

Local Standards for Anonymization Practices in Health, Wellness, Accessibility, and Aging Research at CHI

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ABSTRACT

When studying technologies pertaining to health, wellness, accessibility, and aging, researchers are often required to perform a balancing act between controlling and sharing sensitive data of the people in their studies and protecting the privacy of these participants. If the data can be anonymized and shared, it can boost the impact of the research by facilitating replication and extension. Despite anonymization, data reporting and sharing may lead to re-identification of participants, which can be particularly problematic when the research deals with sensitive topics, such as health. We analyzed 509 CHI papers in the domains of health, wellness, accessibility, and aging to examine data reporting and sharing practices. Our analysis revealed notable patterns and trends regarding the reporting of age, gender, participant types, sample sizes, methodology, ethical considerations, anonymization techniques, and data sharing. Based on our findings, we propose several suggestions for community standards and practices that could facilitate data reporting and sharing while limiting the privacy risks for study participants.

CCS CONCEPTS

• **Security and privacy** → *Privacy protections*; • **Human-centered computing** → *Human computer interaction (HCI)*; *Accessibility*; • **Applied computing** → *Consumer health*; *Health informatics*;

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KEYWORDS

Anonymization, methodology, research reporting, privacy, data sharing, meta-HCI

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1 INTRODUCTION

Human Computer Interaction (HCI) researchers have been studying the challenges people face in their daily lives and developing solutions that address these issues. User studies regularly contribute to the design of innovative and novel technologies, and the results of HCI research can have a positive impact on people's lives. Reporting the results and the data of the studies can help the research community build on existing research and facilitate the design of increasingly impactful sociotechnical solutions.

When describing research findings, researchers have the responsibility to consider *how* participant data is reported and shared. The CHI community has consistently demonstrated its commitment to conducting research ethically, as evidenced by numerous workshops, panels, and town halls over the years (e.g., [26, 27, 73]). In the case of ethical research reporting, it is sometimes challenging to balance the desire to preserve participant privacy with the desire to communicate research methods and findings in detail. Researchers must also reconcile the desire of some participants for recognition/attribution with the responsibility to minimize the risks these individuals undertake by participating in the research.

These tradeoffs are particularly relevant in studies focused on health, wellness, accessibility, and aging, where: 1) re-identifying anonymized data may be easier, 2) consequences of re-identification may be more severe, and 3) considering issues of identity and stigma is nuanced and important.

Therefore, we explored the CHI community's reporting practices for studies in health, wellness, accessibility, and aging. We conducted a systematic investigation of CHI publications on these four topic areas, totaling 509 papers from 2010–2018. We considered existing practices for reporting and sharing participant data. We found notable trends and patterns in reporting participant information, ethical considerations, methodological details, data anonymization techniques, and data sharing practices.

Based on our analysis, we make the following contributions:

- (1) We provide a systematic review of data reporting and sharing practices within the CHI community on the topics of health, wellness, accessibility, and aging;
- (2) We discuss the implications of these practices for addressing potential privacy risks of data reporting and sharing for study participants while respecting the desire of some participants to be recognized via identifiable attribution; and
- (3) We apply our insight to suggest community standards and practices to facilitate data reporting and sharing while limiting the privacy risks for study participants.

In the sections that follow, we first discuss relevant literature followed by a detailed description of our method. Next, we detail the insight that emerged from our analyses and proceed to apply the insight to propose community standards that could improve data reporting and sharing while considering various tradeoffs. We note important limitations of our research and conclude with remarks on future directions.

2 RELATED WORK

We first cover prior research that has discussed the risks and benefits of participant identification on topics pertaining to health, wellness, accessibility, and aging, followed by considerations for anonymization in data reporting and sharing in qualitative and quantitative approaches, respectively.

Risks and Benefits of Identifying Participants in Health, Wellness, Accessibility, and Aging Research

HCI research focused on health, wellness, aging, and/or accessibility is of particular interest from a privacy perspective because of tradeoffs between competing goals. On one hand, the consequences of re-identification can be severe, especially when dealing with stigmatized diseases/disabilities. People may have concerns about seeking support, preferring to disclose relevant information on pseudonymous or specialized social networks where they feel disinhibited or more comfortable openly seeking support [3, 4, 10, 56]. These pseudonymous sites can facilitate many of the positive benefits of self-disclosure and support seeking without having to reveal one's identity [9, 60]. Disclosing a stigmatized health

condition can lead to discrimination, identity devaluation, prejudice, and worsened physical and mental health [51]. Even in aging research where concerns about "disclosure" are less common, there are numerous studies that aim to preserve the privacy of the study population (e.g., [15]) and support the autonomy of older adults in aging in place [5]. When recruiting participants with stigmatized conditions, researchers have had greater success using anonymous online sources than face-to-face methods where identities may be exposed [61], thus leading to investigations of novel and more effective approaches for working with people with these types of conditions [47].

In research on social support, there can be consequences if participants are detailing intimate relationships within support networks. For example, research on caregivers (e.g., [17, 32, 78]) often describes the burden associated with the caregiving role and the associated toll on family relationships. Similarly, publications sometimes describe complaints regarding insufficient (e.g., [42]) or inadequate (e.g., [44]) support. Discovery of the identity of those who made the complaints by the people who are the subject of these complaints could lead to additional challenges in already strained relationships.

