

## The Ethical Context: 'softening' dilemmas in medical profiling and online medicine

Peter Mills

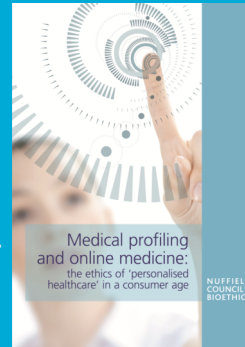
## Nuffield Council on Bioethics



- UK-wide independent body that examines ethical questions raised by advances in biology and medicine
- Contributes to policy making and stimulates debate in bioethics
- Established in 1991; based in UK

## Why did we write *Medical Profiling and Online Medicine* (MPOM)?

- New developments in genetic research and imaging technology
- New applications of ICT in healthcare
- Claimed to herald a new era of 'personalised healthcare'
- Raises issues about consumer choice and personal responsibility in health care, especially in UK health system



## 'P': what can new technologies deliver?

Can they deliver:

- healthcare more closely tailored to our unique individual features?
- healthcare that treats us as a 'whole person'?
- healthcare that we obtain as a consumer good?
- healthcare that puts more responsibility on us as individuals?



## 'C' and 'R' challenges

- Developments in medical ethics
- Pressures from policy makers
- Pressures from commercial providers
- How far should more freedom to choose mean more responsibility?



"Democratizes personal genetics"



"Calculate genetic risk: empower prevention"



"Empowerment: to live your life to the fullest"

## Ethical values

1. Private information should be safeguarded
2. Individuals should be able to pursue their own interests in their own way
3. The state should act to reduce harm
4. Public resources should be used fairly and efficiently
5. Sharing risks, protecting the vulnerable: social solidarity

## ‘Softening’ ethical dilemmas

- The ethical values often conflict
- No one value trumps the others

Our approach:

- Establish benefits and harms in each case
- Attempt to ‘soften’ conflicts between ethical values by respecting each as much as possible
- Recommend interventions that are evidence-based, proportionate and feasible

## Intervention

- Government intervention is justified if it is feasible and if potential harm is serious
- If all else is equal, prefer general to specific interventions
- If all else is equal, prefer non-coercive to coercive interventions



## Recommendations (1)

### Health information websites

- Governments should ensure high quality health information is available on the web
- Health websites should seek accreditation

### Online health records

- Governments should set up accreditation schemes
- Providers should give users information about data security and legal rights



## Recommendations (2)

### Online drug purchasing

- GB registration scheme should be mirrored in other countries
- Doctors should receive training on caring for patients buying online

### Telemedicine

- Telemedicine offered where it can reduce healthcare inequities
- Impacts on doctor-patient relationship to be evaluated



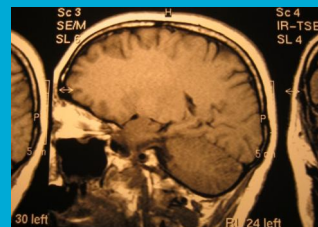
## Recommendations (3)

### Genetic profiling

- Regulators should request evidence for clinical claims made by companies
- Government websites should provide information on the risks and benefits of genetic profiling

### Body imaging

- Companies that sell body imaging as a health check should be regulated
- Direct-to-consumer whole body CT imaging should be banned



## Conclusions

- The technologies are still developing
- They mix **potential** benefits and harms and bring key ethical values into conflict
- They could transform medical practice, but it's hard to predict how much use will be made of them in the future
- They need close and regular scrutiny
- People need support in identifying information to make good choices
- We should be cautious of exaggerated claims made about these developments

## Challenges

- How should we balance individual choice with supporting those in need?
- How can we ensure potential for harms is monitored (e.g. digital divide)?
- How can we place responsibility for handling new risks in the hands of those best placed to manage them?
- Be wary of locking in the personalisation paradigm.
- Find measures other than confidentiality.

[www.nuffieldbioethics.org/personalised](http://www.nuffieldbioethics.org/personalised)



**wellcome**trust