.g. political views, sexual orientation, shopping habits. This contrasts with the information that our internet histories, smartphones, loyalty cards etc. collect about us.

Michelle Morris, University Academic Fellow, Leeds Institute for Data Analytics gave an overview of how lifestyle data are recorded: the traditional methods versus what can be recorded now using schemes such as store loyalty cards and health activity trackers such as Fitbit. How can we use the new data? Is it better than traditional methods of recording data? Twelve weeks of lifestyle data from 800,000 individuals gave 21.5 million transactions. There is great potential for data gathering and data usage, and there are very important governance issues, not least in describing to the public what is gathered, the benefits of its use and ensuring that it cannot be exploited in ways which might cause harm.

Sophia Turner, Patient advocate, use MY data used her own data journey through cancer to illustrate why she joined healthbank. Sophia gave several examples of how she had given permission for her data to be used in studies but that this had not taken place or, if it had, Sophia did not receive any feedback. Trying to promote her data for research eventually led Sophia to healthbank, a system in which data can be stored and shared as the patient wishes. There are many reasons for data sharing but healthbank enables two and these can be taken up immediately:

- 1) data sharing for the patient's own benefit: to be able to share information with different consultants/clinics/countries - for data sharing between specialists (enabling holistic treatment), for the patient's own records, for use when travelling
- 2) for the benefit of research (the added value of a large, international dataset).

A discussion with the audience followed, during which the following issues were raised and debated:

- *GPs often have little information about a patient's secondary care cancer treatment, as the diagnosis pathway or treatment information is often not passed back*
- *Does a patient's mental health state have an effect on their outcomes?*
- *Did the environment I lived in affect me?*
- *Connected Health Cities is a pilot (across the whole of the north) to share data outside of direct care. The opinions of patients are needed on how best to access it.*
- *Can missing parts of a primary care record be added in?*
- *As a patient your data does not travel with you. We need connected data in our systems and we need the patient voice.*
- *When younger your data is more precious and its use can have more of an effect on your life, then when you're older.*
- *The NHS is unique and data could drive the NHS a lot better. Could look at longer effects as individuals.*

Session 2 – The media & patient data: is the patient voice heard?

This session examined the role of the patient voice in the media and the coverage of patient data in the media. We looked at how influential the patient voice could be, why it is not heard at present and how a more balanced media view of the uses of patient data might be achieved.

Polly Toynbee, Journalist, The Guardian said that as well as being at the forefront of stories about data misuse, the Guardian also needs to lead on stories about the good uses of data. The collection of medical data is not something to be scared of, when used properly. We have the greatest longitudinal studies of anywhere in the world. It is fantastic for a whole lot of patients to get together, to try and pay back and think about responsibilities.

Daniel Nesbitt, Research Director, Big Brother Watch stated that Big Brother Watch opposes bad data collection and sharing. In terms of consent Big Brother Watch is always in favour of an opt-in model, as this creates active and engaged stake holders.

The late Dr Rosamund Snow, Patient Editor, British Medical Journal spoke about data in relation to being a patient and a researcher. Dr Snow said that, as her data had been used since her diagnosis, she felt it important to design what happens to the data. As Patient Editor of the BMJ Rosamund was one of only two patient editors in the world. Research that is publicised in the BMJ has to say how patients have been involved and how they will be informed. There is a patient authored series in the educational section of the BMJ, which is changing the curriculum for ongoing patient education. Rosamund encouraged delegates interested in data and research to sign up to the BMJ.

John Reeve, Patient advocate, use MY data & Bloodwise Trustee spoke about research in relation to his youngest son, Tim. Three days before he died Tim was in bed, in the “death room”, when a junior doctor cautiously asked Tim if he would give additional blood samples for research. Tim agreed that, if they would help some-one else, the samples could be taken. Things work best in equilibrium; we’re all very aware of our rights and we have responsibilities too. One of our responsibilities as patients is to help those who follow after us. The future vision for data use could be one of two: either data stops being used and research grinds to a halt or there is a positive vision that highlights all that data can make possible.

