# Who are the "Hard-to-Reach" groups in chronic-health and health technology research?

# A scoping review

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#### Abstract

Many in health and technology research opt to focus on those who are already "engaged", not those who are considered "hard-to-reach" or "unreached". This exacerbates the digital divide and inequity in healthcare. We report findings of a scoping review of literature in PubMed/Medline from 2000-2022. 90 of 795 articles were identified based upon 1) the health researchers' recruitment of unreached groups with a chronic condition for active participation in a study and 2) clear definitions of who they considered to be unreached. Findings support the need for interdisciplinary and community-level involvement to reach and include unreached groups in health studies.

#### Keywords

Chronic, digital health, unreached, underserved, study participation

# **1 INTRODUCTION**

The words we use affect how we perceive and react to the world. The term "hard-to-reach" was first used in the 1970's to describe the police officer's stigmatizing perceptions of gay, lesbian, and bisexual individuals [1]. It was popularized in social marketing, referring to those who are more time and financially expensive to engage in whatever social intervention is offered [2]. In today's healthcare setting, the connotations we apply are still and similarly stigmatising; terms such as "hard-to-reach" or "unengaged" are used to primarily describe those who are non-compliant with or non-receptive to treatment [3]. This implies a lack of effort or blame, which affects how researchers and healthcare providers approach these groups. However, the situation is much more complex than a person simply choosing not to follow a doctor's orders. Reasons for not engaging in the care they need could be within or outside out of their control, and everywhere in between. This is reflected in the different ways these terms are used to describe different groups within the population.

Within the context of chronic conditions - broadly defined as "continuing or occurring again and again for a long time" by Bernell and Howard [4] - the consequences of belonging to a "hard-to-reach" group are more cumulative compared to those of someone with an acute health condition. If health services and resources are not accessible to someone with a chronic condition, symptoms may be experienced in the short-term as well as more severe complications that are more costly to both the individual and the healthcare system, in the long-term. The number of preventable hospitalizations for those with an acute condition in the US. Potentially preventable hospitalizations have also been cited as highly associated with social indicators of health [5]. These numbers also vary considerably by country [6], suggesting a community-level impact to preventative care and treatment.

If health research does not represent individuals living with chronic conditions who are hard-to-reach, here-to-for referred to as unreached, the consequences are interventions that do not address the needs and contexts of these unreached groups.

In this paper, we present the results of a scoping review of literature describing those whom health research considers unreached, who also have a chronic condition. To the best of our knowledge, a review that focuses on how researchers describe unreached groups has not been performed. Recently, factors from environmental to societal infrastructure have changed rapidly. Climate, technological and socio-political activity changes affect our resources, social interactions and priorities, including how we interact with the healthcare system [7]. Therefore, it is prudent to look at who we consider to be unreached in chronic care and what contributes to them being unreached, to properly inform intervention development, testing and implementation. This work is completed as part of the project Watching the Risk Factors (WARIFA): Artificial intelligence and the prevention of chronic conditions [8].

# 2 METHODS

## 2.1 Literature search strategy

We followed the PRISMA-ScR checklist to perform the scoping review [9]. In March 2022, PubMed (including Medline) was searched using the following terms: (Recruit\* OR Participa\*) AND ("Hard-to-reach" OR "Difficult to reach" OR Hidden OR Underserved OR Disadvantaged OR Marginalized OR Unengaged) AND (Population\* OR Group\*) AND (Healthcare OR "healthcare services" OR health) AND (intervention OR survey OR study OR trial) NOT (Adolescent OR child OR children OR infant OR youth). Due to the broad, "catch-all" search strategy, one database was initially used, with the intention of involving

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another if saturation, i.e., of descriptions used to describe unreached groups, was not reached.

# 2.2 Article review and inclusion

All references were uploaded into Rayyan [10]. A trial review of 10 titles an abstracts was conducted between three of the co-authors (MB, HLN, and SAI) to determine interrater agreement (Fleiss' kappa,  $\kappa_{f}$ ) [11]. The interrater agreement was strong ( $\kappa_{f}$ =0.85). Disagreements and uncertainties regarding inclusion were resolved before data-extraction from full-texts.

