

Co-design and Ethical Artificial Intelligence for Health: Myths and Misconceptions

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ABSTRACT

Applications of artificial intelligence / machine learning (AI/ML) are dynamic and rapidly growing, and although multi-purpose, are particularly consequential in health care. One strategy for anticipating and addressing ethical challenges related to AI/ML for health care is co-design – or involvement of end users in design. Co-design has a diverse intellectual and practical history, however, and has been conceptualized in many different ways. Moreover, the unique features of AI/ML introduce challenges to co-design that are often underappreciated. This review summarizes the research literature on involvement in health care and design, and informed by critical data studies, examines the extent to which co-design as commonly conceptualized is capable of addressing the range of normative issues raised by AI/ML for health. We suggest that AI/ML technologies have amplified existing challenges related to co-design, and created entirely new challenges. We outline five co-design ‘myths and misconceptions’ related to AI/ML for health that form the basis for future research and practice. We conclude by suggesting that the normative strength of a co-design approach to AI/ML for health can be considered at three levels: technological, health care system, and societal. We also suggest research directions for a ‘new era’ of co-design capable of addressing these challenges.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)** → **HCI theory, concepts and models**

KEYWORDS

Co-design, participatory design, artificial intelligence, machine learning, health care, health systems, ethics

Introduction

The contemporary field of artificial intelligence / machine learning (AI/ML) is dynamic and rapidly growing, characterized as central to the “4th industrial revolution” that commentators suggest will affect virtually all aspects of our lives (Couldry & Mejias, 2019; Schwab, 2017; Zuboff, 2019). Although AI/ML technologies are multi-purpose, they are particularly consequential in health care, where concerns range from the changing nature of the patient-provider relationship (Goldhahn et al., 2018; Topol, 2019), to the ways in which AI/ML technologies can exacerbate existing societal inequities (Benjamin, 2019; D’Ignazio & Klein, 2020; Eubanks, 2018; Noble, 2018). For example, a study of a resource allocation algorithm by Obermeyer et al. (2019) found that Black patients were referred for additional care half as often as White patients, in spite of having comparable levels of need. As a result, there has been increased acknowledgment by corporate, government, and academic actors alike that AI needs ‘ethics’ – or research and practice aimed at ensuring that the benefits and harms of AI technologies are comprehensively accounted for and fairly distributed (Metcalf & Moss, 2019). How these ‘ethics’ are meant to be established and applied, however, has led to significant debate.

One such strategy for anticipating and addressing the potential benefits and harms of AI/ML for health is patient and public involvement in the design of those technologies, sometimes referred to as participatory design or co-design. As a category of approaches to technology development that aim to involve end-users as meaningful participants in the design process, co-design is often mobilized as a strategy to improve fairness, accountability, and transparency of algorithmic systems (Aizenberg & Hoven, 2020; Cech, 2020; Katell et al., 2020; Malizia & Carta, 2020; Sloane et al., 2020; Whitman et al., 2018). Co-design is also closely allied to other trends in health and health care, such as patient engagement, patient and public involvement (PPI), and patient and family-centred care (PFCC). Co-design and its variants have a diverse intellectual and practical history, however, and have been conceptualized in many different ways. Moreover, the meaning and value of co-design is challenged by AI/ML systems, where

users will always play some role in the production of those systems, for example in producing data used to train models (Hee-jeong Choi et al., 2020; Sloane et al., 2020). As such, the extent to which co-design as commonly conceptualized can be viewed as a suitable approach to ethical or responsible AI/ML has recently come into question (Hee-jeong Choi et al., 2020; Hoffmann, 2020; Sloane et al., 2020).

Informed by perspectives from critical data studies (boyd & Crawford, 2012; Dalton & Thatcher, 2014; Kitchin & Lauriault, 2014) and critical digital health studies (Lupton, 2016, 2017b), in this paper we outline five myths and misconceptions arising from co-design discourse related to AI/ML for health care. We start by presenting our theoretical approach in some detail, outlining three concepts from critical data studies and critical digital health studies that inform our analysis. We then present a brief description of practices of involvement in design, and involvement in health care, leading into a summary of overarching risks for consideration, and conclude by outlining important directions for future research and practice in this area.