Dr Peter Sasieni, Professor of Biostatistics and Cancer Epidemiology, Queen Mary University of London joined the panel for the debate and discussion section.

Together the panel and the audience explored ways in which positive stories about the use of data might appear in the media and how it might be possible for the patient voice to be heard. Current issues with using and accessing patient data for research were discussed alongside this.

- ***How would we go about getting a balanced story about using cancer patient data? It is 100% easier to get a bad story about data published.***

Health correspondents can be targeted. What will make a hardened news editor excited on that day? Particular & personal stories, rather than general issues & lobbying stories. The value of use MY data is that there are individual stories and pieces of expertise. However, use MY data needs to be clearer, as an organisation, about direction and whom to send good stories too.

Social media needs to be used more, particularly Twitter and Facebook. Twitter can be used to highlight the impact of data not being used and links made to use MY data.

use MY data should be responding to/commenting on all publications on medical data, e.g. BMJ & HSJ and building an on-line profile.

Local newspapers, magazines and radio could be a good way to get positive publicity. Consider contacting MPs.

Big Brother Watch would consider a story in favour of data being used. use MY data could highlight stories of organisations which are holding up research, or contrast good and bad data stories.

- ***I would willingly give all of my data: is anyone asking the public where they want research to take place / how are priorities decided?***

Increasingly research funders are including lay people on committees. Concern that government funded research is goal

orientated and that very abstract/obtuse research is at risk. More priorities from the public are needed. The James

Lind Alliance was referenced at this point. The Alliance brings patients, carers and clinicians together in Priority Setting Partnerships, to identify and prioritise the uncertainties/unanswered questions about the effects of treatments. The aim is to ensure that health research funders are aware of the issues that matter most to patients and clinicians.

The patient voice is at the start of research, what about post-research? Lay assessment summaries of the results and the impact are a good target.

In clinical trials researchers are now told they can no longer keep patient contact details. It is distressing when patients, having given their data, cannot obtain results themselves (from researchers).

It is hoped that the BMJ will move towards disseminating trial information.

▪ **What are the obstacles to research in terms of data access?**

The interpretation of consent is an issue. Particularly when consent has been obtained in the past, but changes to structure and more stringent requirements mean that the consent is not 'up to current standards', which can throw up blocks.

For studies, where the intervention is at the level of GP, permission is really hard to obtain, as individual level data is probably needed.

Most clinical trials have informed consent. For many epidemiological studies consent is impossible due to the infrastructure.

The start of Caldicott 3 focuses on the need for data protection and autonomy. It then moves into restricting data and protecting data. Caldicott 3 does not include any responsibilities for sharing data.

It is pointless having a databank if a high proportion of people opt out and statistics are skewed.

Dr Rosamund Snow

Tragically, Rosamund died on Thursday, 2 February.

use MY data had only just begun working with Rosamund, but her experience and insight had already proved invaluable to us. Rosamund was passionate about the patient voice being an integral part of decision making about data.

use MY data's relationship with Rosamund began after members heard her speak in her role as DeepMind Health's patient representative. In her follow up recommendations to DeepMind Health Rosamund argued "that it is never too early to ask for patient input on things that will ultimately affect us".

This session examined 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. In turn we aimed to provide a balanced patient perspective, to aid GPs.

John Rouse, Patient advocate, use MY data gave details of accessing medical records online at a GP practice in Tameside. Password controlled access is via a secure webpage or a smartphone app. Of particular note was the take-up of online access across all age ranges. Patients can input data into the system, which saves time ahead of their GP appointment. Why has there been so little progress with the empowerment of patients at other GP practices? Patients need to become involved in their own GP's practice, possibly through the practice's Patient Participation Group.

