

Data Workshop – 21 April 2016

Feedback & follow up

Delegate feedback – whom will you feed back to?

Patients

- Any patients I come into contact with & family
- Interested individuals and local non-cancer related groups
- Local patient practical group & network
- NHS cancer patient group
- National Cancer Research Institute / Cancer Research UK Consumer Forums
- Northern Ireland Cancer Research Consumer Forum
- Patient and carer research review panel, National Research Ethics Centre (NREC) – London – Hampstead
- West Midlands Strategic Clinical Network (WMSCN) Cancer Patients/Carers Voice / Insight Group + Will ask for information to be shared with local cancer groups across West Midlands and local Health Watch plus Coventry, Warwickshire & Worcester Cancer Forum
- Yorkshire Cancer Patient Forum

Charities

- Bloodwise
- Cancer Research UK
- Independent Cancer Patients' Voice (ICPV)
- Ovacome

Public Sector

- Public Health England

Research

- Academic and patient research groups – various
- National Institute of Health Research (NIHR) Research Design Service for Yorkshire and the Humber (RDS YH) PPI Research Forum
- The Royal Marsden Biomedical Research Centre, Clinical Research Facility (CRF)

Suggested agenda items for the next data workshop

Legislation

- Benefits from most important to least important
 - Disadvantages from most important to least important
- } in simply put language in form of info leaflets for patients to use peer to peer, patient to patient
- Follow up to recent legislation on Section 2.
 - Opt out of consent.
 - UK & EU laws and the merger of the two / how change will affect the consent process

National Consent Model

- Recommendations from Dame Fiona Caldicott
- Look at the difference between the realities & the perception of data use.

Data issues

- Arguments about why data should not be shared
- What is data i.e. ongoing during radiotherapy – how is it recorded, by whom, when?
- Data collection in primary & secondary care if issues arising
- Progress of registries
- Networking and sharing of ‘actual’ issues
- Primary care - looking at what detail GP practices collect
- Patient portals

Campaigning

- Provide information on how to campaign

Research

- Emphasize the benefits of research.

