

Application of the Delphi method to the development of common data elements for social drivers of health: A systematic scoping review

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Abstract

Collaborative data science requires standardized, harmonized, interoperable, and ethically sourced data. Developing an agreed-upon set of elements requires capturing different perspectives on the importance and feasibility of the data elements through a consensus development approach. This study reports on the systematic scoping review of literature that examined the inclusion of diverse stakeholder groups and sources of social drivers of health variables in consensus-based common data element (CDE) sets. This systematic scoping review included sources from PubMed, Embase, CINAHL, WoS MEDLINE, and PsycINFO databases. Extracted data included the stakeholder groups engaged in the Delphi process, sources of CDE sets, and inclusion of social drivers data across 11 individual and 6 social domains. Of the 384 studies matching the search string, 22 were included in the final review. All studies involved experts with healthcare expertise directly relevant to the developed CDE set, and only six (27%) studies engaged health consumers. Literature reviews and expert input were the most frequent sources of CDE sets. Seven studies (32%) did not report the inclusion of any demographic variables in the CDE sets, and each demographic SDOH domain was included in at least one study with age and sex assigned at birth included in all studies, and social driver domains included only in four studies (18%). The Delphi technique engages diverse expert groups around the development of SDoH data elements. Future studies can benefit by involving health consumers as experts.

Lay summary

Collecting and capturing social factors that affect individuals' health is imperative. Social drivers of health data allow researchers to understand health disparities to make healthcare available, accessible, and affordable. However, collecting common health data elements has challenged researchers due to limited resources to facilitate change. Incorporating various stakeholders, such as individuals and patient advocacy groups, can effectively contribute to the research process as community advisors. This article reviews the studies that used the Delphi method and brings together experts to agree on guidelines for collecting common data elements. The article's findings reveal that experts are healthcare professionals and researchers, leaving out the crucial input from patients and caregivers. This article emphasized that developing a standard set of data elements can improve the standardization of social drivers of health. Common data elements provide the opportunity to improve patients' and social circumstances and their efforts toward health outcomes.

Keywords: common data elements; Delphi technique; PhenX core collection; social drivers of health; stakeholder engagement



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Implications

Practice: Establishing common data elements involving patients and caregivers is crucial to creating a clinical patient-centered environment. **Policy:** Policymakers who want to decrease health disparities should explore the standardization of common data elements to capture social determinants of health and improve health data guality and consistency.

Research: Future research must prioritize identifying diverse stakeholders to develop common data elements to enhance data harmonization, exchange, and inter-organizational collaboration.

Introduction

Common data elements for data sharing

Advancements in technology and healthcare have equipped healthcare delivery and public health organizations with the capacity to gather vast amounts of medical and healthrelated data [1]. The capacity to capture data paved the way for inter-organizational collaboration and data team science that stand to generate the highest level of evidence for clinical practice and population health. Yet, collaborative data science requires that captured data are standardized, harmonized, interoperable, and ethically sourced. The ability to easily share and combine data from multiple studies has the potential to increase the scientific impact of individual studies. A key strategy for promoting inter-organizational data science is creating and implementing common data element (CDE) sets [2]. A data element is a standardized, precisely defined question (or variable) coupled with a predetermined set of responses.

The interest in developing health-related CDE sets is a growing practice driven by the need to harmonize data and promote inter-organizational research and quality improvement efforts. In the United States, CDE set development has been stimulated by the 21st Century Cures Act, which mandates health data exchanges and interoperability [3, 4]. Multiple stakeholder groups are working on developing CDE sets for specific patient cohorts, diagnoses, and health outcomes. Many therapeutic organizations and research consortia have worked to develop CDE sets that represent minimally required or essential variables specific to a particular patient population. For example, the Spinal Cord International Consortium has worked to develop data elements for core data capture [5, 6] and subspecialty collections [7–9].

In clinical and translational research, CDE sets allow data to be collected and reported uniformly across multiple research studies and sites [10]. When systematically used across different sites, studies, or clinical trials to ensure consistent data collection, CDE sets enhance data harmonization and exchange and support policy-mandated health data sharing [3].

Consensus methods for the elicitation of diverse perspectives

Developing an agreed-upon set of elements requires that diverse perspectives on the importance and feasibility of the data elements are systematically elicited and effectively integrated across different groups of translational science stakeholders. Applying structured consensus development methods can aid in eliciting and enhancing diverse perspectives. Consensus development generally involves soliciting expert opinions, systematically capturing and integrating diverse perspectives, identifying agreement through voting, and discussing disagreements to inform final decisions. Rigorous in nature, the consensus became a valid and accepted approach for generating reliable evidence in a timely manner [11] to determine priorities and develop hypotheses [12].

The Delphi technique is the most well-known and established approach for reaching consensus for developing shared guidelines, recommendations, and CDE sets. The RAND Corporation initially developed the Delphi technique in the 1950s to forecast the effects of atomic warfare. Since its introduction in research, the method has been used in different academic fields such as health, science, technology, business, communication, policy analysis, and education [13]. The Delphi technique allows for restructuring a group communication process "so that such process is effective in allowing a group of individuals to deal with a complex problem" [14]. The overarching goal of the Delphi technique is to seek the systematic emergence of a concurrent opinion [15]. The Delphi technique promotes equitable participation and knowledge transfer among experts, who frequently bring diverse perspectives based on their scientific expertise, engagement in healthcare practice, community development, policy implementation, participation in professional societies, or lived experiences as patients and caregivers. In practice, it is an iterative process that involves completing a series of questionnaires over several rounds [14, 15]. Such explicit focus on eliciting input and providing structure for exchanging ideas makes the Delphi method particularly suitable for meaningful stakeholder engagement in clinical and translational research.

