Ethics and new technologies using patient data

Michael Parker

The benefits of data-science in medicine

- Ethics is concerned with what should be done as well as with what should not be done
- We heard this morning about the important potential benefits of data-science and use of patient data
- There is good prima facie reason to aim to have the best health service possible
- Using patient data has an important role to play in this

Important requirements

- The closer integration of research and clinical practice
- Data sharing: both nationally and internationally
- Greater emphasis on collaborative research
- The involvement of commercial and technology partners
- A greater acceptance of uncertainty, open-endedness, and revisability
- Justified public trust and confidence

Ethics and non-identifiable data

- Access to many forms of data will be ethically unproblematic and their use ethically obligatory
- For example, collection and analysis of data about treatments at particular hospitals or for populations
- But the uses of such data can sometimes be ethically significant: social justice, inequity of access, stigma etc.
- These aspects need to be taken seriously from outset

wellcome centre ethics+ humanities

Ethox Centre

Consent and its limits

- Not all collection and use of data will require consent: there is a need to reach consensus about when this is and is not the case
- Where consent is appropriate we need to be clear about what consent is to:
    - Specific consent to particular (limited) uses
    - Consent to governance (for others to decide)
    - Broad consent (consent to less specified uses)

Consent is always based on imperfect knowledge

- Whichever model of consent is under consideration, we can be sure that it will be based on imperfect knowledge
- Not an excuse for low standards: but a full understanding is rarely possible
- This does not make such consent 'invalid': unless deception is involved or information is withheld
- Consent is about respecting choices of moral agents in the real world, which is characterized by uncertainty

Public trust and confidence

- Placing too much emphasis on consent means we have failed to pay enough attention to other ethical concerns
- The question we need to ask ourselves is:

    'Given that consent is always based on imperfect understanding, what protections need to be put in place to ensure that those who give consent for their data to be used are not discriminated against or seriously harmed as a consequence?'

Public trust and confidence

- Part of the answer to that question will be about regulation and sanctions:
  - Anti-discrimination legislation
  - Sanctions for deliberate data misuse
- Part of it will be about governance/oversight
- Part will be about wider justice questions such as equity of access to healthcare

Duties of care

- We are used to the idea that health professionals have duties of care to their patients
- How should we conceived of the nature and scope of duties where those involved in healthcare also include researchers, data-scientists, computational biologists, data-managers etc?
- What are the duties arising out of uncertain and potentially revisable information/'findings'

Avoiding blunt instruments

- The types of data, data users and uses will vary
- Some are of more public and individual concern than others: e.g. currently commercial uses and users
- Any ethical approach must be capable of recognizing these differences
- There is also a job of responsible leadership of public debate to be done e.g. in explaining that commercial/technology partners have a key role to play

Privacy and confidentiality

- There is an important distinction being 'harmed' and being 'wronged'. Both are important.
- People can be wronged even if they are not harmed
- It is important that risks of harm and potential for people to be wronged are minimised
- But, some health benefits may require us to tolerate some additional risks to our confidentiality
- We need a sensible public debate about this

To conclude

- The potential benefits of data use are ethically important
- Well-founded public trust and confidence are necessary requirements
- Recognizing both the importance and limits of consent
- Creating the conditions for justified public trust - protections/sanctions/minimizing risks of harm and discrimination
- Thinking carefully about duties of care and what constitutes 'good practice'