The patient voice – who is listening?

Updated 24.01.17

Date	**Thursday, 26 January 2017**
Time	**10:00 to 16:00**
Venue	**Lift, 45 White Lion Street, London, N1 9PW**

1000 - 1030 **Arrival, tea & coffee**

1030 - 1045 **Welcome & aims for the day**
Chris Carrigan
Data specialist, use MY data

1045 - 1215 **Session 1 – Can patients control how their data are used?**

This session will examine existing initiatives where patients lead on the use of their data and the impact of this. It will also look at potential initiatives where patients want to lead on the use of their data & the possible impact for research and outcomes. After a short talk from each speaker, the chair will lead a discussion with the panel and audience.

Why seeing my cancer registration record is important, what I found & why this could be important to others
Andy Smith Patient advocate, use MY data

Other options for linkable lifestyle data – what about your supermarket loyalty card? What sort of insights could be gained & who would benefit most?
Dr Michelle Morris University Academic Fellow, Leeds Institute for Data Analytics

My data in the Health Bank initiative – why it's there and how does the health bank want to use it
Sophia Turner Patient advocate, use MY data

What I would like to add to my cancer registration record and the reasons why
Ian Clements Patient advocate, use MY data

1215 - 1300 **Lunch**

1300 - 1430 **Session 2 – The media & patient data: is the patient voice heard?**

This session will examine the role of the patient voice in the media. Following a short talk from each speaker the panel and audience will examine the coverage of patient data in the media. We will examine how influential the patient voice could be, why it is not heard at present & how a more balanced media view of the uses of patient data could be achieved.

Polly Toynbee Journalist, The Guardian

Daniel Nesbitt Research Director, Big Brother Watch

Dr Peter Sasieni Professor of Biostatistics and Cancer Epidemiology, Queen Mary University of London

Dr Rosamund Snow Patient editor, British Medical Journal

John Reeve use MY data patient advocate & Bloodwise Trustee

1430 - 1445 **Refreshment break**

1445 - 1545 **Session 3 – Primary care & data collection: the impact on the GP & the patient**

This session will examine the role of primary care with regard to the concerns of patients about data usage, sharing and options. We will hear 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 will provide a balanced patient perspective and voice to aid GPs.

Dr Ishani Patel GP & Clinical Advisor for Transforming Cancer Services Team

John Rouse use MY data patient advocate

Dr Anthony Cunliffe Macmillan Cancer Support GP Adviser and Early Diagnosis Lead

1545 - 1600 **Closing summary**
Chris Carrigan
Data specialist, use MY data

* use MY data