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# Potential for Participatory Big Data Ethics and Algorithm Design: A Scoping Mapping Review

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## ABSTRACT

Ubiquitous networked data collection and algorithm-based information systems have the potential to disparately impact lives around the planet and pose a host of emerging ethical challenges. One response has been a call for more transparency and democratic control over the design and implementation of such systems. This scoping mapping review focuses on participatory approaches to the design, governance, and future of these systems across a wide variety of contexts and domains.<sup>1</sup>

## CCS CONCEPTS

• Human-centered computing → *HCI theory, concepts and models*;

## KEYWORDS

Algorithm design, speculative design, research through design

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## 1 INTRODUCTION

Targeted and personalized data collection and machine learning algorithms operating on Big Data have been shown to produce discriminatory outcomes with disparate impact and material consequences. Recent controversies have helped create a new platform for public discourse around the ethical, legal, and social implications of networked and mediated lives. Four areas are of particular

interest: 1) ubiquitous data collection, 2) increased reliance on machine learning algorithms to perform everyday activities, 3) the possibility of informed refusal, and 4) the relationship between 1-3 and increasing societal inequities. Other than a few algorithm auditing studies and recent attempts at governmental regulation, we are lacking in case studies of democratic interventions into the design of these systems. The goal of this review is to map current participatory approaches to the design of such systems, and to explore the possibility of applying a democratic participatory framework to the design of future governance and transparency initiatives.

## 2 BACKGROUND

### 2.1 Calls for Algorithmic Transparency

Recent work has called attention to algorithmic discrimination and inequalities in multiple domains and identified the need for improved transparency and engagement with social justice. Such research has highlighted inequality in search engines [40], automated social services [23], and a variety of algorithmic decision-making tools [42]. Notions of algorithmic fairness and accountability circulate in policy discussions and appear in regulatory standards and legislation (e.g., the European Union's General Data Protection Regulation [55], New York City's algorithmic accountability bill [32]). As machine learning techniques become more prevalent, scholars have called for opening algorithmic black boxes [12]. There is a growing body of interdisciplinary literature which engages with the ethics, design, and governance of algorithms [39, 41, 43], as well as the social body or publics which algorithms are said to enable or bring into existence [14, 16, 27, 33]. This burgeoning field of critical algorithm studies attends to the social production of algorithms and the distribution of power in their structuring,

positions them relationally, and explores how to research them [26, 34, 47, 54, 61]. Scholars have troubled what, exactly is meant by 'algorithm' within in various expert contexts and in public discourse [28]. Clear in this literature is a need for alternative engagement with ethics that take into consideration the complex entanglement of algorithms with daily life, emergent subjectivities, governance, and social control [7, 13]. In addition, many authors have called for a more participatory [2, 33, 39], ethically-engaged, values-sensitive [25], and social justice-centric [13] approach to how we engage with, design and study such technologies.

## 2.2 Participatory Design

Brandt, Binder, and Sanders [8] state that "Participatory Design is not one approach but a proliferating family of design practices that hosts many design agendas and comes with a varied set of toolboxes," but with a common focus on enabling participants to do three things: tell, make, and enact (145). Along with a focus on practice [19], two values also guide PD projects: 1) democratic participation and 2) bringing participants' tacit knowledge and embodied experience into the design process [8](147). While much work claiming affiliation with participatory design (PD) seeks to incorporate human participants (workers/users) into the design process, this work is not necessarily concerned with analyzing power relations within the workplace and broader political and economic contexts. Nor is it necessarily linked to what Robertson and Simonsen [45] describe as the historical social movement roots and underlying ethical concerns of PD which motivated early practitioners and their choice of methodological tools. In this review we identify recent work that applies participatory frameworks and methodologies to the design of a variety of everyday encounters with Big Data and algorithms.

## 3 METHODS

### 3.1 Systematic Search Strategy

Full-text searches of Google Scholar, Jstor, Web of Science, Scopus, ACM, IEEEEXPLORE were utilized using the following terms: 'algorithmic discrimination AND participatory design'; 'algorithm' AND 'participatory design' AND 'big data'; 'algorithmic decision making' AND 'participatory design'. Exclusion criteria included: non-English, dissertation or thesis, not research, book chapter, and off-topic. Abstract, keywords and title were screened for 231 records in EndNote, with 66 eligible articles imported for full-text screening within the NVivo software environment. After full-text screening, a total of 59 articles were selected for inclusion in the study.