Theoretical Approach

Our analysis of involvement in the design of AI/ML for health care is shaped by perspectives from critical data studies (CDS) and critical digital health studies (CDHS). CDS is a diverse interdisciplinary field, bringing together methods and perspectives from across media studies, sociology, anthropology, human geography, and design, among others. While the field is diverse, CDS is united by a concern with the social, cultural, ethical, and political challenges posed by data, including how they are constituted within wider data assemblages (Iliadis & Russo, 2016). To date, data remains largely neglected in discussions of co-design for AI/ML technologies. This is concerning given their centrality to emerging social and economic systems (Couldry & Mejias, 2019; Zuboff, 2019), and the processes and practices of surveillance they enable (Cheney-Lippold, 2017; Lyon, 2010).

A related field originating in health research is CDHS. While a number of scholars have engaged critically with how health technologies (including health information technologies) have influenced relationships to health, illness, and care (Clarke et al., 2003; Rose, 2007), Lupton (2014b, 2016, 2017) was among the first to outline the unique challenges posed by digital technologies. In particular, she highlights the important social, cultural, and political roles played by digital health technologies, and their contributions to notions of health and illness (Lupton, 2014a).

Three concepts in particular from these interdisciplinary domains inform the analysis of involvement in health-related AI/ML development presented in this paper. The first is 'socio-materiality', which indicates that AI/ML technologies are not simply digital algorithms that happen to be embedded in a variety of devices. Rather, AI/ML technologies are better understood as a collection of digital algorithms, technological devices, telecommunications infrastructures, human goals, and human rules that cohere together into 'assemblages' that represent specific AI/ML technologies (Kitchin & Lauriault, 2014). If one is

to understand the ethical significance of co-design for AI/ML technologies, one must acknowledge how deeply intertwined they are with the human and material realities that shape their existence in the world.

The second concept is 'surveillance', which has come to signify the consequences of mass data collection on human experience and action, spurring the development of an entire field of research referred to as surveillance studies (Lyon, 2008, 2010). The notion at the root of studies of surveillance is that the act of collecting data about peoples' activities has significant influence on the activities in which they engage. This is true for both individuals and populations, and has novel implications in contexts of health and health care.

The final concept influencing our analysis is that of the 'political economy' of data and technology, referring to the particular economic assumptions and institutions that are supported by AI/ML technologies and the organizations by which they are developed and used. The concept is more accurately described as 'political economy' as opposed to just 'economy' to represent the inevitable existence of competition for control over resources that comes along with the capitalist economic system in which we find ourselves (Couldry & Mejias, 2019; Zuboff, 2019). These three concepts directly inform our approach to data ethics and our summary of involvement in health care and design, forming the foundation for our description of myths and misconceptions related to co-design of AI/ML for health.

It is also important to note that co-design has been represented in the research literature in a variety of ways. For example, it may refer to *any* form of involvement in design, or be used to describe a *particular* form of involvement distinct from related approaches such as participatory design. Involvement may occur throughout the design process, or only at particular stages. It may be employed as a strategy to improve usability and acceptance of a technology, or to elicit stakeholder values. These differences indicate a diverse field of research and practice, where scholarly communities are concerned with similar topics, but enjoy only partial overlap of assumptions and motivations upon which they are based (Filimowicz & Tzankova, 2018). Nonetheless, we believe there is clear conceptual benefit to critically examining the field of research and practice as a whole. This paper therefore uses 'co-design' as an umbrella term for approaches that involve end-users, patients, or publics in *any* stage of the design process.

Involvement in Design

Within design scholarship, formal involvement in design is most commonly attributed to Scandinavian approaches in the late 1970s and early 1980s which attempted to address workplace transformations brought about by computers. Inspired by action research, these early examples involved very little 'design' *per se*, but rather emphasized the importance of providing workers and union officials with the requisite knowledge and skills to understand the potential impacts of computer systems on their work, with the ultimate aim of strengthening collective bargaining strategies (Vines et al., 2013). This is perhaps best

exemplified by the Collective Resource Approach, which convened 'independent study groups' comprised of union members and academic researchers (Kraft & Bansler, 1994). These earliest forms of co-design were explicitly politically engaged, emphasizing productive tension over immediate consensus in arriving at a decision (Björgvinsson et al., 2012). Worker control and agency were explicit aims (Vines et al., 2013), and most Scandinavian-inspired co-design today is characterized by two core assumptions: that those affected by a decision should have a say in its making, and that stakeholders' tacit knowledge is essential to the success of a design project (Björgvinsson et al., 2012).

