



**University of
Zurich** ^{UZH}

Institute of Biomedical Ethics and History of Medicine

Overdiagnosis and Big Data: An ethical perspective

POD Barcelona – 20-22 September 2016

Corine Mouton Dorey

Ethically driven, Big Data can help reduce ODx

Table of Contents

1. Connections between ODx and big data
2. Narrative approach: Ricoeur's ethics
3. Ethical guidance for Big Data to mitigate ODx harm

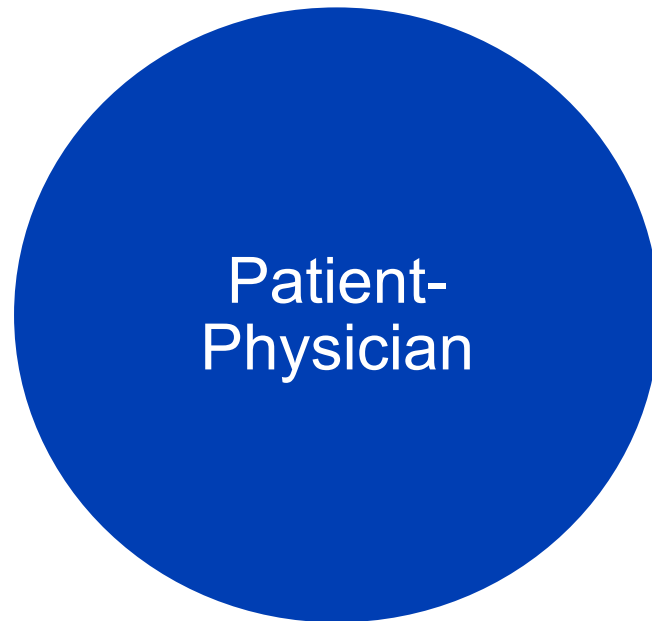
The Big Data Story

Context

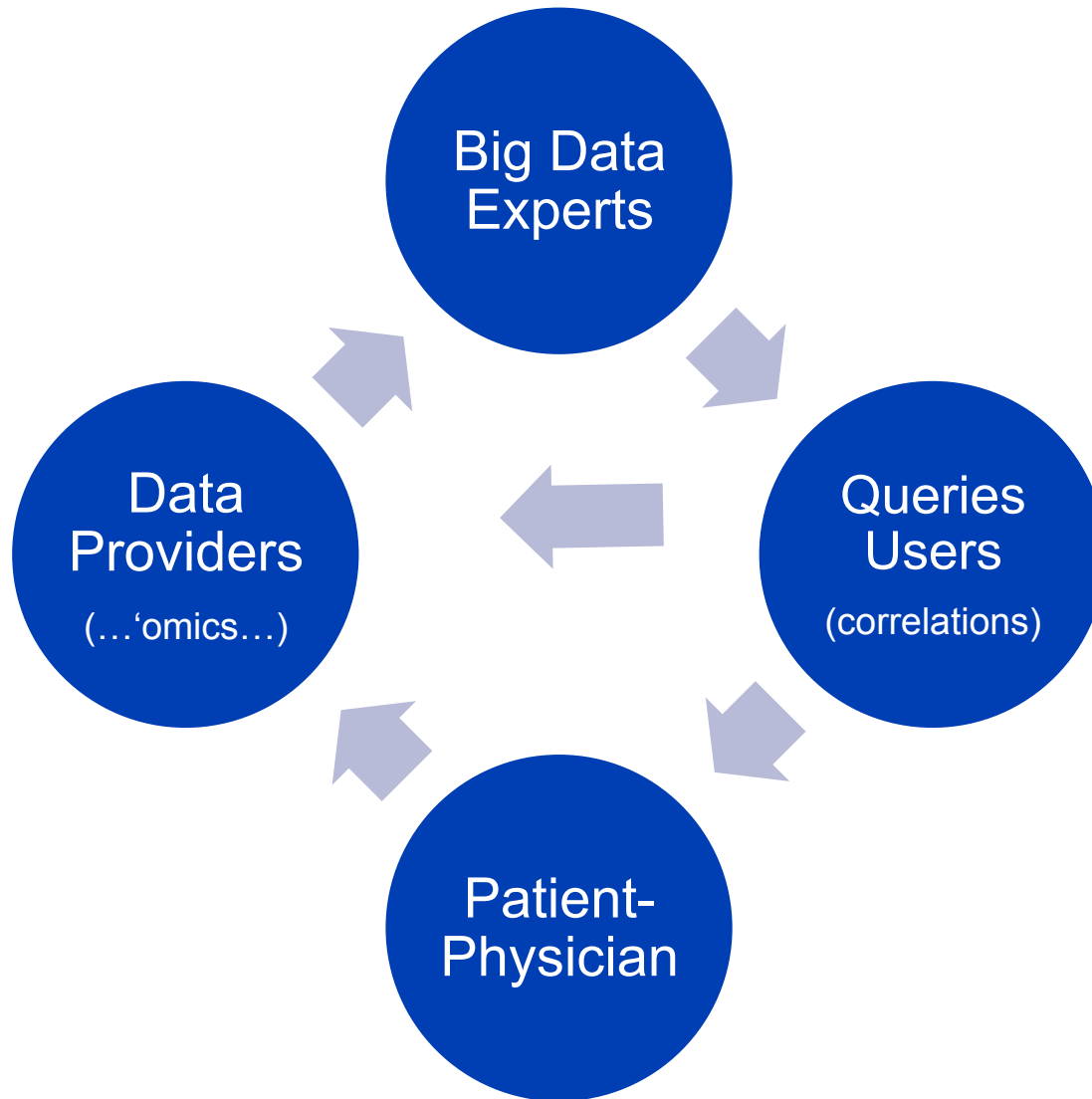
Plot

Characters

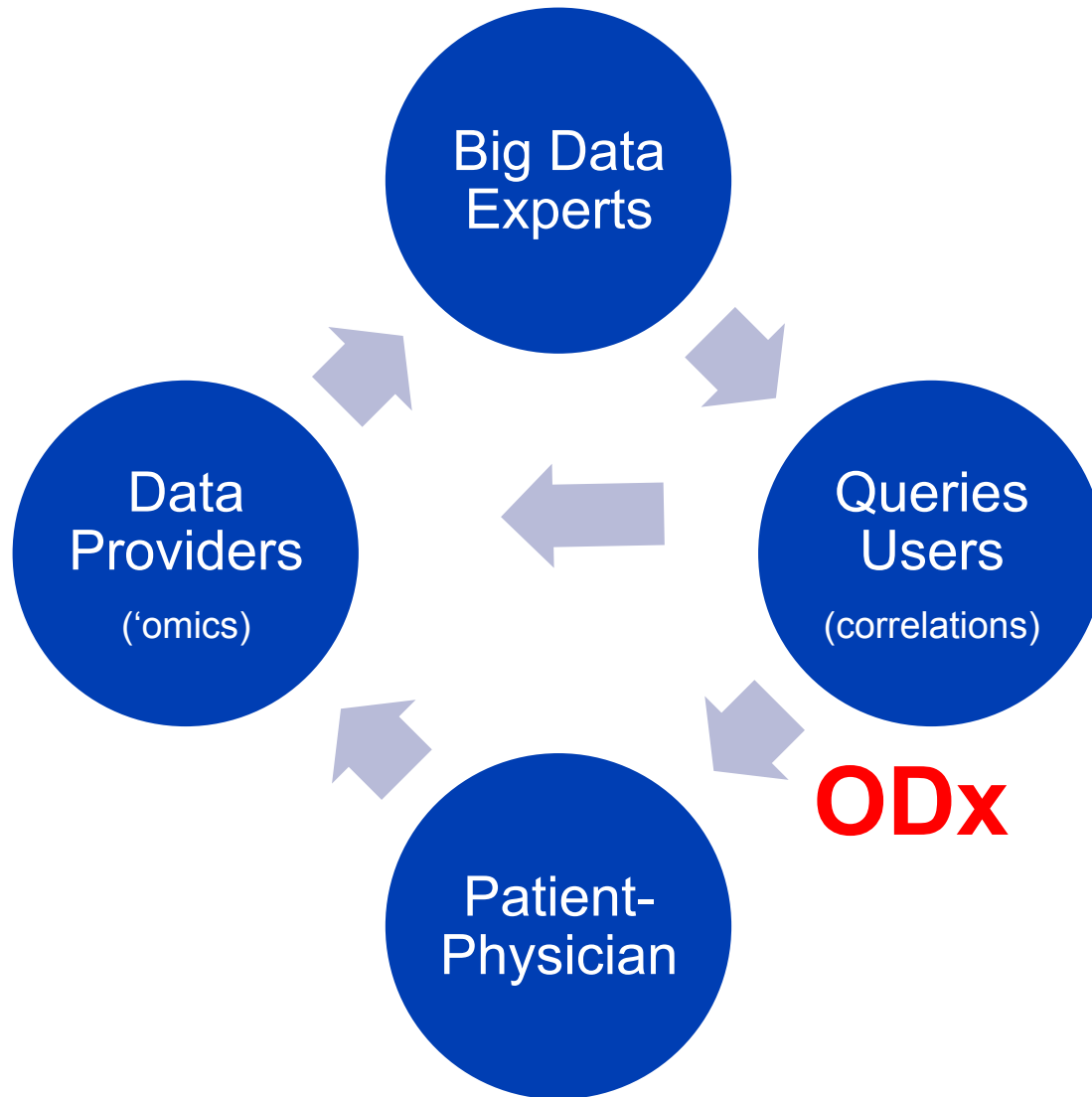
A simple story...