Dr Anthony Cunliffe, Macmillan Cancer Support GP Adviser and Early Diagnosis Lead related that when training as a GP he did not receive any formal training about data, including care.data or other local schemes. Conversations with patients were therefore either non-existent or inadequate due to lack of understanding. A leaflet is not enough to explain data consent options and issues to a patient. Anthony has been working with Macmillan Cancer Support and the Transforming Cancer Team and understands the vast benefits of data that is reliable and up to date. Good data underpins care and research.

Dr Ishani Patel, GP & Clinical Advisor for Transforming Cancer Services Team said that, like Anthony, when training as a GP she received no formal education about patient data; the training did not exist. Access to online records has transformed things. There needs to be basic conversations about GP language and patient language. It is a struggle to get proper timely information from hospitals. Do patients know that Ishani has this access? Ishani highlighted that receptionists are undervalued; they need to know more about data and sign posting, to aid patients.

The discussion that followed focussed on the following:

- **How should we train and educate GPs about the collection & use of data and communicating with patients?**
- **How can data be used better to improve early diagnosis?**

Data and consent issues need to be part of GP undergraduate training. GPs who have more recently trained are likely to be better at note keeping, coding, and understanding data. GPs who trained some time ago are likely to face bigger challenges in terms of data knowledge.

Macmillan has looked at ways that IT systems can pull data, to save the intensive use of resources/manpower.

- **How can we help GPs, who see very few cancer patients a year?**

There is no system to alert GPs to the frequency of a patient's visits. It is a case of a GP manually looking back through a patient's record. Statistics, such as the Cancer Patient Experience Survey, do not accurately reflect the frequency of a patient's visits to the GP. For example, if a patient is seen three times before diagnosis, that could be three times in one week or three times over several months.

Currently there is much research being done on GP records and converting data into algorithms. The QCancer system is active within a lot of practices in England. It works out the risk of a patient having a current but as yet undiagnosed cancer, taking account of their risk factors and current symptoms.

- **Online access for patients – does it lead to more visits, use of resources?**

The primary care community has gone much further than other sectors in accessing online data.

On-line access at Ishani's practice has 1) reduced number of visits due to minor ailments 2) provided feedback to patients on how they can help themselves, 3) improved GP and patient communications 4) improved the navigation of care.

The patient does not see the detailed narrative of their record; they will see the title of the medical problem. A patient can challenge the practice about information that is blocked from view (this challenge cannot be done electronically).

Hopefully it will have a beneficial effect on note-keeping. There could be concerns over a GP being sued for what they have written about a patient. Perhaps a Caldicott Guardian is needed to speak for GPs.

▪ **Data access and consent**

Linking primary and secondary care detail has significant challenges. A lot of patients have opted out from the system allowing GPs to see hospital records. And yet, other patients assume that GPs already have this data. GPs are disparate and keep notes in different ways; there is no uniform way to record notes.

The list of care.data opt-outs still exists. Type 2 opt outs are honoured by NHS Digital, and Type 1 opt-outs do not leave the GP practice and do not reach NHS Digital. Some patients were encouraged to opt out by their GP and asked how they might opt back in. Opting back in can be done via your GP.

Patients do not necessarily realise what they opted out of, for example local care records.

Delegate feedback – organisations that delegates will feed back to

- Anyone who will listen!
- Beat Kidney Stones
- Bloodwise
- Brighton Hove Cancer Communications Group
- Cancer Research UK patient group
- Clinical Commissioning Group
- Chronic Lymphocytic Leukaemia Support Association
- Community Voice
- GP Patient Participation Groups
- Glasgow Biorepository
- Healthwatch
- Healthwatch Central West London
- I Had Cancer
- Independent Cancer Patients' Voice
- Innovation Agency
- Leeds Institute for Data Analytics
- Locality Patient Participation Groups
- Local hospital Cancer Management Board
- Local Cancer Alliance
- Macmillan Community
- NCRI Consumer Forum
- National Coalition for Cancer Survivorship (USA)
- Pancreatic Cancer UK
- The Royal National Orthopaedic Hospital's Patient Group
- Sussex Cancer Action Group
- Sussex Cancer Patient Partnership Group
- University of Cambridge PC Research PPI
- WH Cancer Network PV + I group

