

# Data Workshop – Programme

Date **Thursday, 11 February 2016**  
 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**

**Jane Lyons**  
 CEO, Cancer52

## Session 1 – The rewards of cancer data

- 1045 - 1130
- Examples of the use & value of cancer data – how patient data is used by London Cancer & the London Cancer Alliance (LCA)
  - Benefits for cancer patients – present & future

**Dr Katherine Henson**  
 Senior Public Health Intelligence Analyst, NCIN

**John Symons**  
 Director, Cancer of Unknown Primary Foundation – Jo's friends

1130 - 1145 **Refreshment break**

## Session 2 – The legalities of cancer data release & current risks to obtaining rewards

- 1145 - 1230
- Consent issues: care.data opt outs & GP electronic patient records
  - Legal issues specific to the release of cancer data for research
  - How are rewards & risks balanced by the new Caldicott Principles

**Rachael Brannan**  
 Senior Project Manager, Office for Data Release, PHE

1230 - 1300 **Lunch**

## Session 3 – Cancer data within the UK & the EU

- 1300 - 1345
- Overview of approaches from all four devolved nations
  - Influencing in relation to 'legal issues/barriers' through-out the UK
  - New/potential EU directives & the impact on the UK

**Chris Carrigan**  
 Head of the NCIN

**Richard Stephens**  
 Chair, NCRI Consumer Forum & Patient Member, Independent National Cancer Taskforce

1345 - 1400 **Refreshment break**

## Session 4 – Primary care data

- 1400 - 1445
- The primary care record & insight into pre-diagnosis/post-treatment
  - Tracking non-diagnosed cancer that is discovered later, in order to make improvements in service provision
  - Missing diagnoses: patient behaviour & GP behaviour

**Dr Mark Davies**  
 Medical Director, MedeAnalytics

1445 - 1500 **Refreshment break**

## Session 5 – Communications & advocacy

- 1500 - 1545
- Changing the public's perception of data access
  - Media engagement: changing the negative view of data access

**James Cockerill**  
 Campaigns Manager for AllTrials, Sense About Science

1545 - 1600 **Closing summary**

**Jane Lyons,**  
 CEO, Cancer52