

Nordic AI Meet 2026

P2: AI in Health, Medicine, Care & Human Well-being

6. Re-examining patient (non)participation in Health-AI

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Abstract: Participatory approaches are widely recommended and used across health and AI research. In digital health, this implies including patients with their lived experiences, as well as healthcare professionals such as clinicians and specialists with expertise relevant to the health/medical conditions being studied, through co-creation, co-design or co-production, towards improving health outcomes. This aligns with recent research that finds that patients want to be involved right from the problem identification stage in AI projects. However in practice, patients are seen to be less involved, or even excluded, from the process of designing tools and technologies eventually intended for their use. This aspect was highlighted as one of the ‘grand challenges’ for AI in self-tracking, where, as the authors note, “many contemporary AI powered solutions leave humans out” and instead “often view them only as data contributors, and as receivers of inferences, predictions, and recommendations”.

Further research is hence needed to understand why patient participation in Health-AI is not being followed in practice, especially in light of healthcare organizations’ push towards generating ‘artificial’ patient and public panels, and their increasing use of synthetic patient data. Extending Leder’s prescient words to the age of AI, it seems Health-AI is expunging the very living, experiencing patient it aims to study. Involving patients right from the start (when defining the project scope), rather than later (during the testing or implementation phase), could potentially lead to lesser rates of failure in Health-AI. If there are constraints or challenges to implementing this in practice, there is a clear need to identify these current limitations and barriers from health and technology researchers’ perspectives. There is a growing need to more critically examine the forms of participation afforded by current AI projects, when moving beyond extractive or exploitative modes. To respond to the above, I examine how and why patients are being included or excluded from AI-making processes and practices through the case study of an ongoing Health-AI project.