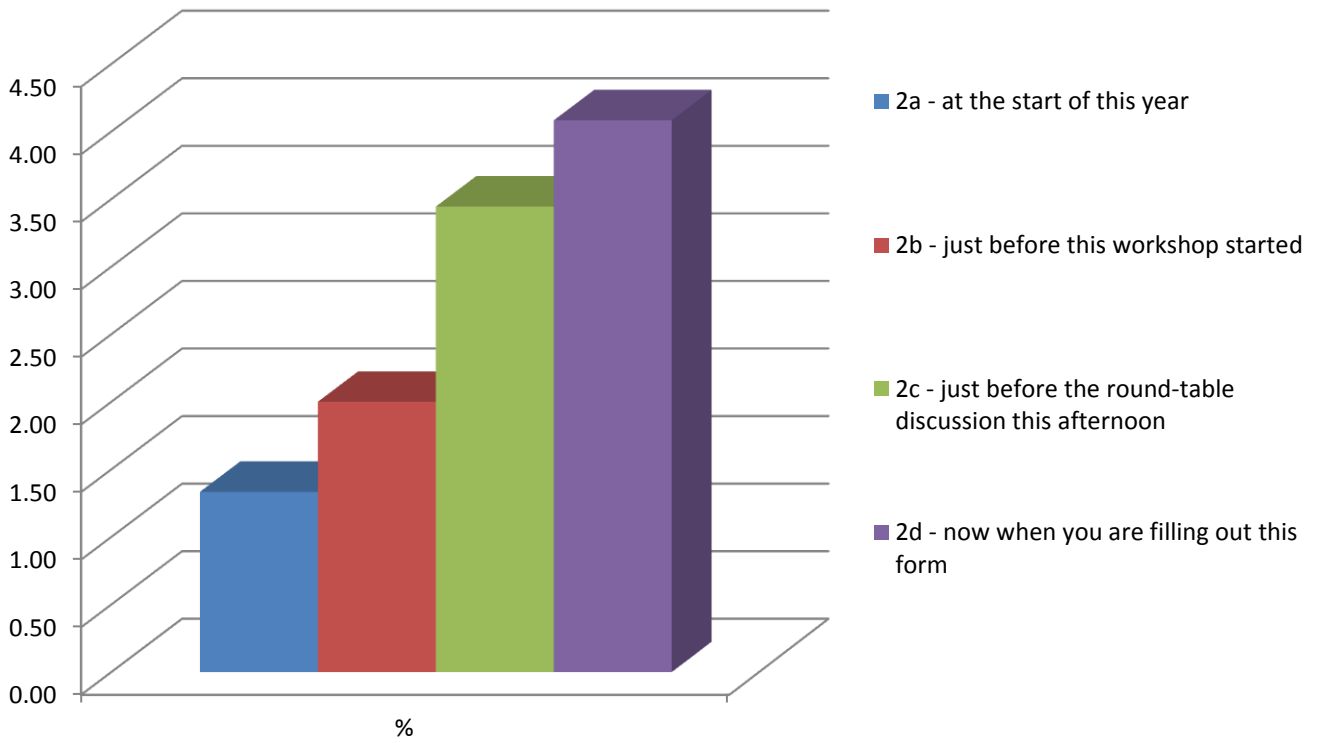
Speakers & format

- Ask the chair & all speakers back again to continue their input.
- Have the ‘privacy lobby’ attend and explain why they fight for the ‘other side’.
- More sessions with the ‘all together’ discussion format.

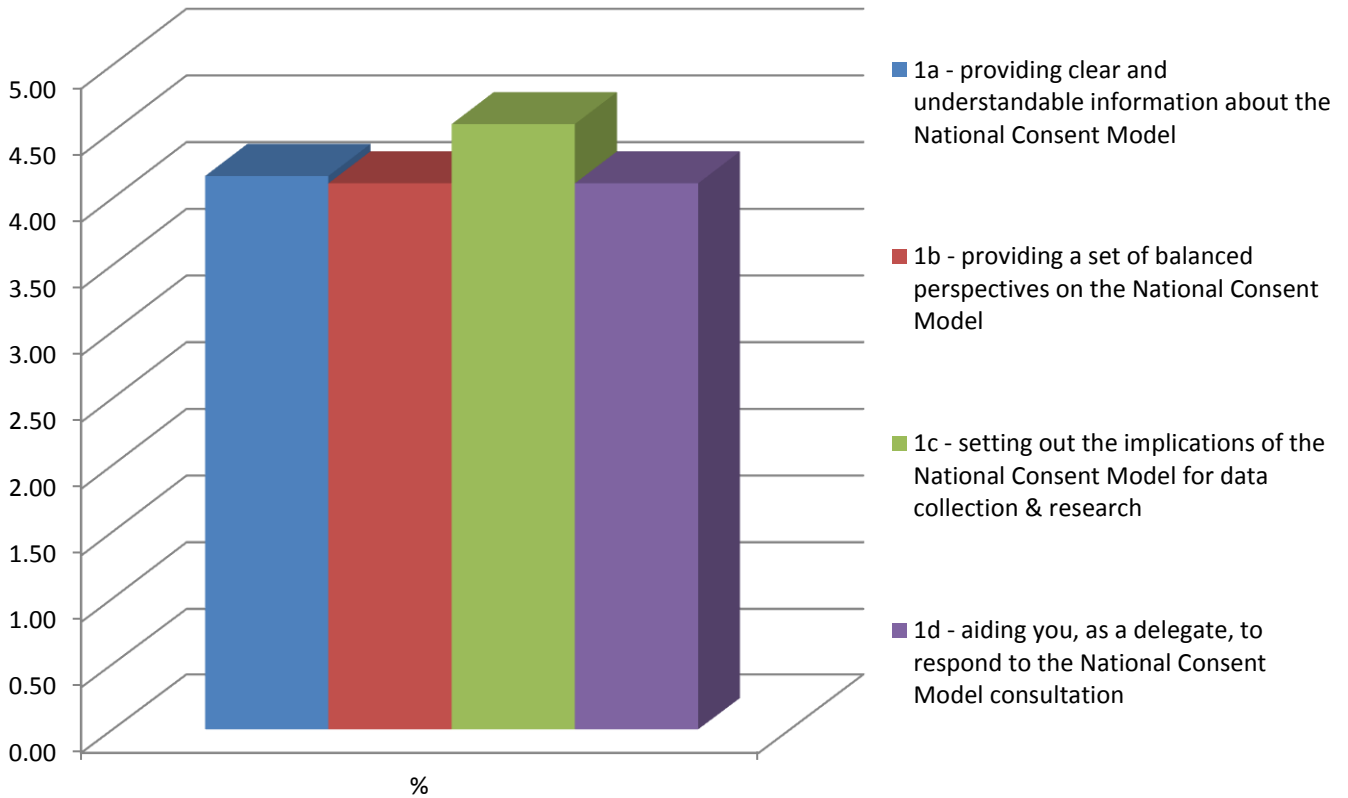
“I want my data shared with whomever will use it, for the good of everybody”

