PRECISE4Q

PREDICTIVE MODELLING IN STROKE

careum

Health Ethics & Policy Lab

Expectations and attitudes towards medical artificial intelligence

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Updating precision: Ethical and societal aspects of precision medicine in the era of big data
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Overview

- Introduction to PRECISE4Q
- Ethics of AI in stroke medicine
- Study: Expectations and attitudes towards AI in stroke medicine
- Reflections on collaboration within Precise4Q & interdisciplinary AI research

PRECISE4Q: The burden of stroke

1,2m strokes per year in Europe

Stroke is the second leading cause of death worldwide.

Over 60% of stroke survivors suffer from permanent restrictions in their daily activities.

€50 billion per year direct medical costs

The direct medical treatment cost per patient in Europe amounts to an average of €42,000.

This results in annual costs of € 50 billion for the healthcare system.

120m people at risk

In Europe, there are 120m people with an elevated risk for cardiovascular events and stroke.

Continuous disease management for this segment would significantly reduce the medical, financial and social impact of stroke.

PRECISE4Q: AI in stroke medicine

PRECISE4Q sets out to minimize the burden of stroke for the individual and for society.

By leveraging existing data PRECISE4Q will develop data-driven predictive models that enable personalize stroke treatment across the patient journey:

prevention, acute treatment, rehabilitation, reintegration

We get the data.
We build the models.
We test the models.
We reduce the burden of stroke.

…but is it all that simple?

We are not there yet

Core challenge of PRECISE4Q data access, data sharing & data harmonization

- A push towards AI-driven healthcare and data sharing for public good but many open questions and challenges remain
- Need for regulatory frameworks and ethical guidance to support policymakers and developers in navigating novel ethical challenges

The rise of AI Ethics and Trustworthy AI

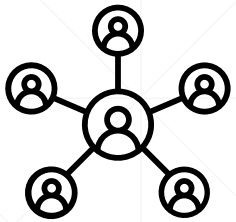
- Academic research on ethics of big data and AI has proliferated across domains
- Professional associations started to issue statements
- Private sector reacted with the installation of ethics boards and guidelines
- International organizations have issued policy documents
- Interdisciplinary and interprofessional discourse is expanding rapidly

Limitations of existing ethical frameworks

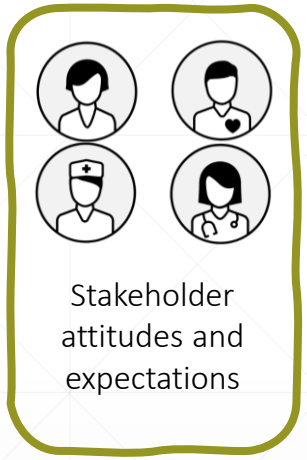
- A plethora of ethical guidelines, frameworks, and policy documents exist
- Guiding principles but no actionable recommendations
- Generic rather than tailored to the specific context
- Lacking translation into practice

Devise an ethical framework for big data health research and ethical guidelines for data-driven predictive modeling in stroke medicine that are rooted in **normative considerations**, build on **existing ethical frameworks**, and consider the **lived experience, attitudes, values, and expectations** of prospective users, beneficiaries, and developers.