In the early 1980s, the UTOPIA project took the participatory tradition one step closer to 'design' as it is practiced today, with the creation of dedicated workspaces for employee experimentation and imagination (Ehn et al., 1981). Key to these processes was the use of mockups or prototypes. As the power of trade unions waned, however, the focus of co-design changed (Kensing & Blomberg, 1998); political aspects became subtler, and a more 'polyvoiced' approach emerged (Halskov & Hansen, 2015). Others have noted that as co-design spread to the United States and Canada, the notion of sharing control with relevant end users became motivated more by commercial concerns, such as developing more usable products (Kensing & Blomberg, 1998; Vines et al., 2015). Sears & Jacko (2007) note that co-design work in Australia and New Zealand appears to have grown out of quality improvement movements, focusing on problem solving more than re-configuring workplace relations.

This movement toward consumerist justifications for involvement now influences technology design today, where iterations of co-design methods and principles are reflected in many different but related AI/ML design approaches. User-centred design (UCD), for example, is an approach to technology design that focuses on eliciting users' 'real needs' in order to improve the 'fit' between a user and a technology (Norman & Draper, 1986). User experience design (UXD) focuses on a users' expected and actual emotions and attitudes when engaging with designed artifacts (Cooper et al., 2014). Human-centred design similarly emphasizes the incorporation of a 'human perspective' in all phases of the design process (Giacomin, 2014). While not exhaustive, these represent highly established approaches, where patient and public involvement may be mobilized as a complementary strategy to improve a technology in some way.

Claims to the normative superiority of co-design approaches, however, whether motivated by consumerist or democratic justifications, are complicated by novel features of AI/ML technologies that make them distinct from other information technologies. These include the ways in which publics 'participate' in the design of algorithmic systems in ways that are unwitting or spectator-like (Vines et al., 2013), for example in producing data upon which AI/ML algorithms are trained (Sloane et al., 2020); that AI/ML technologies can be instantly modified or re-purposed after deployment to achieve new goals (Kitchin, 2017); the 'black box' nature of AI/ML algorithms, which limits

what can be known and addressed through co-design (Cohen et al., 2014; Pasquale, 2015); that AI/ML technologies, and the resources and infrastructures upon which they rely, increasingly lie outside traditional health and medical settings (Bot et al., 2019; Sharon, 2016; Sharon & Lucivero, 2019); and the challenge of accounting for how data produced by AI/ML technologies will be used in the future (Ruckenstein & Schüll, 2017). These challenges inform our co-design risks and myths and misconceptions presented in the following two sections.

Involvement in Health Care

Patient and public involvement (PPI) in health care has an equally long and complex history, however, formal involvement arrangements can be traced to social movements initiated by feminist, queer, and disability rights activists in the 1970s and 80s (Brown & Zavestoski, 2004; Busfield, 2017). These movements rebuked medical paternalism, and sought to legitimate experiential or embodied knowledge in bringing about changes to the institutions of medicine (Brown & Zavestoski, 2004; Tanenbaum, 2015). In 1974, the United Kingdom's National Health Services (NHS) established Community Health Councils as a first example of institutionally supported PPI, with a mandate to improve local service delivery and accountability (Hogg, 2007). While formal PPI has since taken on different profiles around the world (Tritter, 2009; Tritter & McCallum, 2006), it continues to hold interest in many areas of health research and practice, including health professions education (Rowland et al., 2018); health care research (Greenhalgh et al., 2019; Madden & Speed, 2017); health policy (Abelson et al., 2004); and quality improvement and innovation (Boivin et al., 2014; Donetto et al., 2015).

PPI is also closely linked to other influential ideas about how health care should be organized, and to whom health care decision-makers should be accountable. Patient and family centred care (PFCC) has been defined as: "The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care" [9, p. 560]. The basic ideas underpinning PFCC however, are much older. Hippocrates urged physicians to "investigate the entire patient" (Boivin, 2012). At the turn of the 20th century, Canadian physician William Osler is noted for orienting medical education towards the needs of the patient rather than the disease.

As with co-design, conceptualizations of PPI and PFCC vary considerably. Conceptual discussions of PPI have for example distinguished between democratic and consumerist rationales (Wait & Nolte, 2006); direct/indirect, and proactive/reactive forms of involvement (Tritter, 2009); outcome-oriented versus process-oriented involvement (Ives et al., 2013); and domains of involvement, such as direct care, organization, or policy (Carman et al., 2013). Others see PPI as existing on a continuum (Gibson et al., 2012), or as an ongoing process of organising, where patient

roles and identities are constantly being formed and negotiated (Rowland & Kumagai, 2018).