...became complicated



An unexpected event could happen



Big data could help recognize and reduce ODx

- Stratifying patients and relative outcomes
- Linking datasets
- Prophetic correlations
- Investments

Big Data could favour the drivers of ODx

- Multiple actors & more COI
- Translational uncertainty
- Expanded disease borders
- Lack of digital literacy
- Opportunity cost

Paradox

The risk of ODX:

Precise/target medicine (based on big data) (morally good)
leads to inappropriate treatment (morally wrong)

How to use Big Data to resolve this moral paradox?

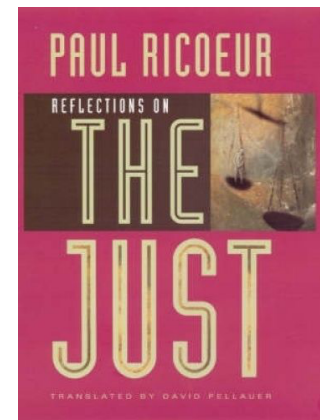
Narrative approach: a lens to analyse our story

- We are in a story (descriptive)
- But how can we understand that story? (mattering map)
- We need to interpret it (correlations)

How interpretation helps for medical judgement?

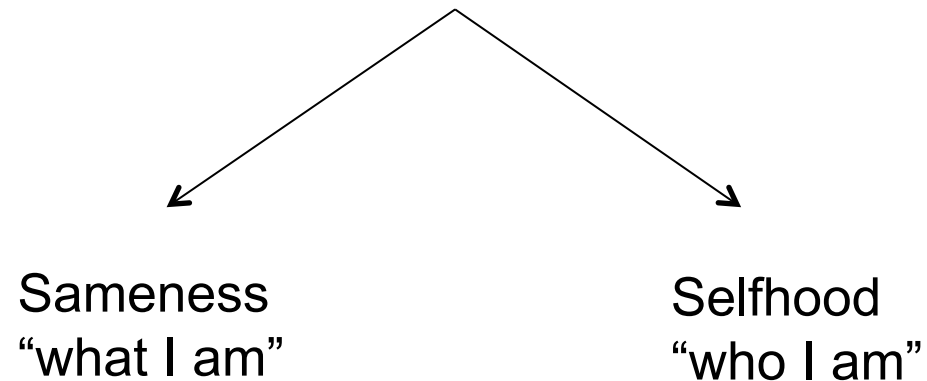
- The interpretation reveals the identity of the character of the story
E.g. Patient – Physicians
- Narrative identities help understand what matters morally (normative)

Paul Ricoeur (1913-2005)



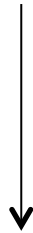
Narrative identities: individual and collective

2 poles in the narrative identity:



Ricœur's ethics aims at:

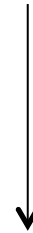
“a good life, with and for others, in just institutions”