Multi-stage participatory approach



Patient-centered care

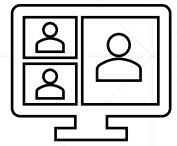


Stakeholder attitudes and expectations

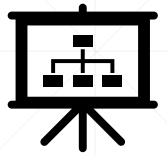
Deliberative dashboard

Precise4Q impact workshop I

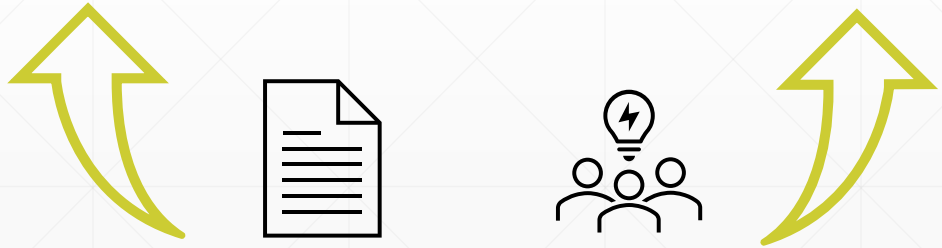
Internal survey



Precise4Q impact workshop II



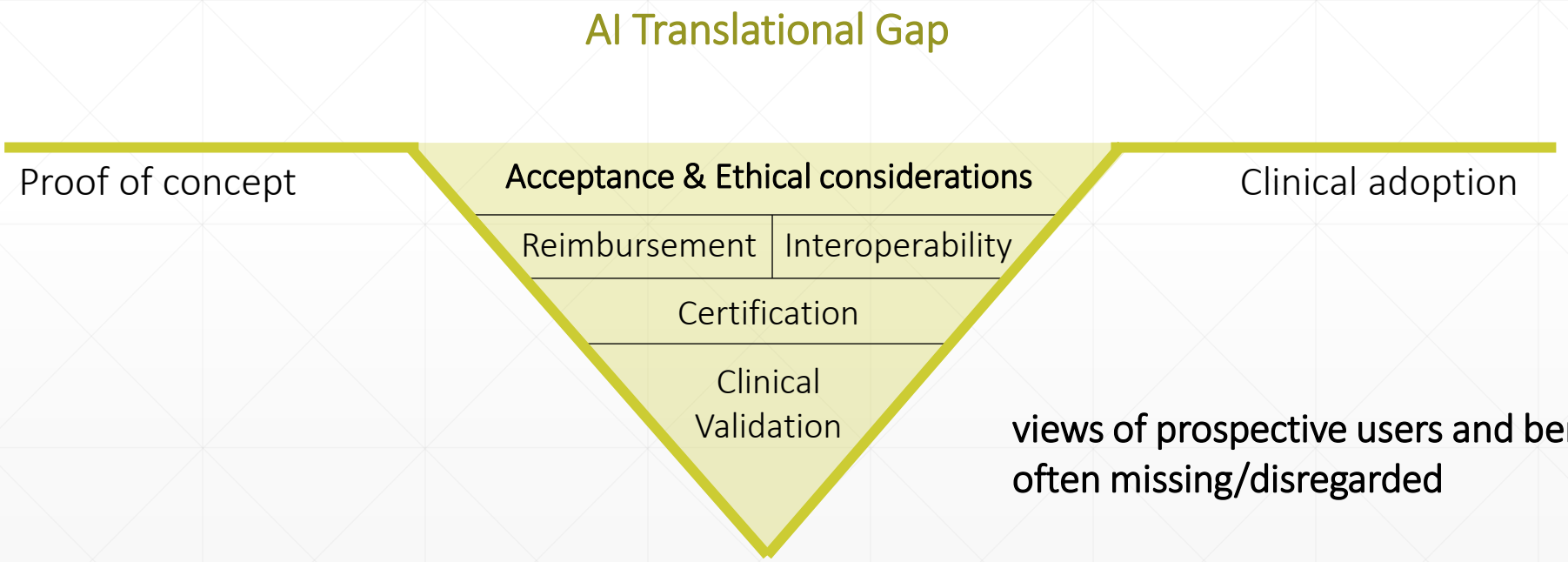
Public symposium



Literature and policy monitoring

Exchange with other initiatives

Medical AI: Spurred by hype and promises



views of prospective users and beneficiaries often missing/disregarded

Amann et al., under review in PlosOne

Adapted graphic (Sources: Vince Madai & biosci consulting)

Addressing gaps in current research

To explore the views of stroke survivors, family members, and healthcare professionals specialized in stroke regarding the use of AI in stroke medicine.

>> elicit expectations and attitudes towards stroke related medical AI, focusing on the perceived benefits and risks when applied in the clinical setting.