Notwithstanding these practical and conceptual challenges, interest in PPI has increased, and as information technologies have matured and become more deeply embedded in health care, strategies and perspectives from design and related fields have also increased in prominence. The fields of health and biomedical informatics (HI), for example, increasingly engage with methods and theoretical perspectives from human-computer interaction (HCI), in spite of paradigmatic differences that have historically made collaboration difficult. While HI and HCI share an interest in the variety of ways people engage with technologies in diverse use-contexts, they often do so via different methods (e.g. experimental versus design-based methods); publication venues (e.g. peer-reviewed journals versus conferences); and topics (e.g. clinical settings versus consumer applications) (Kim, 2019). Some of these divides are narrowing, however, as health services researchers seek new approaches capable of addressing complex design, implementation, and evaluation challenges posed by advanced digital technologies (Pham et al., 2016; Shaw et al., 2018).

Today, the focus of technology design is shifting once again, as information systems and the goals they are intended to achieve, continue to evolve. Some, for example, propose that HCI and related fields find themselves in a new wave concerned primarily with persuasion (Fogg et al., 2007). AI/ML applications in health are broad, but in all instances ‘nudge’ attitudes or behaviors either through direct intervention, or by providing tailored information (Shaw et al., 2019; Yeung, 2017). At the individual/patient level, for example, research in digital behaviour change incorporates methods and perspectives from design and psychology to accomplish self-management of medical conditions, or health promotion via behaviour modification (Michie et al., 2017). AI/ML has also been used in epidemiological modelling and forecasting (Lalmuanawma et al., 2020), clinical decision support (Montani & Striani, 2019), and in health care operations and logistics (Obermeyer et al., 2019). Involvement of patients or publics in the design of advanced digital technologies often emphasizes the *inherent* patient-centred or empowering qualities of co-design approaches (Capecci et al., 2018; Enshaeifar et al., 2018; Triberti & Barello, 2016) or AI/ML technologies (Topol, 2019), especially when directed to health-related goals. As such, co-design, PPI, and PFCC afford legitimacy to AI/ML technologies for health, though the extent to which they always should, remains a topic of debate (Hoffmann, 2020; Sloane et al., 2020).

In sum, the affordances of AI/ML technologies for health, and the challenges they pose to co-design, present three main risks that give rise to the myths and misconceptions presented in the following section. First, co-design risks adding new harms to health systems as a result of putting forward innovations that have not been designed with unintended consequences in mind. These include the ways in which AI/ML technologies, and the data they produce, can be instantly adapted or modified to suit new goals, for which patients and publics have no input once the technology has been deployed. Second, co-design risks

instrumentalizing patients, using their involvement in the design of an AI/ML technology to make advances toward achieving pre-existing goals established by those in positions of power. In AI/ML for health, power is increasingly distributed among both public and private actors. Third, co-design risks obfuscating societal injustices when involvement of patients or publics focuses only on problems that can be solved by technologies.

We now shift to a description of five myths and misconceptions of co-design and ethical AI/ML for health. We suggest that attention to these assumptions is essential to determining the appropriateness and feasibility of co-design for AI/ML for health, and that by addressing them, it may be possible to envision alternative approaches to co-design that better equip it to engage with the normative issues raised by AI/ML for health. We also highlight areas where this work is already occurring.

Co-Design and Ethical AI/ML for Health: 5 Myths and Misconceptions

Myth #1: ‘Better’ involvement strategies result in ‘better’ design outcomes

The central point advanced with Myth #1 is that ‘better’ involvement (indicated by breadth, depth, or impact of involvement on decision-making) does not imply a stronger focus on the entirety of the socio-technical system, much of which is out of view for both users and designers of AI/ML technologies. The consequences of newly designed AI/ML technologies, including the linked effects of data commodification, surveillance, and individualization of care, remain marginal in most approaches to co-design.