### 3.2 Qualitative Coding

Qualitative coding also occurred within NVivo. First-level coding focused on structure (i.e., research questions, research context,

methods, participants, analysis, findings, implications). We then carried out two additional levels of coding: domain and framework coverage, and exemplary status (algorithm and data focused sources). We conducted the initial coding for research frameworks and domain coverage categories using an in vivo approach reliant on the language authors employed to describe their work. We also coded articles according to publication venue title (i.e., conference proceeding, journal, and report series).

## 4 FINDINGS

### 4.1 Domain

We assigned at least one domain to each article to represent the overarching topics and arenas that set the context for the research (see Table 1). Many of the selected articles discussed an application, platform, or interface (n=39) within another domain, such as healthcare (n=10).

### 4.2 Framework

We derived framework categories from how the authors situated their research. The coding process yielded 49 unique framework categories that we condensed into 15 parent frameworks (see Table 1). The consolidation of frameworks drew from the larger context

**Table 1: Domains and Parent Frameworks**

Domain	Parent Framework
Academia	Civic Engagement
Applications, interfaces, platforms	Crowdsourcing
Civics	CSCW
Education	Design Research Methodology
Finance	Educational Theory
Healthcare	Futures
Policy	HCI
Public Health	Human-Centered Design
Science	Participatory Design
Security	Policy Design
Social Interaction	Research Through Design
Social Services	Social Theory
Surveillance	Speculative Design
Visualization	User-Centered Design Value Sensitive Design

of the research and the types of literature that informed the work. For example, we collapsed "Human-Centered Algorithm Design" into "Human-Centered Design" based on how the author depicted it as fitting into a body of Human-Centered Design literature. We also developed parent categories to unite other frameworks. We created "Social Theory," for example, to encompass "Actor Network Theory" and "Critical Data Studies".

### 4.3 Exemplary Articles

Of the 59 articles integrated into the review, 20 addressed intersections of Big Data, algorithms, and participatory approaches. Inclusion criteria for this core set of exemplary articles consisted of 1) a focus on data and/or algorithmic technologies; 2) participatory and/or speculative design approaches that intentionally involve people in the development or imagination of technologies; 3) substantive discussion of engagement with participants who were either affected by or were users of the technologies.

Level of participation in research varied across articles and according to the aims of individual research projects. Some researchers sought to include participants as experts in the front-end design of a technology, some involved participants throughout the entire design process, while others incorporated participants into the analysis of a technology. While some excluded articles had a participatory design component to their research, if the participatory stage was referred to but not discussed, those articles were not included in the core set of exemplary articles. Several of the 59 articles had speculative design orientations in imagining projects in the domain of civics. For example, Di Salvo et al. [17] discuss three research through design projects in speculative civics that clearly engage with participants, but because the authors do not elaborate on their engagement in detail in this particle article, we do not have enough information to analyze participation as part of the core set. This may reflect a limitation of our search strategy and inclusion criteria which may not have identified other publications related to the projects discussed in the identified sources for the review.

What differentiated the 20 exemplary articles from the overall 59 articles was their integration of participants beyond solely testing the effectiveness or usability of a technology. This core set specifically emphasized design *or* highlighted participants' roles in opening up or improving a data technology as part of a design process that exceeds general user-testing. The included articles are defined by their demonstrated investment in stakeholder contributions.

*4.3.1 Algorithm Design.* While published after the initial search, Baumer's [2] proposal of human-centered algorithm design is included as it offers a model specifically focused on a clearly participatory, speculative approach to designing algorithms. Yang et al. [60] uses a human-computer interaction approach to integrate clinicians into the design of algorithmically-informed decision support tools for heart pump implants and identification of potential issues in implementation.

*4.3.2 Big Data.* Eighteen of the core set of articles address design approaches to Big Data, whether through the creation of tools or through engagement with concepts of data both in collection and as representations of people and things.