Amann et al., under review in PlosOne

Methods

Study design: qualitative research design

Data collection:

- Recruitment through professional networks, medical professional/patient associations & snowballing
- Semi-structured interviews (N=33), conducted in person/phone between Nov ‘19 and March ‘20
- Duration: 22-78 min (⌀ 40 min, Σ 22h 38 min)
- Audio-recorded and transcribed verbatim for analysis
- Field notes

Data analysis: Combination of inductive and deductive thematic analysis in MAXQDA complemented by extensive memo-taking both in written and visual form

Amann et al., under review in PlosOne

Findings

Presumed roles of AI in the clinical setting

Perceived opportunities and limits of medical AI

Perceived challenges, risks, and open questions

Amann et al., under review in PlosOne

Discussion: currently under-investigated issues

Need for a more nuanced understanding of medical AI

Implications for role perceptions & relationships

Need to challenge AI solutionism & promote stakeholder engagement

Amann et al., under review in PlosOne

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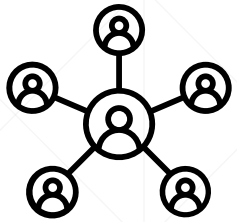

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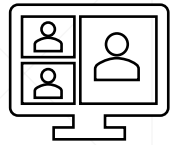

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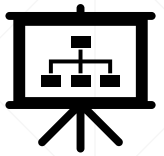

Public symposium

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A reflective framework

Phase	Theme	Guiding questions
Development	Data quality and representativeness	- How much is known about the data quality and its representativeness for the target population? - What measures are in place to account for data quality and representativeness? - Who might be under or overrepresented? - What consequences may this have on the performance of the model for these population(s)?
	Purpose of the tool	- What is the intended purpose of the tool in clinical practice? - In what phase of stroke is the tool to be used (prevention, acute, rehabilitation or reintegration)? - How might the tool be used by clinicians and how may this shape their professional role perceptions? - Is there a risk of inappropriate use and how might this risk be mitigated? - Are there any secondary end-user groups?
	Explainability	- What kind of information on the tool will be available to end-users? - Are models explainable and if so, is there an impact on performance? - If available, are explanations tailored to the needs of end-users? - How may the information end-users have or lack impact their interaction with the tool?
	Usability and user experience	- Have prospective end-users been involved in the development process and if so, how has their input shaped the tool? - If prospective end-users were not involved in the development, what consequences may this have on the tool and its adoption in clinical practice? - Has usability and user experience been assessed, and if so, how?
	Clinical validation	- How is the tool validated? - What does clinical validation mean to developers, what does it mean to clinicians and patients? - What impact may clinical validation have on clinicians'' and patients' trust and responsibility?
Deployment	Disclosure of AI	- How much information can and should be disclosed to the patient? - How much do clinicians need to know about the tool and its application in order to fulfil their role? - What impact may predictive health information with disclosure of AI have on patient trust, compliance, and the doctor-patient relationship?
	Responsibility	- How is responsibility/liability addressed? - Is there a risk of deskilling? - What is the developers' responsibility? - What impact may incorrect decisions caused by the tool have on clinicians' moral responsibility?
	Empathy	- How may the tool impact clinicians' empathy towards patients? - How can patient values, beliefs, and preferences be incorporated into the decision-making process? - Might the tool replace human contact in the clinical encounter and if so, what consequences may this have for patients and clinicians?
	Privacy & Data Protection	- Given that stroke prevention takes place before any symptoms occur, how can health benefits and privacy be balanced? - Should there be different privacy standards for the different phases of stroke (prevention, acute, rehabilitation, reintegration)? - Which mechanisms would need to be in place to ensure patient privacy? - What might be the consequences of failing to ensure patient privacy?
	Monitoring & Evaluation	- What kind of monitoring and evaluation processes should be in place? - Who is responsible for conducting continuous monitoring and evaluation? - What might be the consequences of failing to conduct continuous monitoring and evaluation?

- Ten sub-sections across the domains “development” and “deployment”, non-exhaustive, guiding questions as basis for interprofessional exchange and reflection within and beyond the consortium
- Purpose: stimulate discussion and reflection among the consortium partners, allowing them to identify and anticipate potential ethical challenges that might jeopardize the successful translation of the Precise4Q tools into clinical practice.
- Pilot-tested with consortium partners as part of the second PRECISE4Q Impact Workshop Series

Thank you for your attention

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PRECISE4Q

PREDICTIVE MODELLING IN STROKE

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