Scholarship and practice related to co-design (Kensing & Blomberg, 1998; Steen, 2013a, 2015), and patient and public involvement more broadly (Abelson et al., 2010, 2016; Armstrong et al., 2013; Boivin et al., 2018), tends to emphasize the importance of processual and contextual characteristics of isolated involvement events, for example ‘moments’ or ‘stages’ of involvement, patient and public latitude in decision-making, organizational support for involvement, and the proximate impacts of those characteristics on designed artifacts. The implicit assumption advanced by these viewpoints, is that better involvement strategies will result in better design outcomes, as evaluated by the impacts of those strategies on design products and their consequences. This perspective is complicated by both normative and epistemic challenges related to AI/ML for health (Mittelstadt et al., 2016) that frustrate coherence between co-design goals and strategies, and AI/ML outcomes.

First, AI/ML technologies are capable of *analyzing* vast amounts of data, introducing forms of surveillance not previously possible (Andrejevic & Burdon, 2015). By definition, AI/ML technologies discriminate between categories or ‘measurable types’ (Cheney-Lippold, 2017)). These judgements directly affect individuals’ lives in important ways (e.g. higher insurance premiums, exclusion from participation in particular health and social domains), but

may bear little resemblance to their own interests, priorities, or identities. Categories of *worth* are decided by those with the power to know and decide (Couldry & Mejias, 2019; Dencik et al., 2019; Zuboff, 2019).

Second, they push responsibility for monitoring and management further into the domain of the individual patient or caregiver (Rich et al., 2019), encouraged through design features that 'nudge' data *generating* behaviors (Yeung, 2017). These nudges shape our everyday practice and engagement with the world, directing us toward actions determined to be more desirable than others, for example toward healthier or safer behaviours at the individual level.

Third, the data produced by AI/ML technologies is not only of interest to patients and providers, however, but also to insurers, employers, advertisers, and consumer technology companies. An entire industry of data brokerage firms has also formed around the aggregation and sale of personal data, leading the United States Federal Trade Commission (FTC) in 2014 to issue a call for greater transparency in their practices (FTC, 2014). AI/ML technologies therefore not only result in new geographies of responsibility (Schwennesen, 2019), but also new asymmetries of knowledge (Mittelstadt et al., 2015), and new modes of capitalist production (Couldry & Mejias, 2019; Zuboff, 2019).

Any claims to the ethical standing of co-design must therefore be evaluated against the sociotechnical configurations it produces, rather than the proximate effects of co-design processes on stand-alone products (which arguably, never stand alone) (Taylor, 2013). Without doing so, co-design, no matter the depth, breadth, or rationale, is unlikely to achieve a positive vision for AI/ML for health.

Myth #2: 'Good' co-design increases the agential capacities of patients and publics

The central point advanced with Myth #2 is that 'better' involvement does not mean that people are entirely free from agential constraints that inevitably shape their participation in design activities. These constraints do not only apply to patients and publics, but others implicated in design processes, too.

Scholarship on co-design often focuses on 'levelling the playing field' in co-design processes, for example by articulating strategies for shared language in design (Burrows et al., 2016) or studying how co-design methods might 'distort' participation in favour of designers' interests (Compagna & Kohlbacher, 2014). While these theoretical and practical developments are crucial, what is not explicitly acknowledged in these perspectives is how structural limitations imposed on *designers* also influences design outcomes. The practices, goals, and perspectives of designers are diverse, and influenced by a broad range of actors, interests, and values. These include other project stakeholders, financial incentives, broader economic trends, and social and professional norms. Similarly, AI/ML systems are not static objects, but contingent and emergent, an outcome of a complex network of constant negotiations involving thousands of choices about who and what

to prioritize, how, and when, long before an actual AI/ML system comes into view (Ruckenstein & Schüll, 2017; Schwennesen, 2019). For example, in a study of a physical rehabilitation algorithm intended to reduce in-person clinic visits, Schwennesen (2019) notes that crucially important parameters used to assess the bodily movements of patients were not only determined by physiotherapists, but also the capabilities of the algorithmic system itself. Acknowledging these limits on designers' agency underscores the importance of also attending to the agential capacities of those *leading* design and development processes. By focusing only on enabling or empowering patients and publics in isolated design events, strategies to improve the processes and outcomes of co-design risk being ineffective or short-sighted at best.

Ethical co-design of AI/ML technologies for health must engage with this broader ecosystem of design, expanding the view of who and what is considered relevant. Attending to this expanded ecosystem is the only way to illuminate strategies for co-design that go beyond the proximate issue of user agency in artifact design, to consideration of the institutional and infrastructural arrangements that have made the particular design event and its configuration of people and ideas possible.

