

Public Benefit and Individual Interests in the Secondary use of Health Data

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Overview

1. The Problem: Public benefit versus Individual interests
2. Public benefit – What and why
3. Individual interests – What and why
4. Can the interests on both sides be reconciled
5. Conclusion

The problem

Health information is generated in individual clinical encounters between health care professionals and patients. This usually happens under conditions of confidentiality.

But,

1. it is necessary for the health information to be used outside of the clinical setting, e.g. for public health, administrative and planning purposes.
2. important health research can only take place if researchers have 'easy' access to large, complete datasets of health information.
3. There are other potential uses that may also generate public benefit even though they are carried out by private firms.

Public benefits

Research:

Well conducted health research produces public benefits.

Some of the public benefits are economical, but the main benefits are better understanding of health and disease, the causes of disease, the effectiveness of treatments etc.

'Industry':

There is a potential public benefit in effective insurance underwriting, evidence based planning of pharmaceutical research portfolios etc.

Many of the benefits come from linking information from different sources. This linkage can be performed in ways so that researchers only have access to anonymous datasets.

Public and individual interests

A public interest is an interest in securing a public good, which is not necessarily the same as something that the public is interested in

There is a public interest in road safety, but not a public interest in Peter Andrés love life (despite some segments of the public being interested in the latter)

There is an overlap between public and individual interests.

- As citizens we all have an interest in health research taking place, i.e. we all have an interest in the progress of medicine and in the welfare of our fellow citizens
- It could also be argued that if we willingly use the NHS, then we have an obligation to contribute to the NHS and allow our health data to be used for health research

Individual interests in protecting and controlling health data

In relation to identifiable information:

- Confidentiality*
- Privacy
- Individual harm caused by disclosure

In relation to anonymous information:

- Control over use
- Group harm

**Important to note that there is also a strong public interest in confidentiality being maintained in health care*

Specific informed consent is not the solution

We could require that individuals should be asked for their informed consent every time their data are used for health research (or for non-research purposes by industry)

This would, in theory enable them to protect their own interests by consent or refusal

But, this is in reality not a good solution. It is bad for research and does not really protect individuals:

- It would be very costly
- It would make research very difficult
- We need to question whether the consent would be valid:
 - Would people really think about the issues
 - Would we get 'routinisation of consent', i.e. will a person really think carefully about their decision when they are asked for the 10th time in a year

Can the interests be reconciled 1?

Identifying interests is not enough, we also have to decide their 'weight'

Individual interests are stronger / more weighty in relation to the use of identifiable information than in relation to the use of anonymous information

Individual interests may be stronger in relation to specific types of information (e.g. about mental health or sexually transmitted diseases), or specific research questions (e.g. related to race or religion)

Public interests in research are stronger the more important the research question is = the more important the health problem that is being investigated is

Can the interests be reconciled 2?

Is individual control the only way forward, or are there other tools in the toolbox?

- Data security requirements
 - Strict access control with logging of users
- De-identification
 - Datasets with minimal possibility for re-identification
 - Anonymous linkage
- 'Licensing' of researchers
 - Sanctions if rules are breached
- Body to approve research proposals
 - Different levels of requirements depending on sensitivity of data and sensitivity of research question
- Making information easily available about ongoing research

We could also consider more sophisticated ways of getting individual consent using modern ICT technologies

Further on 'industry' use for activities that are not health research 1

Perhaps additional worries about:

- Is the activity really in the public interest?
- Will agreements about restricted use of data be kept?
- Will the NHS be tempted (or compelled) to sell data for purely commercial purposes, e.g. to enable better targeted advertising of health related products?

Further on 'Industry' 2

These concerns are not theoretical and fanciful, but the best way to guard against systematic misuse of data is not individual, specific consent, but strong regulatory mechanisms

Conclusion

Most health research using anonymous health data does not significantly go against the interests of individuals

If appropriate strong safeguards are introduced, individual specific consent is only needed in circumstances where research is especially sensitive because of the type of data used, the research question, or because it uses identifiable data