Values in Health Research

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Structure of Talk

1. Health Inequities
2. Why do health research?
3. Research ethics regulation
4. A broader agenda for research ethics
1. Health Inequities

- Differential access to health care and public health focused on prevention
- Differentials in average lifespan – both within and between countries
- Average global healthy lifespan – 58yrs
- Men in Africa – 45yrs and Women in Europe – 70yrs
Inequities

- However, due to increasing affluence, urbanisation and globalisation – danger that the many future equity will be in deaths from chronic disease
- Product of socioeconomic determinants
Inequities

- So let’s take it for granted that there are significant health inequities in relation to morbidity and mortality.

- And, intuitively, it seems very hard not to seem as being wrong.
2. Why do health research?

- Cynics might say that the aim is to make money for pharmaceutical companies – but this is not a necessary feature of research.

- I take the main aim to be to improve human well-being (largely through decreasing avoidable morbidity and mortality).
Why health research?

- So that means research can also make an impact in terms of addressing health inequities
- It allows policy to be informed by evidence
- It might also be said that research allows people to make choices about their lives
Why H research?

- Perhaps the knowledge that comes through medical research is also intrinsically valuable.

- What’s interesting is that this suggests that the *aims* of research as such are shaped by ethical values.

- And note the variety of values...
3. Research ethics regulation

- However, if we look to the Helsinki Declaration and other research regulations – they don’t capture this range of values.

- Instead the focus is largely on what we might call individual values (e.g. individualised harm) and issues (e.g. consent, confidentiality etc).
Regulation

- This individualistic approach can also be seen in the appeal to the idea of *rights* of patients etc.
- Given historical events it is understandable why there is a focus on ‘protecting’ individuals.
- However, isn’t it time we had a broader and more balanced approach?
4. A broader agenda for research ethics

- Wider idea of research - e.g. why not include epidemiological research? Public health research is focused on a population or group
- Wider range of values in discussions about research ethics – e.g. justice, solidarity, common goods
Broader

- This would allow us to move away from the obsession with the individual focus in research ethics (on things like informed consent) and individual values such as respecting autonomy.
- Other values are just as important and in some cases are more important.
Broader

- There are other reasons to be cautious of informed consent anyway
- Sceptic about the degree of understanding
- E.g. go through motions – report that ‘written informed consent was obtained’
- E.g. NEJM Typhoid vaccine study in Kolkata (Sur et al. 2009)
So I’m not claiming that justice is not sometimes invoked in some discussion of research ethics (e.g. access to trial benefits etc)

But what is missing is other values as part of the core of research ethics

I think they ought to be, and that research ethics would to be built around them
Conclusions

- If we are really serious about global health inequities then we need to reformulate research ethics.
- Having comprehensible information is important – but there is more to research ethics than correcting typos on a patient information sheet.