Myth #3: Representation and inclusion reduces risk of harms of designed artifacts

The central point advanced with Myth #3 is that the inclusion of communities in design processes does not necessarily address problems that lead to marginalization in the first place. Indeed, it rarely does, and instead risks supplanting consideration of the causes of marginalization, with easy-to-use technological solutions that may exacerbate inequities.

Representation and inclusion of communities or individuals presumed to be affected by an AI/ML model is often positioned as a strategy to reduce potential harms associated with designer bias, ignorance, or neglect. The more accurately co-design processes represent the *perspectives* of particular individuals or groups in society, the more technologies will reflect their *interests*. However, this view obscures two core challenges posed by AI/ML technologies to involvement.

First, not all groups benefit equally from AI/ML technologies, even where representation and inclusion is mobilized as a strategy to improve access or reduce bias. Just as an emphasis on the agential capacities of users risks ignoring limitations places on designers, so too does an emphasis on inclusion risk ignoring the systemic nature of injustice (Hoffmann, 2019). Making claims to ethical co-design demands designers engage with the social determinants of health (SDOH) – or the social, political, and economic predictors of our individual and collective well-being. In spite of decades of research demonstrating the centrality of age, gender, job security, housing, and racism to health, they remain marginal in most AI/ML-based solutions.

Second, the demands made on those intended to 'represent' communities or groups poses a challenge to the immense diversity

of identities and experiences in the world. As Asaro (2000) notes, the aim of representation is not completeness or objectivity, but *practical usefulness*, and its value is therefore determined as much by what it brings in, as what it leaves out. The ways in which representation and inclusion are operationalized in design processes – typically in the form of ‘average’ users or community members – therefore requires re-thinking. Popular design methods such as personas, for example, which are intended to produce archetypal representations of intended users, can contribute to limited or essentialized understandings of communities (Cutting & Hedenborg, 2019). In these cases, inclusion and representation risk entrenching the same problematic social relations that technologies are intended to resolve. These biases take on new forms when produced algorithmically. Will users have the ability to contest categorizations or risk labels such as ‘old’ or ‘young’, ‘healthy’ or ‘not healthy’, ‘compliant’ or ‘non-compliant’? Will they even be aware of them? As Bucher (2018) notes: “The politics of categorization is... one that fundamentally links database architecture and algorithmic operations to subjectification” [17, p. 5].

Rather than emphasizing representation and inclusion for its own sake, ethical co-design ought to include provisions for reflecting on *why* particular individuals or groups are being pursued to begin with, what upstream causes of identified ‘problems’ might exist, and how co-design and AI/ML can (and importantly, cannot) mitigate those consequences.

Myth #4: Co-design is an inherently ethical approach to design

The central point advanced with Myth #4 is that co-design is only as ethical as the consequences of the artifacts and socio-technical systems it produces. These consequences are often further away in time than designers tend to look, which raises the importance of accountability for consequences of design beyond its immediate effects, to those that are geographically and temporally more distant.

Implicit in any undertaking of co-design is the belief that the approach is inherently more ethical than other design strategies not involving patients and publics. Creating an ‘arena’ for moral inquiry in design processes (Steen, 2013b), however, is insufficient to achieve ethical design outcomes, and involvement for involvement’s sake is not an unalloyed normative good. Arguably, co-design can be seemingly ‘ethical’ in its process, as indicated by depth, breadth, and impact of participation in decision-making, and unethical in its consequences as evaluated by the downstream effects of those processes on individuals, groups, or society more broadly. If, as Bucciarelli & Bucciarelli (1994) suggest, all design practices are also *social* practices and therefore all design can be considered co-design, does co-design as it is currently practiced really do more good than harm? What implications does this have when considering the ways in which publics are ‘enrolled’ in data collection schemes intended to train AI/ML models, for which they may have no meaningful input once it is deployed? What is

the value of co-design when AI/ML systems are modified after-the-fact, or adapted to different contexts by different actors?

These questions are not easily answered. Hopefully, however, they represent a starting point for examining the assumptions that underpin *interest* in co-design, and illuminates a need for acknowledgement of the potential ways co-design can fall short of its normative intentions. If the inherently contingent and social act of co-design fails to achieve ethical outcomes beyond the design process, can we really call it co-design? And who benefits most when we do?

Myth #5: All problems can be (co-)design problems

The central point advanced with Myth #5 is that design is not always the best practice to mobilize to address a problem. Furthermore, when design is chosen as a strategy to solve an identified problem, its limitations must be acknowledged.