Articles were included if they described any type of study that 1) specifically recruited unreached groups with chronic conductions to actively participate, 2) were conducted from 2000-2022, 3) were written in English, 4) included only adults, and 5) explicitly described why they described their recruited groups as unreached. Reviews and protocols without results were excluded, as well as articles that did not describe recruitment strategies specifically for the group they define as unreached. A protocol is not registered but exists and can be made available upon request. Quality assessment of the articles was not performed because this review focused only on the definitions or characteristics used to describe the unreached populations.

# 2.3 Data extraction

The following data were extracted from each article: year, country, study type, intervention type, health condition, group(s) recruited, number recruited and definition of that/those group(s) (i.e., description of why the target group was considered unreached).

"Definitions" of unreached groups were considered by the authors to be an explanation or characteristics of why certain groups of people were not receiving the care that they needed or were not achieving their health goals. The exact text used to describe these groups and their definitions were cut and pasted into a common document and underwent a thematic content analysis.

# 3 RESULTS

Of the 795 articles identified in the literature, 158 were included for data extraction. In this paper, we focus on the 90 articles that recruited groups with chronic conditions, who were described as unreached (Figure 1). We present a summary of the terms the researchers used to describe the unreached groups as well as factors that answered the question "why is this group(s) not receiving the care that they need?". Note that some terms, e.g., socioeconomic status or rural residence/geography, may appear in both the group type and definition, based on the descriptions given by the authors.



Figure 1 PRISMA flow diagram.

## 3.1 Articles focusing on chronic conditions

More than 76.6% of the articles that focused on chronic conditions were from one country, the United States (n=69), followed by Australia (n=4) and the UK (n=4). Nearly 66.6% (60/90) of the articles described randomized controlled trials (RCTs), followed by feasibility studies (6/90) and quasi-experimental studies (6/90). In terms of the intervention types, to which groups of unreached individuals with chronic conditions were recruited, half were programs (45/90), i.e., interventions coordinated via healthcare services or run by healthcare personnel, followed by telehealth/eHealth interventions (15/90), i.e. those that used technology initiated by/controlled by healthcare personnel, and screenings (10/90), i.e. those that offered screening services offered by healthcare professionals, primarily for cancer. Only three studies described mHealth interventions, i.e., those that used self-management technologies initiated by end-users. Cancer was discussed in 28.8% (26/90) of the articles, followed by diabetes (22/90), mental health conditions (21/90), and cardiovascular conditions (13/90).

# 3.2 Recruited group types

The results of the qualitative analysis of the text used to describe the groups recruited to the studies are summarized in Table 1. One group may be described by more than one category, indicating the complexity of group needs or deprivations. The most common descriptions of groups were those described as People from racial/ethnic minority groups (n=42), followed by Residents of deprived, medically underserved, or rural areas (n=38), and people of Low socioeconomic status and/or uninsured (n=30), and Women (n=13).

