

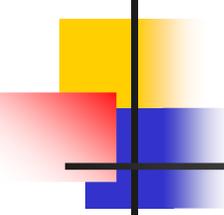
Values in Health Research

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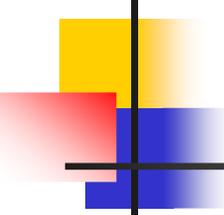
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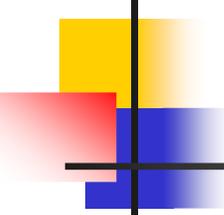
Structure of Talk

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



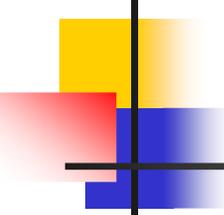
1. Health Inequities

- 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



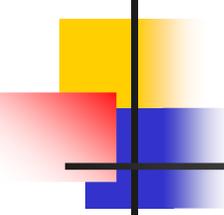
Inequities

- 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



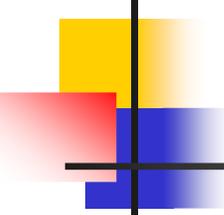
Inequities

- 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



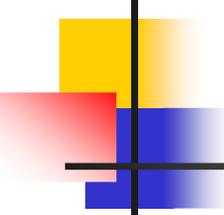
2. Why do health research?

- 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)



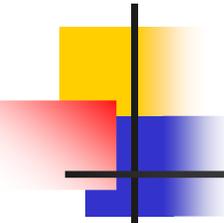
Why health research?

- 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



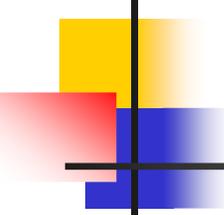
Why H research?

- 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...



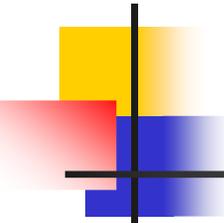
3. Research ethics regulation

- 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)



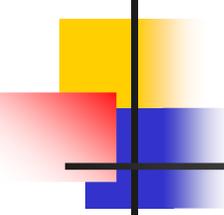
Regulation

- 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?



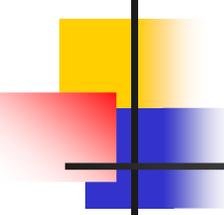
4. A broader agenda for research ethics

- 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



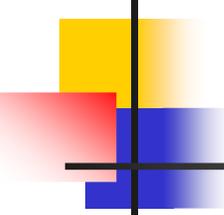
Broader

- 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



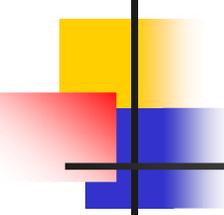
Broader

- 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)



Broader

- 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