Conversely, researchers have illustrated cases where people engage in advocacy or feel empowered via being identified in research reports. People often leverage social media to advocate for change in their community, such as youth advocating for addressing health disparities [35], people using digital storytelling to advocate for abortion rights [52], or parents of children with special needs coordinating efforts at local and national levels [1]. These content creation or expression tools can be useful for combating stigma. In the case of potentially stigmatized health circumstances, Andalibi et al. [2] found that such awareness campaigns on social media facilitate self-disclosure that might otherwise have been uncomfortable because of fears of stigmatization. Similarly, Brewer et al. [12] showed that blogging can foster self-expression of values for older adults, Lazar et al. [40] found that art exhibitions can help challenge the dominant view of dementia as deficient and declining, and Liu et al. [43] proposed that creating video blogs about one's condition can even serve as a form of "self-therapy." Sometimes, people with disabilities may choose to disclose their disability preemptively to prevent negative outcomes later on, such as in the case of online dating where such information can be useful for filtering ableist matches or preventing possible rejections for not having disclosed a disability [57].

It is clear that people negotiate tradeoffs in deciding when, where, and how to disclose a condition or disability. Therefore, we considered existing practices by researchers that

may contribute positively or negatively to these goals, supporting them in advocacy goals or creating the risk of unwanted exposure for study participants.

Anonymization in Qualitative Research

Qualitative researchers generally adhere to a “convention of confidentiality” [7] to prevent distress, humiliation, harm, or other negative consequences for participants [7, 24]. It is common practice in qualitative research to use quotes from participants and include tables summarizing participant demographics. Although it is unusual to see direct identifiers (e.g., real names) included in qualitative publications, indirect identifiers, such as pseudonyms, do not necessarily block the ability to identify participants.

Deductive disclosure occurs when characteristics of study participants make them potentially identifiable in research publications or presentations [36, 68]. Sieber et al. [62] use research about teachers as an example, suggesting that if the researcher names the school district where the research took place, a person with knowledge of that school district may be able to identify the participants based on traits like age, gender, years with the district, etc. This requires researchers to make decisions between tradeoffs; including demographic criteria helps readers understand and assess the research but can increase the risk of deduction.

Researchers sometimes make uncomfortable tradeoffs between an absolute commitment to privacy and the responsibility of making the participants’ input known [29, 36, 74]. Researchers need to take responsibility for determining which parts of a participant’s contributions present a privacy concern [55, 68, 76] and account for these concerns by changing details in quotations [36], altering non-essential details to make the participant unrecognizable [74], or creating new personas that are composites of several participants without directly representing any real individual. However, participants have been known to object to having their words or characteristics altered in reports [18]. Moreover, these approaches risk rendering the data useless for answering the research questions or distorting the original meaning of the data [55]. Privacy protections can further make it difficult for reviewers and readers to understand or assess the validity of the work [76]. Bruckman [13] explains: *“In an open scientific community, individuals ideally publish results sufficiently detailed for others to attempt to duplicate those results and affirm or question the findings. This idealized model from the physical sciences is always hard to replicate in social sciences, but even harder when the act of protecting subjects adds substantial new barriers to follow-up inquiry by others.”*

Jerolmack (in a conversation with Murphy [53]) even goes as far as to suggest that there may be value *to participants* in providing the choice of being identified: *“There was very little that I could offer my participants for all the time they*

gave me, but they viewed seeing their name in print as intrinsically rewarding. When I handed out copies of [my book], most quickly thumbed the pages looking for their name and some excitedly took photos of the printed pages they appeared on and texted them to friends and family. This has convinced me that, at least some of the time, naming may be more ethical than masking.”

Bruckman [13] makes a similar argument about content creators online, discussing the tradeoff between *“the right of Internet users to receive credit for their creative and intellectual work”* and *“the need to protect vulnerable human subjects in research studies.”* In health and accessibility research, issues of content creation and attribution of intellectual property are less common (although may exist in cases like art therapy [39] or participatory design [64]) but there is still a tradeoff between participants’ goals of advocacy and research and their desires for privacy and dignity.

A possible approach proposed by some researchers is to allow participants to choose their own aliases or pseudonyms (e.g., [11, 25]). This humanistic [63] approach engages participants directly in a conversation about how they are represented and empowers them to communicate something about themselves through a name, while still providing some level of anonymity. Moreover, it provides participants an avenue to identify themselves in publications and disclose the attribution to others.

Guillemin et al. [30] argue that ethics procedures within organizations are largely a formality. The processes are helpful for encouraging researchers to think about ethical issues, but do not appropriately address the specific ethical dilemmas in qualitative research. A standard part of ethics procedures is a participation agreement between researchers and participants at the beginning of the study. Such an agreement is crucial to acquiring informed consent and building rapport with participants [19]. However, these discussions take place before the participant has actually disclosed any information, and confidentiality is rarely an ongoing conversation [36].

Kaiser [36] suggests dealing with deductive disclosure risks by *“making respondents better informed of the use of data”* and encourages *“discussing the specifics of audience and confidentiality after data collection,”* noting that many participants are driven by a desire to help others [8, 16, 22, 34]. Kaiser states that, *“discussing the use of their data can help them to grasp the outcomes of their participation”* [36]. Member checking [41] (providing the interpretation and report to the informants to check the authenticity of the work) is one approach that can address this deductive disclosure risk while also serving to enhance validity of research by allowing participants to point out inaccuracies [49].

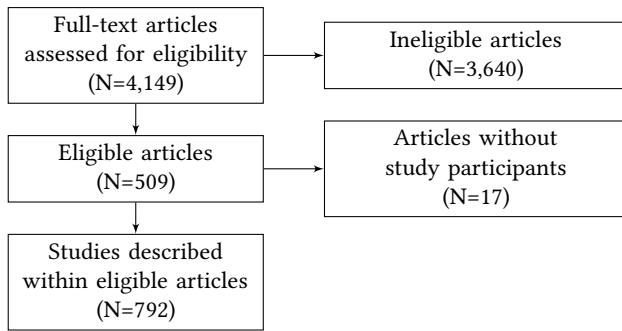


Figure 1: Review of papers published at CHI between 2010–2018. We screened each paper to identify publications in the health, wellness, accessibility, and aging domains.

Anonymization in Quantitative Research

Making anonymized data publicly available can be extremely beneficial and lead to further advancements in research that might not otherwise be possible. The challenge is that sensitive data is rarely easily anonymized; simply removing identifying information is insufficient because only a small number of attributes are needed to re-identify an individual from such a data set.

This is particularly true in domains of health and accessibility. For example, Amyotrophic Lateral Sclerosis (ALS) [37] is a disease that, although widely known because of the recent ALS ice bucket challenge [69, 75], impacts less than 0.01% of Americans. Using only gender and age, one can narrow down to approximately 1,000 people in the US. For people living in a smaller country, one could narrow down even further to as few as 10–15 people.

There are numerous examples of health data having been re-identified by linking “quasi-identifiers” (features that are not directly identifying, but can be combined with other quasi-identifiers to uncover a unique identifier) to other public data sets (e.g., [23, 66, 77]). In one example, Sweeney et al. [66] were able to link a database of health insurance claims (with direct identifiers removed) to a voter registration list, using quasi-identifiers (date of birth, zip code, and gender) to re-identify individuals listed in both databases. Similarly, Malin and Sweeney [48] were able to re-identify people based on genomic datasets using disease genes. Solomon et al. [65] demonstrated the likelihood of re-identification of behavioral/social science health data given certain kinds of attacks [54], finding that almost any attribute could be used to make a participant unique, either by itself or combined with at least one other attribute.

3 METHOD

Similar to Caine’s approach [14], we reviewed manuscripts published at CHI between 2010–2018 (Figure 1). We limited our analysis to papers addressing the health, wellness, accessibility, and aging domains. To identify papers for inclusion, two researchers independently screened papers by consulting the paper’s title, abstract, keywords, and full text. The paper was included if it addressed at least one of our domains of interest (i.e., health, wellness, accessibility, and aging). Inter-rater reliability (Cohen’s Kappa) between the two coders was 0.909, indicating a high level of agreement. Out of the 4,149 papers published at CHI between 2010–2018, we identified 509 that addressed health, wellness, accessibility, or aging.¹

For each manuscript, we considered the number of studies that involved recruited participants. We considered a paper to included multiple studies if the reported studies or analyses involved *different sets of participants*. This is different from cases where multiple methods were used with the same group of people, which we considered as single (mixed methods) studies. Across the 509 papers we analyzed, we found a total of 792 studies; 17 papers did not contain any studies that involved participant recruitment.

For each study, we recorded the sample size, the methodology (qualitative, quantitative, or both), the participant type, and the specific disease, diagnosis, or disability of the participants, if applicable. Our goal in conducting this research was understanding the information that is provided about participants in CHI publications and the potential for deductive disclosure of identity when this information is provided. Therefore, for each study, we considered the information provided about the age, gender, ethnic background, literacy, location, and institution of the participants. For instance, we considered whether ages were provided individually for each participant, as a range, as a mean, as a median, as counts of participants in different age brackets, or as an approximate description. Similarly, for gender and ethnicity, we noted whether these were provided for each individual participant or as overall counts. For literacy, we examined whether the authors reported levels of literacy related to education, health, technology, reading, and language. We recorded whether the authors disclosed the location of the study at a city, state, country, or continent level. Additionally, we checked whether the papers named a specific institution where participants were recruited. It is often easy to infer location and institution of participants based on the location and affiliations of the authors. However, in our analysis, we considered location and institution information to be disclosed only if it was mentioned explicitly within the paper.

¹A complete list of publications included in our analysis is provided as supplementary material.

Year	Included Papers	Year-Over-Year Growth (Included Papers)	Total Papers	Year-Over-Year Growth (Total Papers)	% of total CHI papers included
2010	24	N/A	302	N/A	7.95%
2011	34	41.67%	410	35.76%	8.29%
2012	33	-2.94%	370	-9.76%	8.92%
2013	45	36.36%	392	5.95%	11.48%
2014	63	40.00%	465	18.62%	13.55%
2015	66	4.76%	379	-18.49%	17.41%
2016	86	30.30%	565	49.08%	15.22%
2017	79	-8.14%	600	6.19%	13.17%
2018	79	0%	666	11.00%	11.86%
TOTAL	509	229.17%	4,149	120.53%	12.27%

Table 1: Number of health, wellness, accessibility, and aging related papers in CHI by year.

Finally, we looked for specific approaches to anonymizing participant information if reported by the authors, potential privacy risks based on the reported data, and mentions of public release of the data.

4 FINDINGS

The number of accepted papers related to health, wellness, accessibility, and aging at CHI has more than doubled in the last nine years (see Table 1). This rate of growth is faster than the overall number of accepted papers at CHI. The greatest share of papers related to health, wellness, accessibility, and aging was at CHI 2015 and CHI 2016 (17.41% and 15.22%, respectively). However, the most recent years have seen a drop with 13.17% of the papers at CHI 2017 and 11.86% at CHI 2018 covering the health, wellness, accessibility, and aging domains.

Among the set of 509 papers we analyzed, 149 (29.27%) explicitly mentioned acquiring approval from an ethics body, such as an Institutional Review Board (IRB) in the US. As seen in Figure 2, mentions of such approvals were increasingly common over time. Still, more than half the papers neglected reporting whether external ethics approval was necessary and, if so, whether it was acquired. Papers labeled as “N/A” in Figure 2 did not involve human subjects or explicitly mentioned not requiring an approval from the respective institutions. Overall, 85 (57%) of the papers that reported ethics approvals used qualitative methods, followed by 45 (30.2%) with mixed methods, and 17 (11.4%) employing quantitative techniques. The remaining 2 reported ethics approvals were from papers that did not conduct studies but discussed ethical considerations of their research.

Across the 509 papers, we coded and analyzed 792 different studies, with 8 studies being the highest number of studies reported in a single paper. We further classified studies as using qualitative methods, quantitative methods, or

a mix of both. Figure 3 shows the percentages of studies by method for each year covering the period covered by the papers we examined. The range of the number of qualitative studies was between 12 in 2012 and 89 in 2018 with a mean of 46.78 and a median of 51 per year. Mixed method studies ranged from a minimum of 3 studies in 2010 to a maximum of 51 in 2016, with a median of 25 and mean of 26.44 each year. The highest number of quantitative studies in an individual year was 24 in 2013, the only year where quantitative studies outnumbered qualitative ones. The median number of quantitative studies per year was 16, with a mean of 14.78 and a reported minimum of 6 studies in 2012.

Types of Participants

In our analysis, we considered what kinds of participants were being recruited. Across the 792 studies we identified, we observed and coded 35 unique participant types. We found that the plurality of studies specifically recruited people with diagnosed health conditions or with disabilities (N=246; 31%) or recruited broadly from the general population (N=138; 17.4%). Within the broad category of “People with diagnosed health conditions disabilities,” we identified 58 different health conditions or disabilities covering the various mentioned diseases, diagnoses, or disabilities. Of these, the top ten categories were:

- Visual Impairment (N=98; 12.4%)
- Autism (N=36; 4.5%)
- Mental health (N=34; 4.3%)
- Dementia (N=28; 3.5%)
- Cancer (N=25; 3.2%)
- Mobility Impairment (N=25; 3.2%)
- Diabetes (N=18; 2.3%)
- Parkinson Disease (N=18; 2.3%)
- Chronic Pain (N=18; 2.3%)
- Hearing Impairment (N=16; 2.0%)

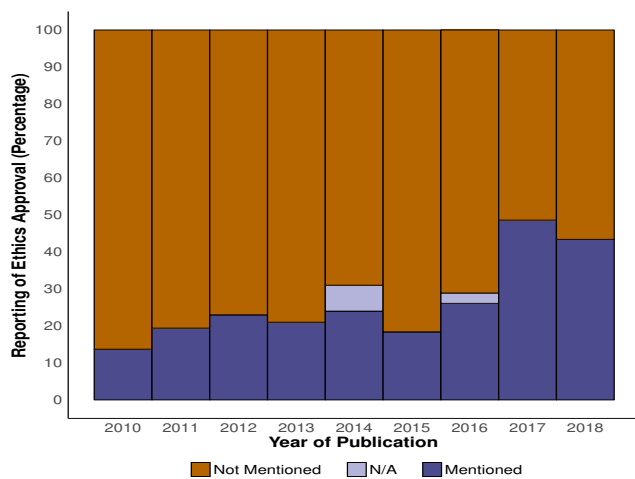


Figure 2: Papers by year based on the mention of approval by an external ethics body, such as an Institutional Review Board (IRB).

Other popular participant populations included older adults (N=60; 7.6%), medical professionals (N=48; 6.1%), college students (N=45; 5.7%), children (N=43; 5.4%), informal caregivers/family members (N=36; 4.5%), teachers (N=21; 2.7%), fitness conscious individuals (N=20; 2.5%), and therapists (N=18; 2.3%). The remaining 25 participant types covered 140 (17.7%) studies.

Studies that employed qualitative and mixed methods involved people with diagnosed health conditions or disabilities as the most frequent participant type (N=139; 33% and N=84; 35.3% respectively), but those that used quantitative methods typically included participants from the general population (N=52; 39.1%) followed by people with diagnosed health conditions or disabilities (N=26; 19.5%).

Table 3 shows the top three categories for each year, including the corresponding number of unique papers related to the topics. Visual Impairment was among the top 3 topics each year between 2011 and 2018, with 2010 being the only exception. Autism and Mental Health appeared the second and third most frequently, respectively, and each made the top 3 list in three of the years.

Reporting on Participant Information

We were interested in how authors reported participant information in their publications. We found that nearly two thirds (N=533; 67.3%) of the 792 studies described in the CHI publications related to health, wellness, accessibility, and aging provided some information about participant gender. The studies most frequently (N=345; 43.5%) reported gender counts by groups (e.g., “25 men and 15 women”) along with the corresponding percentages, with a smaller number of

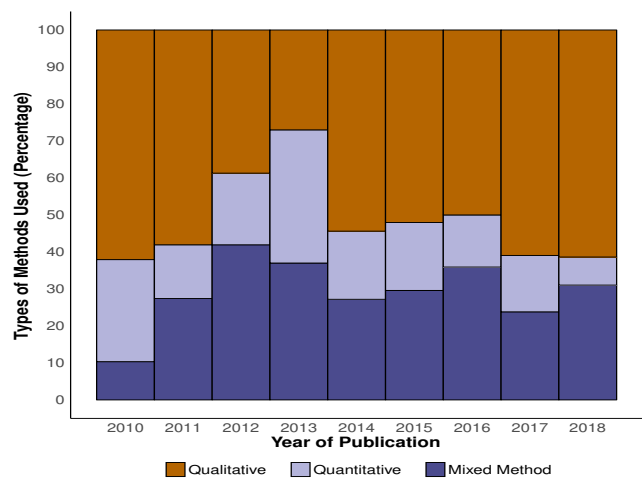


Figure 3: Papers by year based on the type of methodological approach followed by the research.

studies providing simply overall counts of gender (N=53; 6.7%). Genders were reported for each individual participant in 135 (17%) of the studies. Fewer than 1% of the studies reported non-binary genders or mentioned providing an option other than Male and Female.

Roughly one third (N=240; 30.3%) of the studies did not report the ages of the participants. When ages *were* reported, the information provided most often involved a combination of ranges and averages (N=169; 21.3%) (e.g., “Participants in this study were between the ages of 18–25 with the average age being 19.”) or only ranges (N=150; 18.9%). Reporting the ages of individual participants occurred in 109 (13.76%) cases.

Studies rarely reported on the ethnicity of participants (N=52; 6.6%). The majority of studies that reported ethnic backgrounds reported only counts and percentages (N=31; 59.6%), while a smaller subset specifically reported interacting with participants from a single ethnic group (N=18; 34.6%). While uncommon, a few studies did report the ethnicity of each participant (N=3; 5.8%).

Locations of participants were reported in only 249 studies (31.4%). The countries were reported in 164 (20.7%) of the studies, followed by 20 (2.5%) reports denoting the states. The specific cities were disclosed 62 (7.8%) times. Only a single study specified participant location at the continent level. The remaining 547 (69.1%) studies did not report any location data for the participants. Compared with the number of studies that disclosed participant location, fewer studies listed the specific institutions, such as hospitals, where the studies took place. Such studies were coded as directly providing institution information. Only 81 studies (10.2%) reported specific institutions. Qualitative studies reported institutions the most frequently at 42 (51.9%), followed by mixed method

Participant Type	2010	2011	2012	2013	2014	2015	2016	2017	2018
Children	1 (3.4%)	2 (3.2%)	4 (10.8%)	4 (6.1%)	1 (0.9%)	1 (1.0%)	8 (5.7%)	2 (1.9%)	20 (14.1%)
Employees	-	-	-	2 (3.0%)	2 (1.7%)	-	2 (1.4%)	6 (5.7%)	3 (2.1%)
Fitness Conscious Individuals	-	-	3 (8.1%)	2 (3.0%)	2 (1.7%)	7 (7.2%)	7 (5.0%)	-	-
General Population	3 (10.4%)	15 (24.2%)	4 (10.8%)	24 (36.4%)	34 (29.6%)	28 (28.6%)	27 (19.2%)	21 (20.0%)	11 (7.8%)
Informal Caregiver/Family	-	2 (3.2%)	2 (5.5%)	7 (10.6%)	5 (4.4%)	6 (6.1%)	9 (6.5%)	5 (4.8%)	12 (8.5%)
Mechanical Turkers	-	-	-	2 (3.0%)	3 (2.6%)	2 (2.0%)	4 (2.8%)	2 (1.9%)	1 (0.7%)
Medical Professionals	4 (13.8%)	2 (3.2%)	8 (21.6%)	-	6 (5.2%)	5 (5.1%)	10 (7.1%)	7 (6.7%)	8 (5.6%)
Older Adults	6 (20.7%)	3 (4.8%)	3 (8.1%)	6 (9.1%)	12 (10.4%)	7 (7.2%)	11 (7.8%)	8 (7.6%)	4 (2.8%)
People with Diagnosed Health Conditions or Disabilities	9 (31.0%)	20 (32.3%)	12 (32.4%)	13 (19.7%)	31 (27.0%)	31 (31.6%)	33 (23.4%)	40 (38.1%)	61 (43.0%)
Researchers	-	1 (1.6%)	-	2 (3.0%)	2 (1.7%)	-	4 (2.8%)	-	-
Students	-	4 (6.5%)	1 (2.7%)	4 (6.1%)	4 (3.5%)	7 (7.2%)	12 (8.5%)	4 (3.8%)	9 (6.3%)
Survivors of Specific Conditions	2 (6.9%)	-	-	-	-	-	-	1 (0.9%)	-
Teachers	-	3 (4.8%)	-	-	3 (2.6%)	-	5 (3.5%)	-	10 (7.0%)
Teenagers	-	6 (9.8%)	-	-	-	1 (1.0%)	3 (2.1%)	-	1 (0.7%)
Therapists	-	2 (3.2%)	-	-	9 (7.8%)	2 (2.0%)	-	5 (4.8%)	-
Women	1 (3.4%)	1 (1.6%)	-	-	1 (0.9%)	1 (1.0%)	4 (2.8%)	3 (2.9%)	2 (1.4%)
Young Adults	3 (10.4%)	1 (1.6%)	-	-	-	-	2 (1.4%)	1 (0.9%)	-

Table 2: The types of participants covered by the 792 studies by year. One study may involve multiple types of participants (e.g., older adults and their caregivers).

Year	#1 Topic	#2 Topic	#3 Topic
2010	Cancer (4)	Cardiac Issues (2)	Mobility Impairment (2)
2011	Visual Impairment (3)	Weight Management (3)	Mental Health (2)
2012	Visual Impairment (4)	Autism (2)	Insomnia (2)
2013	Autism (4)	Visual Impairment (4)	Motor Impairment (2)
2014	Cancer (3)	Visual Impairment (3)	Chronic Pain (2)
2015	Visual Impairment (8)	Diabetes (3)	Mobility Impairment (3)
2016	Visual Impairment (9)	Autism (7)	Mental Health (7)
2017	Visual Impairment (11)	Mental Health (10)	Dementia (6)
2018	Visual Impairment (17)	Hearing Impairment (5)	Dementia (4)

Table 3: Top three health related categories for each year.

studies with 25 (30.9%), and quantitative studies with 14 (17.2%) instances.

The literacy requirements for participants varied across studies. However, only 74 (9.3%) of the studies reported requiring adequate understanding of specific topics. The most commonly incorporated literacy measurements were technology (N=28; 37.8%), reading (N=22; 29.7%), education (N=16; 21.6%), health (N=4; 5.45%), and language (N=4; 5.45%).

We found no significant differences between the type of method (qualitative, quantitative, or mixed) employed by a study and the corresponding reporting of participant information.

Sample Sizes

The reported sample sizes varied greatly across studies depending on the employed methodology and the population under study. Qualitative studies made up 421 (53.2%) of the 792 studies with a median of 11 and a mean of 27 for the sizes

of the study samples. The sample sizes for the qualitative studies ranged from 1 to 1000 participants. While quantitative approaches were employed by the fewest number of studies (N=133; 16.8%), these studies reported the highest median and mean sample sizes at 24 and 40, respectively. The sample sizes of quantitative studies ranged from 1 to 5795. The 238 (30.1%) studies that used mixed methods reported sample sizes from 1 to 3000, with a median of 18 and a mean of 32, respectively. Depending on the method used, many of the studies that involved a single participant reported a great deal of detail regarding the interaction or measurements taken from the participant.

The number of participants involved in studies using qualitative methods is often smaller than those utilizing quantitative approaches. Comparing the two groups of studies using the Mann-Whitney-Wilcoxon Test revealed that quantitative studies reported statistically significantly larger sample sizes than those of qualitative studies ($W=14690$, $r=0.096$, $p<0.001$). Moreover, we also found a statistically significant difference in sample sizes between studies that employed mixed methods compared with those that used only qualitative techniques ($W=31375$, $r=0.144$, $p<0.001$). No statistical difference was found in the sample sizes of studies using mixed methods when compared with quantitative studies ($W=15328$, $p=0.08$).

Privacy and Exposure

A number of studies did not specify whether any steps were taken to ensure the privacy of their participants when publishing information (N=378; 47.7%). Most frequently mentioned steps taken to protect the privacy of participants included the use of codes (e.g., P1, P2, etc.) (N=320; 40.4%), pseudonyms (N=54; 6.8%), and blurring of faces in images (N=19; 2.4%). Other anonymization techniques were used rarely (<3% combined) and included paraphrasing quotes, selecting images that do not contain faces, and converting photos to line drawings in order to thwart face recognition.

Despite a number of authors taking precautions, a number of papers included occurrences of *possible* participant identity exposure that were not always addressed or mentioned. The most common of these risks was the inclusion of complete direct participant quotes in (N=456; 57.58%) the studies. Although the remaining (N=336; 42.42%) studies were found not to involve potential exposures of participant identity, some of those that provided quotes also used the participant names with quotes (N=23; 2.9%), photos with participant faces visible (N=17; 2.15%), and photos paired with participant quotes (N=10; 1.26%). However, it should be noted that it was often difficult to tell from the publication alone whether the participant name was a real name or a pseudonym.

Data Publishing and Sharing

Only 3 of the 509 papers in our sample made their data publicly available, with data sharing agreements required in 2 of these cases. On the other hand, 18 papers used data from external sources, such as study data shared by other researchers or publicly accessible information on the Web. However, none of these papers mentioned a waiver or acknowledgement by the participants for consenting to the broader sharing of the data. Of the 18 papers that used data from external sources, 2 used quantitative methods, 8 incorporated mixed methods, while the remaining 8 papers made use of qualitative methods. The remaining 491 papers did not share their data and made no mention of options or terms for the sharing of the data with the community.

5 IMPLICATIONS FOR RESEARCH

Our analysis identified trends and patterns in data reporting and sharing in CHI publications in the health, wellness, accessibility, and aging domains along with the strategies adopted by researchers to protect the privacy of their study participants. However, our analysis did not consider the degree to which participant privacy *needs* to be protected and the extent to which participants *understand and consent* to the identifiable reporting of their information. In this section, we discuss the tradeoffs involved in the commitment to protecting participant privacy and the benefits of more open data sharing.

Data Collection vs. Data Reporting

It is likely that there are differences between the level at which the data was *collected* and the level at which it was *reported* in the published papers. This is illustrated in Threatt et al.'s [67] work with older and post-stroke adults. The authors opted not to report the demographic data collected, stating: "*In the interest of protecting the privacy of this small exploratory sample population, and based upon the conditions of approval for this study-design [...] demographic data for these participants cannot be presented here.*" In contrast, many papers we analyzed did not discuss how the data was actually collected and recorded. For instance, we found that participant ages were reported in just over 70% of the studies; however, the style of reporting varied between the use of means, medians, ranges, a combination of the former, or provision of the individual ages of each participant. It was unclear whether individual ages were recorded but reported in the paper in terms of buckets or ranges or averages or collected as buckets or ranges in the first place.

Collecting data at a finer granularities allows researchers to use these details for analysis if needed. On the other hand, collecting information at lower granularities ensures that participant privacy would be protected through more

stages of the research at the cost of making the finer grain details unavailable for analysis. **Researchers should consider the appropriate level of granularity for analysis and reporting.** How data should be collected (to carry out analyses) and reported (to inform the readers) should be determined based on a thoughtful consideration of the purposes for the various pieces of data and the importance of reporting the data for communicating the findings. Researchers already make these decisions for specific research questions. We suggest that papers include the information about *how* these decisions were made so that the research community can benefit from the discussions of these tradeoffs.

Assessing Validity vs. Minimizing Exposure

As noted earlier, 18 papers used pre-existing data from external sources. Yet, none of these were replications of previous studies. On the other hand, 3 papers mentioned publicly releasing their data. Two of these papers noted that other researchers could access the data after completing a data protection agreement. If the community wishes to push forward with open science and community data sharing, then the need for anonymization techniques will continue to grow. There is potential for increased research impact when data is shared with other researchers such that results can be verified via replication or extended by looking at existing data through a different lens. Although replication is not typically considered a core component of “validity” in qualitative research (and it is unusual to see entire transcripts released publicly), detailed reporting in publications can shed light on the interpretive work involved in qualitative research and the reasons we have for believing the claims [20]. The challenge is that sharing human-subjects data publicly or providing rich details, while valuable for researchers, creates an immediate increase in privacy risks for the study participants. While we found a number of privacy preserving practices employed by researchers, we also uncovered risks of the potential exposure of participant identities.

The sharing of data was more common in quantitative studies, although rarely with direct identifiers. However, such data can often be re-associated with individuals by using quasi-identifiers and connecting it with other publicly available datasets. It may be possible to create anonymized versions that are better tailored to specific purposes, using techniques such as k-anonymity [66] or differential privacy [21]. However, releasing multiple differently protected versions of the same dataset may enable identification attacks based on combining the different versions. **Researchers should consider as many purposes as possible prior to anonymizing and releasing the data.** Considering a variety of purposes for the data could require soliciting community input. If researchers know as much as possible about potential uses of the data, they can better generate a single anonymized

version that takes these tasks into consideration. One option is to release a description of the data or a list of the variables/features without releasing the actual data itself. Without access to the data, it might not be possible to assess the full extent to which each specific feature or variable provides utility or information gain for the purposes at hand. However, the researchers who own and control the data can receive questions the community members wish to ask of the data and share data appropriately to help answer those questions. Such an approach has been successfully employed by Wagner et al.’s [71, 72] Device Analyzer project.

In qualitative work, papers often used participant codes or pseudonyms to hide participant names. Still, many studies provided direct full quotes from the participants. While including such quotes does not necessarily mean that participants will be re-identified, depending on the length, content, and source of the quote, it can increase the risk of re-identification, especially when combined with other information that may be provided about the participant. Just under 3% of the papers reported quotes with participant names that did not use pseudonyms. A small number of papers even paired photos with quotes from the participant that was portrayed in the photo (1.24%). Depending on the quote and source of the data, the practice of using pseudonyms offers “*at best, an illusory promise to protect confidentiality*” [53]. In some cases, researchers may omit quotations altogether if the likelihood of participant re-identification is high and the associated consequences are severe. In other cases, there may not even be a need for pseudonyms and participants may choose to be identified in publications. **When deciding whether to include detailed participant quotations, researchers should take into account that participants could be re-identified based on the quotations. Researchers must balance the importance of the quotations for conveying research with the likelihood of re-identification and the severity of the associated consequences to the participants.**

Protecting Participants vs. Empowering Participants

The above discussion has been based on the assumption that researchers *should* be protecting the privacy of study participants. However, as researchers like Jerolmack [53] and Bruckman [13] have pointed out, there may be cases where naming participants is valuable. It is not always clear which of these priorities (protecting privacy or naming participants) is more important or how they should be handled when one is in conflict with the other.

As an example at the intersection of health and HCI, consider the case of people with rare diseases. People with rare diseases often encounter stigma around their conditions. Being identified as someone with a rare disease may have negative social consequences [6, 44]. In some countries,

there may be additional consequences pertaining to health insurance or employment. Researchers have a responsibility to protect people from these risks. However, many people with rare diseases are actively involved in advocacy related to their conditions or rare diseases in general; they are highly interested in spreading awareness of their conditions and feel a responsibility to participate in research about their conditions as they are aware that little research exists [28, 46, 59]. Many people with rare diseases actively seek to participate in clinical trials to gain access to treatments that would otherwise be inaccessible and to increase sample sizes for existing clinical trials in order to ensure that more research is available to future generations. Given this background, it may be the case that, people with rare diseases would be willing to accept the privacy risks of having their data shared for research purposes if it means that more research about their experiences and conditions can take place.

Participants desiring recognition in papers is nicely illustrated in Hofmann et al.'s [31] work involving people with upper-limb amputations, where most participants were anonymized but one requested to be identified. The authors explain, "Kevin and Ellen are anonymized, however Brett asked us not to anonymize him. He works hard to educate others about prosthetics and we provide more details about him in the acknowledgements section of this paper." The information provided in the paper's acknowledgements recognizes this participant and contributes to his goals of educating others.