Health condition category	Recruited groups by category [reference] Low socioeconomic status and/or uninsured [12-21]	Disability	People who are socially isolated or unengaged [73] People who have been institutionalized, disabled and/or are dependent on others [73, 74] Women [73]
Cancer	People from factal/ethnic minority groups [13-15, 18, 19, 22-31] People who are not compliant/up to date with health recommendations [18, 20] Residents of deprived, medically underserved, or rural areas [32-37] Seniors [14] Women [13, 16, 21, 34, 35]	Ĵ	Criminal offenders and/or people who use illicit drugs [75, 76] People from racial/ethnic minority groups [77] People who are not compliant/up to date with health recommendations [78] People without permanent homes
	Immigrants, migrant/transient workers, refugees, or manual	Hepatitis	Veterans [78]
	Laborers [38] Low socioeconomic status and/or uninsured [39-43] People from racial/ethnic minority	Kidney disease	People from racial/ethnic minority groups [80] Residents of deprived, medically underserved, or rural areas [80]
Cardiovascular conditions	groups [38, 40, 44] Residents of deprived, medically underserved, or rural areas [40, 41, 45-49] Women[39, 45, 47]		Criminal offenders and/or people who use illicit drugs [81, 82] Immigrants, migrant/transient workers, refugees, or manual laborers [83]
Chronic conditions (non-specific)	Immigrants, migrant/transient workers, refugees, or manual laborers [50] People from racial/ethnic minority groups [50] Residents of deprived, medically underserved, or rural areas [51]		Low socioeconomic status and/or uninsured [56, 81, 83-87] People from racial/ethnic minority groups [56, 82, 88-94] People who are socially isolated or unengaged [83, 84] People who have been
Chronic obstructive pulmonary disease (COPD)	Criminal offenders and/or people who use illicit drugs [52]	Mental health	institutionalized, disabled and/or are dependent on others [95, 96] People with (serious) mental health conditions [82, 97-100] Residents of deprived, medically underserved, or rural areas [56]
	uninsured [41, 53-56] People from racial/ethnic minority	conditions Multiple sclerosis	Women [84, 85, 98] People with underserved chronic condition [101]
	groups [53, 54, 56, 57] People who are socially isolated or unengaged [54] People with underserved chronic condition [58] Residents of deprived, medically underserved or rural areas [41, 56,	Alcohol, tobacco, or substance use/abuse	Criminal offenders and/or people who use illicit drugs [82] People from racial/ethnic minority groups [82] People with (serious) mental health conditions [82]
Diabetes (non-specific)	57, 59-63] Women [53]	Table 1Typepopulations, by h	s of recruited unreached groups of ealth condition.
	Immigrants, migrant/transient workers, refugees, or manual laborers [64] Low socioeconomic status and/or uninsured [64-66] People from racial/ethnic minority groups [64, 66-71] Residents of deprived, medically	<b>3.3 Definitions</b> The most common definitions of unreached groups with chronic conditions were based upon limitations due the <i>Healthcare system infrastructure, Socioeconom status/factors</i> , and <i>Engagement in healthcare system</i> . The definition category of <i>Healthcare system infrastructur</i> included the following factors; access to and availability of the following factors is to and availability of the following factors.	
Diabetes (Type 2)	underserved or rural areas [49, 64- 66, 69, 71, 72] culturally appropriate and relevant services/resources, complexity of medical voca care pathways, healthcare quality and treatment well as racism experienced during health consulta		propriate and relevant healthcar is, complexity of medical vocabulary an ealthcare quality and treatment options a perienced during health consultations from

providers and care coordination and continuity. *Socioeconomic status/factors* included income, education, and insurance as well as migrant-related work, and stressors of living in poverty. *Engagement in healthcare system* included factors such as adherence to recommendations, patient-provider interactions, and relationships as well as screening, other prevention and treatment seeking behaviours and use of healthcare resources.

Also of note were the community, social and political-level factors. *Community resources and setting* included factors such as inherent availability of community resources, socioeconomic status of the community, food security, place of residence or geography and history of community industrial downsizing. *Psychosocial/cultural factors* included culturally based beliefs toward health, e.g., cultural norms that do not support health recommendations, shame, stigma, social isolation, and social capital, i.e., an individual's level of support and participation in a community. *Socio-political factors* included devaluation of their culture, immigrant or minority status, marginalization, discrimination, and risk of deportation.

Of the more internal definition categories were *Personal skills/capacity, and logistic constraints* which included responsibilities of parenthood and caregiver status as well as skills to prepare fresh food, if available, and language. *Perception of/history with treatment/healthcare* was often mentioned as a barrier, citing such factors as knowledge of the healthcare system and level of experience using the healthcare misconduct as well as fear of hospitalization, treatments, and diagnosis. The complete set of factors upon which definitions were based are listed in Table 2.