*Data engagement:* This subcategory of articles demonstrates the contestation of data as a concept and the imagining of data as a participatory process. Elsdon et al. [21] designed speculative workshops to explore how participants imagine their data. Rosenbak and Feckenstedt [46] described a speculative and participatory workshop where participants are asked to speculate with metadata and engage with their "digital shadows." Vandenberghe and Slegers [56] used Lillidot principles to ask health application users to anthropomorphize health data in order to make data meaningful. Baumer et al. [3] utilized the Delphi method to find out how people who are the subjects of social media research interpret researchers' claims and the data researchers collect on them.

*Data collection:* These articles discuss the stakes of data collection and incorporate data collection and related tools into their daily lives. Bowser et al. [5] investigated how people who participate in citizen science projects think about data privacy as they contribute to data collection. Volda et al. [58] discussed data collection for the design of an inventory system at food pantries and the ways in which stakeholders improvise with data through units of measurement. Longo et al. [38] used data collection via participatory sensing to impact policy design, namely by incorporating the "digitally invisible" into temperature sensing technologies. Passe et al. [44] discussed participatory action research in smart city decision-making and design, focusing on community engagement and developing partnerships with city residents. Bogers et al. [4] employed "data-enabled design" through involving users in the design of a connected baby bottle through multiple probes. Verdezoto et al. [57] conducted a series of workshops to improve the design of blood pressure self-monitoring systems, specifically seeking to understand how users routinize self-monitoring through their health data.

*Data tools:* Day et al. [15] examined health hackathons as a venue for people to participate in the design of data tools for health. Estiri et al. [22] utilized a participatory design approach to design a data profiling tool based on electronic health data with biomedical researchers. Tolmie et al. [52] designed a dashboard prototype for journalists, drawing from a series of ethnographic observations and interviews in a newsroom. Traore and Hurter [53] used a participatory design approach with airport security practitioners to design a tool that provides 3D scans of luggage.

*Data visualization:* These are articles that describe the design process for tools that visualize data. Landstorfer et al. [35] co-created a visualization tool with network security engineers. Liu et al. [37] developed a topic graph through participatory design with identified experts. Hall et al. [30] assessed visualizations in relation to service design, drawing from a series of workshops with service providers. Xiao et al. [59] designed a visualization tool with and for stakeholders involved in an oral history database.

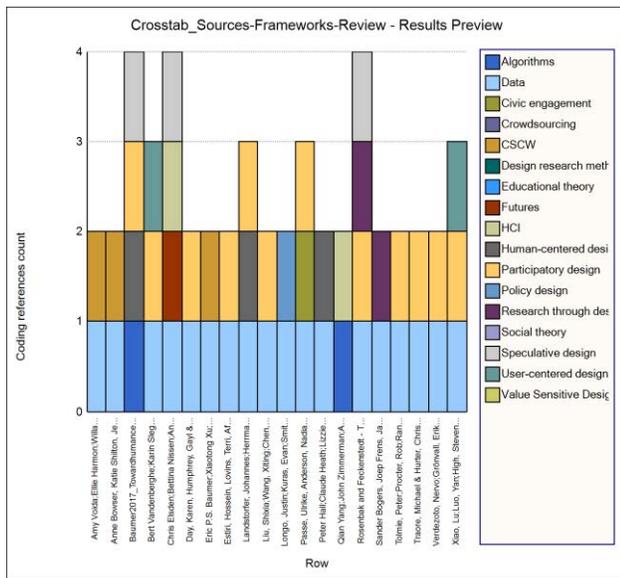


Figure 1: Distribution of frameworks across core articles

4.3.3 *Domains and Frameworks.* The exemplary articles primarily fit into domains covering visualization tools (n=5) or applications, programs, and interfaces (n=11) as products or foci of the research that overlap with domains of healthcare (n=5), civics (n=2), policy (n=2), science (n=2), security (n=1), social interaction (n=2), social services (n=1), and surveillance (n=1). Given that all exemplary articles discuss data and/or algorithm technologies, the prominence of applications, interfaces, and platforms is representative of the sample. Healthcare as a key domain in the core set of articles might showcase trends in participatory medicine and increasing focus on accessibility of health data and related data tools. Of the parent frameworks attached to exemplary articles, Participatory Design (n=12) had the most pronounced presence, followed by Speculative Design (n=3), CSCW (n=3), and Human-Centered Design (n=3). Other frameworks represented in the core set include User-Centered Design (n=2), Research Through Design (n=2), HCI (n=2), Civic Engagement (n=1), Policy Design (n=1), and Futures (n=1) Figure 2 depicts the distribution of these frameworks across each of the exemplary articles.

