

Patient data – why & how it should be used

use MY data & Independent Cancer Patients' Voice

Britain Against Cancer 2016, Central Hall Westminster
Tuesday, 6 December, 15:00 to 16:00

In this talk we will set out a proposal for how the patient community can drive the data agenda, so that patient data is collected and used in the most effective way.

We'll illustrate how easy this could be if current & proposed barriers were removed, alongside looking at the safeguards that would need to be in place. We will do this by examining patient led initiatives and using examples from the devolved nations.

We will clearly demonstrate why politicians, the NHS and the public should be accountable to patients and listen to the patient voice.

1500 - 1505	Chair's opening remarks	Professor Sir Alex Markham Director, MRC Medical Bioinformatics Centre Professor of Medicine, University of Leeds
1505 - 1515	The patient community driving the data agenda	Dr Helen Bulbeck Patient advocate, use MY data & Independent Cancer Patients' Voice Director of Services & Policy, brainstrust
1515 - 1525	Linking data sets to provide real-time intelligence for patients, clinicians & health system leaders	Dr Jem Rashbass Director, National Cancer Registry and Analysis Service, Public Health England Co-Chair, United Kingdom & Ireland Association of Cancer Registries
1525 - 1535	Northern Ireland is leading the way to mandate Cancer Registration – how might the other UK nations follow this?	Margaret Grayson Patient advocate, use MY data & Independent Cancer Patients' Voice Chair, Northern Ireland Cancer Research Consumer Forum
1535 - 1555	Defining the next steps - the panel & delegates	All
1555 - 1600	Chair's closing remarks	Professor Sir Alex Markham Director, MRC Medical Bioinformatics Centre Professor of Medicine, University of Leeds