Clinical data sharing and social drivers of health

Clinical data captured through electronic health records (EHR) constitutes a significant aspect of health indicators. However, there is evidence that capturing other data elements, including patient-reported outcomes and social drivers, can be more effective in shaping health outcomes [16]. A mere 20% of the population's health factors pertain to medical service delivery. The residual 80%-typically referred to as individual and social domains of health (SDoH)-encompass patients' socioeconomic status, health-promoting and limiting behaviors, physician and environmental factors, and accessibility, availability, and affordability of health care [17]. While there is widespread recognition of the importance of SDoH, overall scientific progress in addressing SDoH has been hindered by the lack of a resource to facilitate the collection of CDE sets for SDoH. Broad adoption of CDE sets on SDoH across behavioral, clinical, and translational research will facilitate cross-study analysis, domestically and internationally, accelerate translational research, and lead to a greater understanding of the causes of health disparities and the design and implementation of effective interventions to reduce health disparities.

In 2018, the National Institute on Minority Health and Health Disparities (NIMHD) led an effort to develop a CDE set for SDoH as part of the existing PhenX collections [10]. The PhenX SDoH toolkit is an expert-selected collection of CDE sets used to improve the quality and consistency of data acquisition and facilitate collaboration. The PhenX SDoH collection makes it easier for investigators to compare results, combine data from different studies, and promote the adoption of comparable data on SDoH across studies. The Core collection consists of 16 measurement protocols, including demographics (e.g. ethnicity and race, age, gender identity, annual family income, employment status) and social driver variables (e.g. English proficiency, occupational prestige, and access to health services). These protocols were designed to create SDoH CDE sets for cross-study analyses that compare or combine data from different studies, and the NIH encourages the use of the core SDoH variables for all primary data collection to connect data from various studies, advance minority health and health disparities science, promote a culture of scientific collaboration, and improve human health [18].

Study objective

As the utilization of the data and the application of consensus-building methods continue to expand, there is a critical need to evaluate (i) the extent to which the diverse perspectives around the health CDE sets are elicited and (ii) the rate of the inclusion of the social drivers of health as routinely captured data elements. Consequently, this study aims to report on the systematic scoping review of literature that examines the application of the Delphi method to achieve consensus regarding CDE sets, the inclusion of diverse stakeholder groups, and the integration of SDoH as data elements.

RQ1: What stakeholder groups are represented in Delphibased clinical CDE sets?

RQ2: What are the sources of SDoH variables in Delphibased clinical CDE sets?

RQ3: What types of SDoH variables are included in Delphi-based clinical CDE sets?

Methods

Study design

We conducted a systematic scoping review and followed the guidelines by the Joanna Briggs Institute in performing a literature review [19] and guidelines [20] in creating a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-ScR) flow chart (see also Supplementary Appendix 3 for the checklist) without protocol registration.

Information sources and search strategy

A comprehensive search string was developed with guidance from a health library and information specialist (see Supplementary Appendix 1 for an example of the PubMed string). The Systematic Review Accelerator [21, 22] was then used to translate the PubMed search string into the language used by the Embase, CINAHL, WoS MEDLINE, and PsycINFO databases.

Inclusion and exclusion criteria

Studies were included in the review if they were published in the English language in academic, peer-reviewed articles; reported on the use of Delphi or modified Delphi technique, alone or in combination with other methods; focused on developing consensus for data elements, data items, data sets, indicators, or data domains; and were related to human health. Exclusion criteria included non-English language, review, protocol, or commentary articles that referenced but did not apply the Delphi technique and studies that did not present health-related data elements or indicators. Specifically, we excluded studies that reported using the Delphi technique to develop clinical training outcomes, health policy recommendations, and clinical guidelines. Furthermore, based on the feedback from experts in SDoH research, studies were screened for geographic application. Studies developed specifically for low- and middle-income county contexts were excluded as the social drivers of health for populations in these countries differ significantly from those in high-income countries.

Screening and data charting process

The first author searched databases and uploaded the search results into the Covidence online platform for deduplication and review management. Two authors screened the title and abstract of each article. Screening decisions were discussed during weekly meetings and noted in study settings. Emerging conflicts were resolved by the senior author after discussion. Data from the studies included in the final review were extracted by three reviewers using Excel. During the extraction, verbatim text describing the engagement of stakeholder groups in the Delphi process and the inclusion of SDoH elements was captured. Finally, unstructured extraction data were systematically reduced. Descriptions of participating stakeholder groups were retained without changes, as reported in the reviewed articles. SDoH CDE sets were classified using the PhenX Core toolkit. Inclusion of demographic variables was classified using 11 protocols (Annual Family Income, Birthplace, Current Address, Current Age, Current Employment Status, Educational Attainment-Individual, Ethnicity and Race, