

When you have completed the reading and participated in the taught components for this week, we hope you will be able to....

• Describe the way in which ideas about science, scientific knowledge and technological development shape medicine and healthcare

• Demonstrate a good operstanding of the ethical principles and practices underpinning health research.

• Outline the potential opact of new technologies on the future of health, readicine and society.

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2. Research ethics

A Barts and The London

- 3. Summary
- 4. Debate

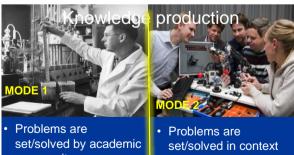


# Historical and social change

- Examine shifts over time and why these occur
- Science as a social activity, guided by e.g.:
  - Expectations and hopes about the future
  - Funding
  - Scientists
  - Existing knowledge
- · Implications for what kind of knowledge is produced, by whom and how

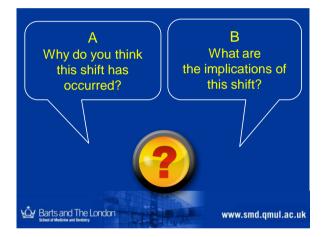


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- community
- Focus is on increased understanding
- Discipline-based
- of application
- Focus is on practical goals and being useful
- Interdisciplinary







## Characteristics

## Big science

- Big budgets
- Big staffs
- Big machines
- · Big laboratories

## **ENCODE** initiative

- \$36m funding
- International consortium
- Over 30 research groups
- More than 400 scientists in government, industry and academia





# Biotechnology

- Genetics, genomics, pharmacogenetics
- Immense gains and insights
- Does not represent complete knowledge
- Fails to account for complex living systems
- · Guides particular way of seeing the world







DNA double helix

Measles in

Cell division

# Paradigms Different ways of seeing the same information REVOLUTIONS Different ways of seeing the same information WWW.smd.qmul.ac.uk

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# Ethical principles and *human* subject research

- Ethical issues are present in ALL research
- Tension between the aims of research for the good of society and the rights of participants to maintain privacy
- Respect and maintain the dignity, rights, safety and wellbeing of all involved in research, or who could be affected by it.

# Harm can be prevented or reduced through the application of ethical principles

Good research design and practice
Protecting participants from harm
Honesty and integrity
Avoiding conflicts of interest
Consent to research
Respecting confidentiality

Review by Research Ethics Committee

### Clinical drug trials ROBERTO ABADIE History of clinical trials & 'captive populations' Poor, unemployed working class Professional volunteers · "Economy of the flesh" Risks by trial (not PROFESSIONAL successive, long-term) GUINEA PIG Challenge to ethics and informed consent A Barts and The London www.smd.qmul.ac.uk

Have India's poor pigs?  By Sue Lloyd-Roberts BBC Newsnight	or become human guinea
Drug companies are facing mounting pressure to investigate reports that new medicines are being tested on some of the poorest people in India without their knowledge.	CIV
<u>http</u>	://www.bbc.co.uk/news/magazine-20136654

# Ethics and qualitative research

- Subtle and different compared to problems in quantitative research
- Shift away from thinking of human subjects
- Power between researchers and participants

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# Ethics and qualitative research

- Potential risks include:
  - anxiety and distress
  - Exploitation
  - Misrepresentation
  - identification of the participant
- · Critical reflection on:
  - researchers own role
  - potential bias and influence during formulation of the research, data collection, and analysis



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Good research practice is essentially an attitude of mind that becomes an attitude to work. It is about the way in which research is planned and conducted, the results are recorded and reported, and the fruits of research are disseminated, applied, and exploited.

Medical Research Council, 2000

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Science and technology play a significant role in society

This impacts on the kind of research that is funded and undertaken in relation to health, illness and medicine The current emphasis is on producing knowledge to solve problems and create wealth

Biotechnology is seen as particularly important

The history of clinical trials is one littered with exploitation and this continues into the current day

Ethical issues are present in ANY kind of research... informed consent is key...



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Barts and The London School of Ministers are Described.	www.smd.qmul.ac.uk