Categories of factors upon which definitions were based	References	
Community resources and setting	[32, 36, 40-42, 48-50, 55, 56, 63, 65, 67-69, 71, 72, 74, 83, 84, 89]	
Digital divide	[41, 60]	
Engagement in healthcare system	[12, 13, 15, 17-19, 21, 23-27, 29, 31, 33, 36, 38, 42, 45, 50, 52, 57, 58, 64, 67, 75-79, 82, 83, 85, 87, 88, 90-97, 100]	
Health beliefs and knowledge	[12, 21, 23, 26, 29, 31, 32, 38, 40, 41, 48, 57, 64, 67, 75, 77, 85, 87, 91]	
Health history, status/capacity	[12, 14, 32, 37, 40, 43, 55, 58, 59, 63, 67, 70, 73, 74, 79, 84, 86, 97, 100]	
Healthcare system infrastructure	[13, 15, 17, 21-25, 28, 29, 31-37, 39-41, 46-48, 51, 52, 55-62, 64-68, 70-73, 75-82, 84-87, 90-94, 96-99, 101]	
Perception of/history with	[16, 22, 28, 38, 39, 48, 51, 64, 65, 75, 77, 82, 83, 86, 94, 97, 101],	
Personal skills/capacity, logistical constraints	[12, 22-24, 29-32, 37, 41, 44, 49- 51, 53, 54, 64, 65, 67, 68, 70, 74, 83, 85, 92, 95, 97, 101]	

Psychosocial/cultural factors	[23, 25, 28-31, 39, 43, 47, 50, 55, 58, 64, 67, 73-77, 79, 82-87, 89-92, 94, 97],
Safety/security	[55, 78, 79, 86]
Socioeconomic status/factors	[12-18, 20-26, 28, 39-46, 49, 53- 56, 63-67, 69, 70, 73, 74, 78, 79, 81-87, 92, 97, 99]
Socio-political factors	[13, 19, 22, 23, 27, 28, 30, 40, 41, 49, 51, 54-56, 64, 66, 67, 70, 73, 81-84, 86, 87, 90, 94, 99]

**Table 2** Factors upon which definitions of unreached groups or populations are based.

# **4 DISCUSSION**

Of the total 795 articles, we identified 90 that described the recruitment and active participation of those who were considered unreached and had chronic conditions. The most common reasons for being described as unreached were related to supply of healthcare system resources, socioeconomic factors related to a community or individual, and individuals' engagement in healthcare.

The variety of unique reasons given by the authors for why certain groups with chronic conditions were unreached was quite frankly disconcerting. Several articles cited a scepticism or lack of trust with the healthcare system due to a history of mistreatment of people like themselves [22, 65], e.g., the 1932-1972 Tuskegee syphilis experiments [102]. Unfortunately, this mistrust persists today due also to personal experiences with racism and stigma during encounters with the healthcare system or from healthcare providers [82].

While the promise of telehealth is greater access and use of healthcare resources amongst those with chronic conditions, the contextual barriers described in this review, including socioeconomic status, where they reside, and logistical challenges could stop them from using, or continue to use, a technology intervention [103]. Those in need exist within the general population, yet most studies include those who are already engaged in their health and care. If we in health research wish to pursue digital health interventions for the general population, we first must consider barriers, including cost and resources needed to support the use of such interventions – from recruitment of diverse informants to the implementation and continuity of the intervention [104].

The strengths of this review were the inclusive search strategy. We aimed not to limit the type of paper based on a certain classification of a "chronic" condition. This allowed us to explore a greater breadth of factors associated with a group not receiving the care they need.

The limitations of this review include human error. We do acknowledge the possibility that a factor was excluded in the extraction of the definitions from the article. We did attempt to minimize this possibility by copying and pasting article text for qualitative analysis instead of paraphrasing. Also, the introductions were primarily used to identify the definitions. Therefore, information presented in other sections would have been omitted.

## **5 CONCLUSION**

As researchers and healthcare providers, we need to know not only why certain groups are not receiving the care that they need but also how those reasons came to be - the history behind them. It was made clear by the articles that described personal and systemic history of healthcare misconduct, racism, stigma, and social exclusion, that perception is indeed everything. Awareness of the root causes of reluctance in addition to the systemic, political, or infrastructural barriers to seeking or receiving care is the only way in which we develop and effectively implement interventions for those with chronic conditions, including health technologies. Results from this work will contribute to WARIFA in terms of recruitment strategies and understanding the impact and barriers to reaching different populations for health technologies, specifically artificial intelligence.

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