One option that balances privacy and empowerment is to invite participants to choose the names they wish to be assigned in data collection and reporting. One example of this approach is Eschler et al.'s [25] work with cancer survivors where participants *picked their own aliases*, including everything from names like "Veronica" to adjectives like "Gorgeous." This humanistic approach involves participants directly in a conversation about how they are represented, allowing them to preserve some privacy while giving them the option to identify themselves to other people in a publication.

Accordingly, researchers should engage in active and ongoing conversations with participants concerning the use of their study data. Revisiting the user experience of informed consent can open up additional options for data sharing. Kaiser [36] points out that informed consent often takes place *before* a participant has actually provided any data and consent is rarely an *ongoing* conversation. Communicating with participants regarding their involvement in past research typically occurs only when inviting participants to return for the continuation of the study or for a follow-up. One notable exception is McNaney et al.'s [50] work involving people with Parkinson's disease in which the authors provide a note at the beginning of the paper stating: "This paper has been co-authored by participants who

collaborated on this project. The group have paid particular attention to ensuring they have been appropriately represented in the findings. We discussed with each participant individually about their choice to be named as co-author and how this might make them identifiable. We also discussed how they would like to be identified in the paper via quotations (e.g. name, P1, pseudonym). Participants chose to use pseudonyms to protect their privacy in relation to direct quotes but agreed they would like to be named as co-authors."

The challenge is to ensure that consent is truly *informed* consent, especially in cases where no researcher is physically present to explain things (e.g., in an online survey). It is crucial that participants understand the risks and the associated consequences of being re-identified so they can make informed decisions about how they want to be represented. This is certainly an important area of study, and researchers have started exploring ways of enhancing how informed consent is obtained online (e.g., [45, 58, 70]). **Researchers should continue exploring methods for clearly communicating study information, assessing participant understanding of this information, and revisiting informed consent as needed throughout the research process.**

Researchers could consult participants after data collection but before publication in order to verify that the participants are comfortable with the reporting of their data (e.g., via member checks [41, 49]). Such an approach that seeks participant consent prior to reporting could ensure that researchers make appropriate decisions about the level of detail in data reporting and sharing. However, some researchers have pointed out concerns with member checking, warning that participants may object to the way they are portrayed in the report [18, 24, 38], and researchers may report differently because they know that the report will be seen by their informants [33].

Making Space to Talk About Ethics and Compliance

Researchers and their institutions have the responsibility to protect the participant data collected during a study, regardless of whether the information is reported in a publication. External research funding may impose contractual obligations regarding data ownership and control that must be followed. To that end, many institutions require that study protocols be reviewed and approved by an ethics board prior to carrying out the research. Some institutions require further institutional approvals prior to publishing the results. An overwhelming majority of the papers we analyzed made no explicit mention of ethics approvals. From the papers, we could not determine whether the lack of information regarding ethics approvals is because: 1) no ethics approval was required, 2) no ethics board was available at the institution,

3) no ethics approval was sought or granted, or 4) ethics approval was granted, but not reported.

Researchers must also consider legal obligations regarding data protection and usage. The Family Educational Rights and Privacy Act (FERPA) and Health Insurance and Portability and Accountability Act (HIPAA) in the US and the General Data Protection Regulation (GDPR) in the European Union are examples of laws that govern the usage of corresponding data in the respective regions. Given that laws and regulations differ across jurisdictions, it may be necessary to consider a broad variety of community guidelines for data reporting and sharing.

It may be worthwhile for all papers that deal with human-subjects research to include considerations of ethics and compliance discussed during the design and implementation of a study. If an institution requires approval by an ethical board, it would be trivial to report that the proper steps were taken. Even if no ethics approval is required, it may be beneficial for the community to know the ethical aspects that were considered during the planning and execution of the study. In recent years, CHI submissions have required authors to certify that the research reported in a submission followed appropriate ethics approval processes. *We suggest that information concerning specific ethical tradeoffs or decisions be included within the paper itself since it can be helpful to the readers.*

6 LIMITATIONS

We analyzed only those papers that we coded as being related to health, wellness, accessibility, or aging. Additionally, the set of papers we considered was restricted to those from the CHI conference, the main yearly conference in HCI. As a result, the set of papers excludes publications from other venues that publish research on health, wellness, accessibility, and aging. Due to these limitations, the results of our analysis may not be representative of the entire HCI community. It should be noted that we considered only publicly available information. Therefore, we did not contact the authors of the papers we studied in order to inquire about details not provided in the paper, such as ethics approval.

7 CONCLUSION

Our systematic review of health, wellness, accessibility, and aging papers published at CHI provides significant insight regarding data reporting and sharing in these domains. Our coding of 509 papers in this space found differences in reporting based on the methods used and identified trends and patterns regarding how information of study participants is disclosed. We found that open publishing of research data is low and replication is essentially non-existent in the CHI health literature. Similar analyses of papers in other research domains within CHI are needed to examine the extent to

which these data reporting and sharing practices apply more broadly within the HCI community.

The insights from our review point toward specific directions for the community regarding consideration and reporting of ethical aspects of human-subjects research, guidelines for protecting participant data from risks of re-identification, building mechanisms for ongoing communication with participants over the full span of the research, and sharing of appropriately anonymized participant data with the research community. We further suggest that CHI submission and reviewing processes be refined to promote and facilitate data sharing practices in order to bring into reality the community's increasing recognition of openness and replication as valued contributions.

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