Overdiagnosis and Big Data: An ethical perspective


Corine Mouton Dorey
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 mitigate ODx harm
The Big Data Story

Context

Plot

Characters
A simple story…

Patient-Physician
...became complicated

- Big Data Experts
- Data Providers (...‘omics…)
- Patient-Physician
- Queries Users (correlations)
An unexpected event could happen

![Diagram]

- **Big Data Experts**
- **Queries Users** (correlations)
- **Patient-Physician**
- **Data Providers** (‘omics)

**ODx**
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:

- Sameness  
  “what I am”

- Selfhood  
  “who I am”
Ricoeur’s ethics aims at:

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

Self

Others

Society
Ricœur’s 3 propositions for medical judgment

Anterior Ethics  →  Morality Norms  →  Posterior Ethics

Anterior Ethics

Morality Norms

Posterior Ethics
"Ricœurian" matrix for Big Data to reduce ODx

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

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Thank you

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No conflict of interests
Main references