Self

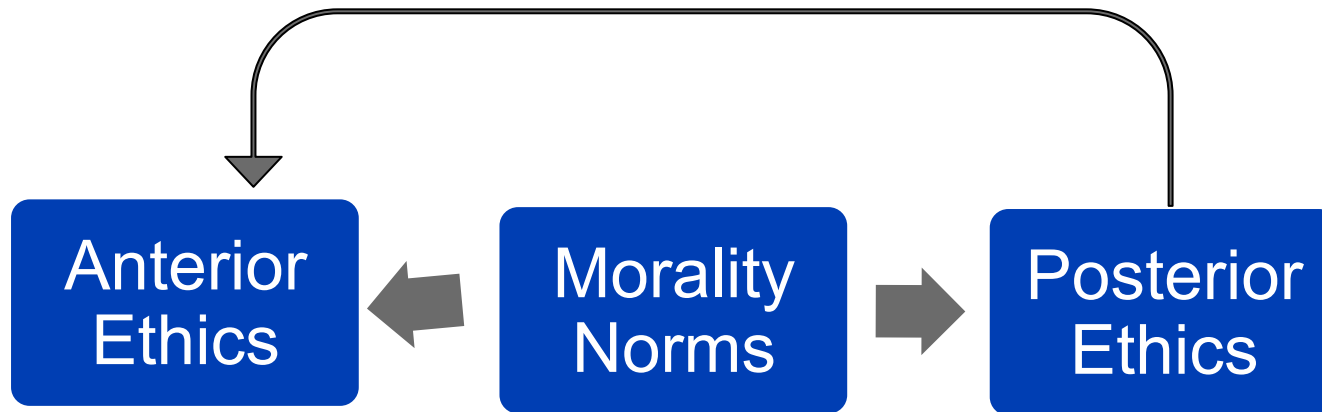


Others



Society

Ricœur's 3 propositions for medical judgment



“Ricœurian” matrix for Big Data to reduce ODx

| Big Data ↘ ODx | Anterior ethics | Morality norms | Posterior ethics <i>“Applied to Medical judgment”</i> |
|-------------------|--|---|---|
| Self | Self-esteem Virtues Standard of excellence | Self-respect Autonomy Free choice | Trust agreement: decision Patient agency Physician accountability |
| Others | Solicitude Benevolent sharing | Respect for others Reciprocity Benevolence as no harm | Medical contract Confidentiality Professional codes Trustworthiness |
| Society | Sense of justice Living together Equality Sharing and Repairing | Distributive justice Legal authority Legitimacy (testing, screening, and commercialization) | Research goals aligned with common good Solidarity, digital literacy Prudence Equity in access to big data |

Ethical recommendations require political will

1. **Clarifying accountability** when medical judgment is based on big data information.
2. **Reducing asymmetry in digital literacy** between citizens, patients and care providers (patient information, education)
3. **Continue research and innovative queries** looking for evidence on big data and ODx.
4. **Sharing governance** between experts, policy-makers, clinicians and patients.
 - Transparency, access to algorithms
 - Democratic deliberation on common good
 - Compensation for harm due to ODx

Ethically driven, Big Data can help reduce ODx

1. Connections between ODx and big data
2. Narrative approach: Ricoeur's ethics
3. Ethical guidance for Big Data to reduce ODx

Thank you

corine.moutondorey@uzh.ch

No conflict of interests

Main references

- Carter, S.M., Degeling, C., Doust, J., and Barrat, A. (2016). A definition and ethical evaluation of overdiagnosis. *J Med Ethics*, doi:10.1136/medethics-2015-102928
- Montello, M. 2014. Narrative Ethics: The role of Stories in Bioethics, special report, Hastings Center Special Report 44 (1): S2-S6.
- Morrison, M. (2016). Overdiagnosis, medicalisation and social justice: commentary on Carter et al (2016) "A definition and ethical evaluation of overdiagnosis". *J Med Ethics*, doi:10.1136/medethics-2016-103717
- Mouton Dorey, C. (2016). "Rethinking the Ethical Approach to Health Information Management through Narration: Pertinence of Ricœur's 'Little Ethics'". *Medicine, Health Care and Philosophy*, doi:10.1007/s11019-016-9713-6.
- Moynihan, R.N., Cooke, G.P.E., Doust, J.A., Bero, L., Hill, S., Glasziou, P.P. (2013). Expanding disease definitions in guidelines and expert panel ties to industry: A cross-sectional study of common conditions in the United States. *PLOS Medicine*, 10(8), e1001500.
- Moynihan, R., Henry, D., and Moons, K.G.M. (2014). Using evidence to combat overdiagnosis and overtreatment: Evaluating treatments, tests, and Disease Definitions in the time of too much. *PLOS Medicine*, 11 (7), e1001655.
- Murdoch, T.B., Detsky, A.S. (2013). The inevitable application of big data to health care. *Journal of American Medical Association*, 309(13), 1351-1352.
- Nuffield Council on Bioethics. (2015). Biological and health data: The collection, linking and use of data in biomedical research and health care: ethical issues. <http://nuffieldbioethics.org/report/collection-linking-use-data-biomedical-research-health-care/chapter-downloads-2/> Accessed 17 August, 2016.
- Ricœur, P. 1992. *Oneself As Another*, (trans: K. Blamey). Chicago and London: The University of Chicago Press. Originally published as *Soi-Même Comme un Autre* 1990. Paris: Editions du Seuil.
- Ricœur, P. 2000. *The Just*, (trans: D. Pellauer). Chicago and London: The University of Chicago Press. Originally published as *Le Juste* 1995. Paris: Editions Esprit.
- Ricœur, P. 2007. *Reflections on the Just*, (trans: D. Pellauer). Chicago and London: The University of Chicago Press. Originally published as *Le Juste 2* 2001. Paris: Editions Esprit.
- Rogers, W.A., Mintzker, Y. (2016). Casting the net too wide on overdiagnosis: benefits, burdens and non-harmful disease. *J Med Ethics*, doi:10.1136/medethics-2016-103715