Cancer data within the UK & the EU

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use MY data

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A reflection on this morning

- When its used, cancer data can show variation, and be used to change behaviour and outcomes
- It also exposes what has been previously hidden (e.g. CUP)
- When its not available (Katherine’s 3 hospitals), you just can’t tell…..
- Data/Information only has an effect when the right people have it

A reflection on this morning

- This probably doesn't help you, but it has helped others
- We can (within reason) count how many have of these others benefited…
- My simplistic view:
  - More data → better analysis → more lives saved
  - Less data → poorer analysis → fewer lives saved

And a reminder…

- Everything on this agenda has been requested by patients following previous workshops
- We previously covered lots of sessions on the risks, so this afternoon looks at risks again, but also about what we can do to mitigate these risks

Some questions……

- How many people have heard about cancer registration?
- About 2/3 of this room are patients. How many of you were told about cancer registration, during your treatment or care?
- For those that were, were you asked if you were ok about it?
- If you had been asked, would you have felt capable of making a decision?
- Different question. Have you heard of care.data?
- Did you opt out? How did your GP advise you?

Overview of approaches from all four devolved nations

- Overview of approaches from all four devolved nations
  - England
  - Wales
  - Scotland
  - Northern Ireland
- Current developments
- Frequently asked questions

Influencing in relation to “legal issues/barriers” throughout the UK

- Common Law
  - Complex, case law, brinkmanship
- Move to notifiable
  - Public health “risk”, e.g. TB
- Consent
  - For what and when