Brain Models and Digital Twins: Neuroethical Reflections

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Structure

- Attention to ethical and social considerations should be considered an integral part of scientific research
- Snapshot of some of the current ethical or ethically relevant issues raised by computational modeling and DTs in the context of healthcare





On scientific excellence

- Scientific excellence: lack of agreement on how to understand it
- Embedded in research itself and revealed by peer review
- Linked to fundamental discoveries and breakthroughs
- Linked to marketability
- Generally disconnected from ethical, philosophical and societal considerations





Science and values

Scientific knowledge, in particular, is not a transcendent mirror of reality. It both embeds and is entry social practices, identities, norms, conventions, discourses, instruments and institutions – in short, building blocks of what we term the social. The same can be said even more forcefully of technolog Jasanoff 2004)

- Science and technology are not neutral
- Separatist view of ethics, society and science as a roadblock
- More encompassing understanding of excellence can facilitate a fuller mapping of the issues, and promote a more productive ethical approach



Brain Modelling and DTs

- Primary value of computational brain models lies in the extent to which by representing an aspect of the brain they can enhance our understanding of this organ and guide further research on it
- When personalized, they are projected to transform healthcare by enabling a wide range of personalized activities
- Additional value as a stepping stone for the development of digital twins of the brain as a dynamic simulation (representing the physical entity in real time) that in the clinical context can predict possible progressions of a brain disease
- As the models move into the clinic, it is important to include robust ethical reflection on the issues they raise.





Ethical aspects in TVB and DT research and application



Four main themes

- Terminological and conceptualissues
- Philosophical issues
- Technical issues
- Practical ethical issues



Terminological/Conceptual issues

- Importance of language and terminology:
- lack of clarity in the terminology and the use of misleading terms are ethically relevant when discussing science and its impact

"the choice of language is both, symbolic and persuasive. It intervenes in political and policy debates and research and healthcare funding decisions" (Lupton, 2021)

"unclear conceptualizations increase the risk of hypes, whether in the form of inspiring unrealistic expectations or unfounded worries" (Evers and Salles, 2021)

- In the case of models and DTs
 - distinction between personalized brain models and digital twins of the brain is often blurred (term "twin" at times used for every effort to digitalize the human body)
 - term "Digital Twin" in particular, quite ambiguous





Do concepts matter ethically?

Terms shape conceptualizations

Concepts carry:

- normative
- theoretical
- social weight

Misleading conceptualizations can

- distort citizens' perceptions of science or emerging technology
- negatively shape people's attitudes towards scientific findings or resulting technologies
- Be an obstacle to the trust needed for public acceptance & support of science and its products





Philosophical issues in DT technology

We may be discussing the ethical implications of a technology far too early in its development its future course, technical feasibility, features and impact remain highly uncertain, and thus are at greatest risk of extrapolating into science fiction (Mittelstadt, 2021)

What are DTs?





What are they?

Different options

- "representations" that function as surrogates of the brain in the context of medicine
 - result of a process based on data about the brain so, can it be accurate?
 - And what does accuracy mean in this context? How much accuracy is needed?
 - Representations +
 - Prescribe
 - Predict
 - An extension of patient's body
 - Consent
 - A technique "used to steer a physical entity by means of representations"

Ethical relevance: how we answer shapes the discussion about practical issues such as IC





Techno-ethical issues

- Formulation of the computational model
- Validity





Formulation of the computational model

Computational models are complex codified artefacts

Developers make choices at the level of software, hardware, boundaries, to create them and choice a shaped by developers' goals, institutional interests, legal considerations, values, and some general assumptions about what is worth asking or revisiting

"a process based on human choices and interpretations, in combination with the material characteristics of the representing artefact, in this case, machine encoding, decoding and computation" (Korenhof et al., 2021)

Ethical relevance:

- If unknown this may affect the understandibility and usability of model itself
 - Transparency (pros and cons)
- Users' rights and researchers' duties
 - What information do users have right to?
 - Are there limits to the responsibility to disclose? How to determine those limits?



Validity

Model developers must ensure that models actually connect to the real phenomenon and that inputs and outputs are validated Complex and opaque organ such as the brain makes this particularly challenging

Ontological Epistemological

Ethical relevance:

• The ultimate goal of the models is to help patients,... General understanding that In order to be successful, models must match the functionality of physical counterparts: accuracy seems key. How to ensure such accuracy?





Practical-ethical issues

- 1) Data protection
- 2) Justice related issues
- 3) Human relations
- 4) Dual use
- 5) Consent





Two practical ethical issues

1) Justice

- Will computational models be drivers of further inequality at individual and global level?
- Can they perpetuate errors and inaccuracies leading to bias and discrimination?

2) Patient-physician relation

- a. Empower or disempower patients?
 - i. prerequisites for people to exercise their freedom in certain contexts vs disempowering people because
 - ii. If treated as a reliable source of information, they might be seen as providing more "objective" information
 - iii. Their predictive capacity and warnings might exercise undue pressure on people's lives
- b. Predictive capacity raises issues as well
 - i. Responsibility: who is responsible for diagnosis?
 - ii. Could it lead to overdiagnosis?
 - iii. Could it make practitioners more reluctant to question what the model suggests? Disempowering practitioners?
- c. Minimizing contact? Could models and DT become more interesting to engage with?





Moving forward

- Relation between science, technology, and society is intricate
- A purely technical understanding of scientific excellence unintentionally promotes that idea that science and its products are fundamentally value neutral and that ethics and societal considerations are external to the research
- Significance of involving individuals with different expertise in order to evaluate ethical and societal issues in research projects and their outcomes
- Good science requires careful attention to the evidence, adequate research methodologies and appropriate questions AND attention to value judgments, to issues related to the creation of scientific knowledge, how problems are framed, how the framing shapes solutions, and what are the conceptual frameworks used





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Thank You!

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