

# Obtaining informed consent

Managing and Sharing Research Data workshop  
London, 2 December 2009

# A good consent form...

- Meets requirements of DPA
  - purpose of the research
  - what is involved in participation
  - benefits and risks
  - mechanism of withdrawal
  - usage of data – for primary research and sharing
  - strategies to ensure confidentiality of data (anonymisation, access,...) where this is relevant
- Simple
- Avoids excessive warnings
- Complete for all purposes: use, publishing, sharing

# Issue 1: When to ask for consent

	Pros	Cons
One-off	<ul style="list-style-type: none"><li>•Simple</li><li>•Least hassle of participant</li></ul>	<ul style="list-style-type: none"><li>•Research outputs (even questions, not known in advance)</li><li>•Participants will not know all content they will contribute</li></ul>
Process	<ul style="list-style-type: none"><li>•Most complete for assuring active consent</li></ul>	<ul style="list-style-type: none"><li>•Might not get consent needed before losing contact</li><li>•Repetitive, can annoy participant</li></ul>

# Issue 2: Right to withdraw

- Right to withdraw – one of key features of consent
  - Extensible information
  - Free to discontinue
- What about already collected data?
  - Not usually allowed (at least in most surveys)
  - But most likely would be discussed
- What if project is longitudinal?
  - Timescapes solution

# Issue 3: Format for consent

- Written
  - More solid legal ground (participant agreed to disclose confidential info)
  - Not possible for some cases: infirm, illegal activities
  - Can be perceived to be off-putting
  - Can help (or even be “required”) by RECs
  - May offer more protection for researcher
- Verbal-with or without recording
  - Can be difficult to make all issues clear verbally
  - Possibly greater risks for researcher
  - Best if recorded
- Law is not specific
  - Written consent not used on large surveys-implicit by taking part
  - Need to match format of consent with research content

# Issue 4: Types of material

- Ranging from less sensitive (survey) to highly sensitive (NHS protocols for medical)
- Most qual research falls in-between...
- Text and transcripts
- Audio recordings
- Still and moving images
  - Data more likely to reveal identities
  - Data more likely to be rendered useless by anonymising (blurring)
  - Gaining consent or limiting access are better alternatives

# Issue 5: Special cases of participation

- Children
  - under 16s not presumed competent
  - But if they “understand”, then parental consent not *necessary*, but...
- Employees
- Vulnerable-need to balance
  - Protection from harm with
  - Right to participate