

WHY PATIENT INVOLVEMENT?

Terms

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- Participation – patients as subjects of research eg: taking part in a trial, completing a questionnaire
- Engagement – patients receiving information, knowledge about research eg: open day, science fair
- Involvement – patients as **decision makers** and **direction setters** in research eg: serving on committee, priority setting, advising on methods

ARTICLE

‘You should at least ask’. The expectations, hopes and fears of rare disease patients on large-scale data and biomaterial sharing for genomics research

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By Chris Vallance
PM, BBC Radio 4

News • UK News • NHS

Less than half of the UK understand the NHS' new Care.data system, reveals latest poll

Feb 17, 2014 13:50 | By Ben Burrows

Three reasons why

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- Epistemological – increased/improved knowledge
- Moral – because it's the right thing to do
- Consequential - get better results

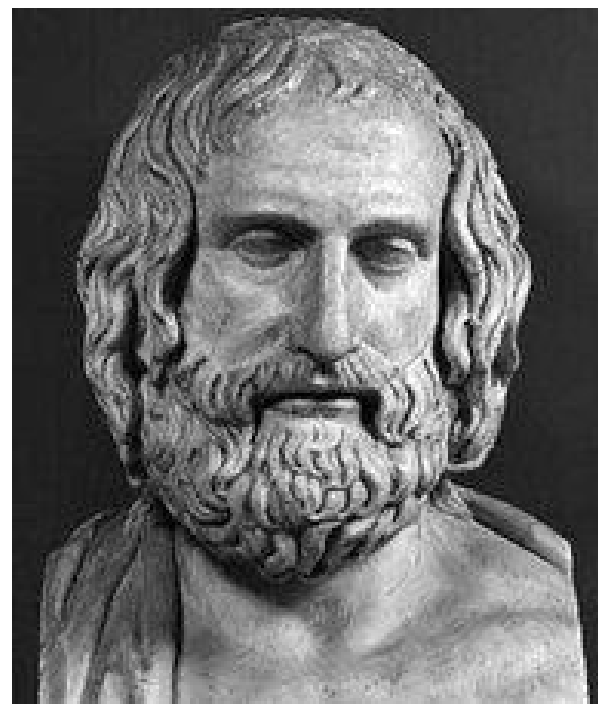
(Boote 2012)



Epistemological

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- Scientific and empirical knowledge not mutually exclusive
 - Innate and rational
- Particularly powerful in RD
- Long shadow of
 - Unethical behaviour in research
 - Genetic determinism – creating barriers with funders/IRBs/regulators



Moral

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- Patient groups as instigators
- Emphasis by patient organisations on rights rather than duties
- Authority for decision making (self determination)
- Negotiation and exchange (tissue, data as assets)
- Accountability – legal uncertainties, changing contexts

Consequentialist

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- Better outcomes/results
- Guaranteed relevance
- More impact
- Effect on quality of research is contested (Staley 2011)



Shared goals

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1. Looking for a cure
2. Improved quality of life
3. Making a difference
4. Building a community

(Pinto 2017)

Solidarity – important shared, social endeavour (Prainsack 2011)