Workshop delegate

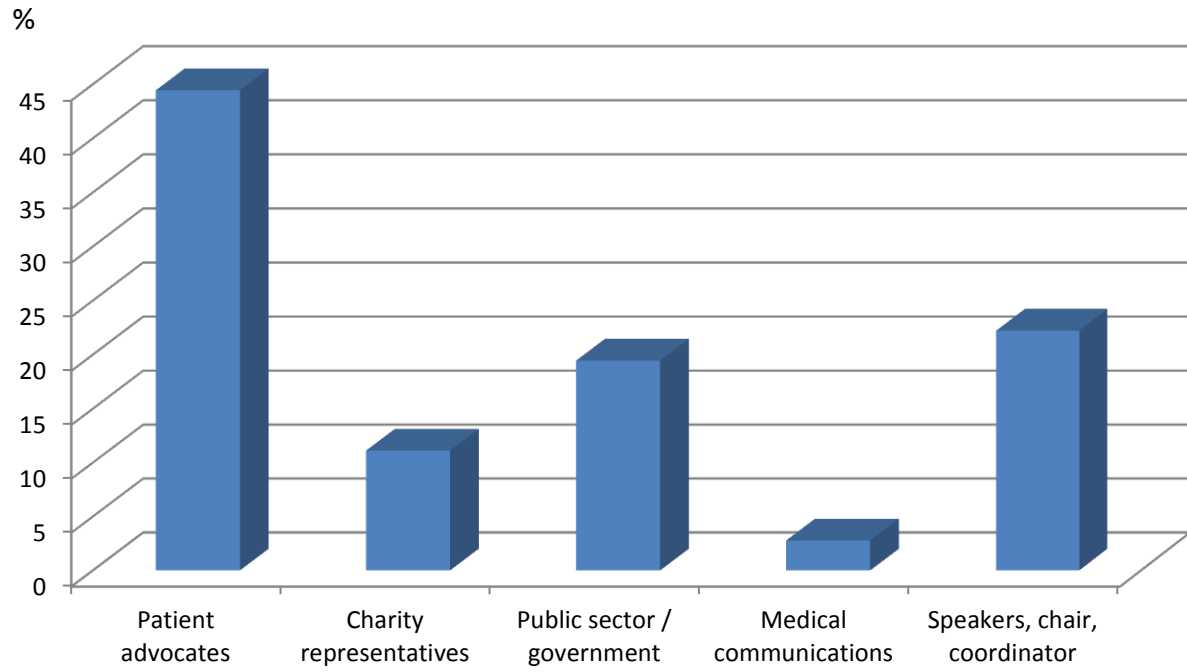
How well-informed were delegates about the proposed changes to patient consent:



How well did the workshop meet its aims:



Breakdown of attendees



* use MY data