## 5 DISCUSSION

### 5.1 Broader Themes

Many of the articles in the core set demonstrate authors' commitments to facilitating participants' engagement with data, whether through probing privacy issues [5] or exploring how data might represent participants [21, 46]. Speculative approaches, in these cases, give participants space to critically

reflect on their data. A Quantified Self approach to data, in which data can inform participants, is visible in literature in which the researchers investigate how to expand participant interactions with health data and related tools. The availability and accessibility of data for participants informs the production of applications and systems. In these cases the researchers centered users in the development of technologies. However, less common in the core set of articles is the democratizing and opening up of data and algorithms beyond Quantified Self initiatives. For instance, in the process of our review we did not discover work specifically focused on algorithmic decision-making. Bowser et al. [5] examine participants' perceptions of privacy in relation to the research ethics of citizen science and report that participants prioritized open data over privacy protections, but otherwise values and ethics are not a focal point in the reviewed articles. While several articles touch on issues of algorithmic discrimination and bias by referencing marginalized populations who are "digitally invisible" [38] or ongoing data surveillance [46], bias and discrimination was not the focus of participatory or speculative approaches. Bias and discrimination are outside of the scope of most of the reviewed articles, where manufacturing effective, engaging tools, especially in the domain of healthcare, drive the research.

### 5.2 Gaps in Literature

Given current public discourse, we expected the search to yield literature addressing criminal justice, especially related to predictive policing and sentencing procedures [1, 10, 24], in addition to research pertaining to other domains where algorithmic discrimination has prompted controversy: news/journalism, credit scoring, internet search and advertising [40, 51], job ads and hiring [6], and critical engagement with surveillance [11] and smart cities [9]. Despite not meeting our inclusion criteria, such work is starting to appear in academic theses, dissertations, single-author and edited volumes.

## 6 FUTURE DIRECTIONS

### 6.1 Critical Algorithm Studies

The intersection of participatory design research and critical algorithm studies can provide potential trajectories for the transparent and democratic design of Big Data and algorithm dependent technologies. As these technologies develop, attention to the design processes that support their architectures and outputs is essential. While not all of our exemplary articles integrate critical approaches with participatory design, they open design processes up for intervention, as does some work in critical algorithm studies. For instance, Seaver [47] and Kitchin [33] offer a critique and overview of recent ethnographies that engage with aspect of the algorithm design process and/or use. As critical algorithm studies scholars call for more engagement and potential intervention into algorithm design practices, much

can be learned from engaging at the intersections of critical algorithm studies and participatory design.

## 6.2 Participatory Design and Related Fields

There are acknowledged limits to participatory design, including the use of participatory methodology for non-democratic goals and questions of whether designers have (or should have) the power and influence assumed by some practitioners [18, 43], as well as specific challenges to the study and potential interventions into the design and governance of algorithms [33]. Going forward, we see potential for cross-fertilization with critical algorithm studies in three areas: 1) Democratic Participatory Design [20, 36], 2) Values-Sensitive Design [48, 49], and 3) experiments with speculative and critical design [18]. Also of relevance to this discussion is work that engages with design anthropology [29, 50] and making or art practice in anthropology [31]. These scholars have grappled with the epistemological and methodological implications of such interventions for both the design process and disciplinary knowledge production.

## 7 CONCLUSION

As public discourse grows around the impact of ubiquitous data collection and algorithmic decision-making in everyday life, we expect to see an increased interest in designing for transparency, accountability, and participatory governance of algorithm-based systems especially as it relates to private/public partnerships, the use of proprietary systems by government, and corporate owned semipublic services such as social media and internet service providers. We see continuation of ongoing debates over how competing values and goals might be designed into such systems, especially in regard to questions of fairness, social justice, informed refusal, and the right to be forgotten, as well as the right to be visible within such systems. These trends necessitate careful transdisciplinary work that engages with both immediate needs and desires of interlocutors in the field and the lab, as well as a recognition of the broader socio-technical assemblages and economic and political transformations in which these demands are entwined. Politically aware participatory design can play an important role in furthering public engagements with the design of such systems. The history of participatory design can also inform potential adopters and collaborators about the limits of such methods, and design in general, in full-filling broader political goals and aims in democratic societies.

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