Although ‘design’ may be considered a near universal human activity (i.e. any generative process involving conceptualization, imagination, or creation) (Terzidis, 2007), when it is practiced in professional settings it represents a particular social, economic, and cultural formulation that prioritizes formal, research-oriented practice (Julier, 2017). These processes are ‘owned’ by particular individuals with substantial professional, economic, and cultural clout (Benjamin, 2019) and represent an orientation to design that is considerably different from informal design practice as a general creative process. Design may therefore be considered both a verb and a noun (Costanza-Chock, 2020), and any claims that capital ‘D’ Design in its various forms substitutes other potentially more egalitarian, community-driven, or radical approaches to creativity or change (Benjamin, 2019; Costanza-Chock, 2020) deserve attention.

Humility in design (i.e. consistently attending to what professional design *cannot* do for a problem) ought to be an important starting point for any professional or aspiring design researcher. Such a design humility might ask questions like: when does co-design substitute other expressions of public interest and action?; what are the epistemic limits of design research as it is currently practiced?; who is sidelined by professional design practice and what might we learn from them? and perhaps most importantly, when *shouldn’t* we design? Observing what is gained and what is lost in different approaches to design may shed light on the limitations of professional design practice as it currently stands, opening up new forums for the exploration of ethical AI/ML for health.

Design justice, for example, is an intersectional approach to community-informed and community-driven design that engages with how designed artifacts and their systems impact upon dominant and oppressed groups in society (Costanza-Chock, 2020). Costanza-Chock urges us to consider not just equity, but community ownership of design, and non-exploitative solutions that connect communities to each other in solidarity.

Others have highlighted the hegemony of Western design practice, and proposed alternative ways of knowing, doing, and

thinking. Ansari (2019), for example, asks: “What does it mean to design for people who are not like us, even before we ask whether we should design for people who are not like us? What does it mean to design for people who have different histories, different backgrounds, and different commitments from us? What does it mean to design for people who might relate to the world differently from the way we do?” (p. 3).

Both Ansari and Constanza-Chock open up space for critical reflection on the epistemic, cultural, economic, and political significance of design practice, and their consequences for human experience and action. If co-design of AI/ML for health is to be ethical, there must be space to consider alternative approaches that go beyond design itself.

A New Era for Co-design?

This review has elucidated some of the key challenges posed by AI/ML technologies to patient and public co-design of those technologies. In some cases, AI/ML for health has amplified or modified existing PPI challenges, such as questions of representation and purpose. In others, AI/ML technologies have presented new challenges, such as the capability of co-design to address the future uses of those technologies and the data they produce. These risks and challenges apply not only to patient and public involvement in the design of individual technologies, but also more broadly to health services and systems, and to health policy and governance.

The normative strength of co-design can therefore be considered at three interconnected levels, each requiring different theoretical perspectives and methodological tools sensitive to diverse use-contexts and stakeholder values. First, at the technological level, for example in questioning the problem intended to be solved, and the appropriateness of co-design and AI/ML technologies to solve it. Second, at health system level, for example in questioning how AI/ML technologies and their sponsors impact upon the broader goals of health and health care systems. And third, at the societal level, for example in questioning who benefits from AI/ML technologies now and into the future. When considering the entirety of this sociotechnical system, however, the question remains as to how to identify the most suitable way forward for realizing a positive vision for AI/ML technologies for health.

Future research setting the stage for this new era of co-design might examine the extent to which achieving ethical co-design at these three levels is tenable. For example, it may address limitations imposed on the agential capacities of both users and designers in applied AI/ML projects, and propose new strategies for overcoming these obstacles.

A new era for co-design also requires theories and methods that are context-appropriate, amenable to black-box nature of AI/ML technologies, and anticipatory in scope. For example, future research may propose new ‘theory-methods packages’ that go beyond a focus on individual users and technologies, to the entirety of the sociotechnical system in which they are embedded. While some scholars have made important contributions to this

domain (Forlano & Mathew, 2014; Lupton, 2017a), less is known about the practical feasibility of anticipatory or speculative methods in applied AI/ML projects with more established agendas.

Finally, future research may example how different design and research traditions approach these conceptual challenges. For example, if HCI and related fields finds themselves in a new wave concerned with persuasion, what does this mean for how various research communities view the ethics of their work? While difficult, we believe these challenges represent a unique and rewarding opportunity for the field, and will likely only increase in importance with time.

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