Suggested agenda items for the next data workshop

Media

- Journalist from the Daily Mail / Senior Editor, Daily Mail – Paul Dacre
- Journalist who is pro data use, such as Polly Toynbee

Research & Clinical Trials

- What has been done with our data? E.g. over the last 12 months

NHS & DH

- NHS & Social care data sharing
- Jeremy Hunt
- Simon Stephens

Data issues

- Continue on the interface between primary and secondary care and the data implications
- Cancer registration data
- UK Biobank – how they use / secure / analyse their data from 500,000 donors
- National Data Guardian
- Jo Churchill MP's private members bill
- General consent to share
- Human tissue as data and issues around consent and historical diagnostic material
- Role of NHS Digital and/or PHE and how they manage and provide access to data
- Integrity, quality & validation of data, at Trust level, GP level
- Modern equivalent of a shared care record: patient held – smart card?
- Examples of best practice & also of best practice not being taken up through the NHS

Primary care

- Continuing discussion about GPs and primary care
- GP lead at CQC

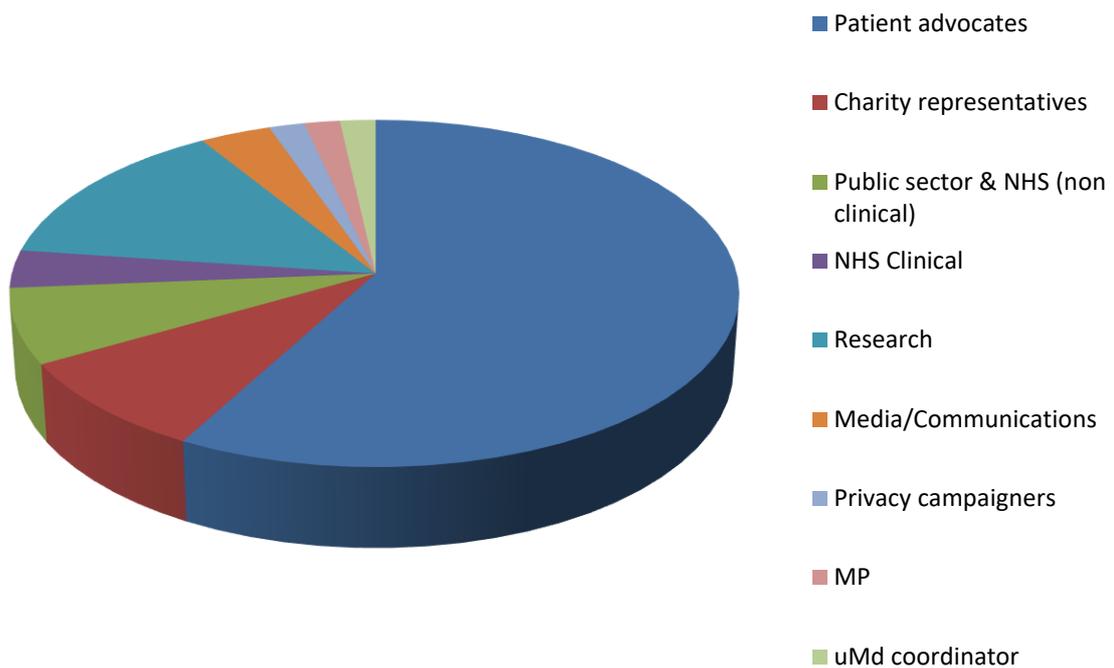
MPs

- Jo Churchill
- Political input/views
- How to use MPs more to gain support for using data

Patient advocacy

- How to engage with patients not involved in patient advocacy?
- Strategy & coordination for getting the patient voice 'out there'
- Break-out sessions and plenary to develop a work plan with clear outputs timescales and accountabilities
- How can use MY data move forward? What are use MY data members & other patient groups who attended the workshop doing?

Breakdown of attendees



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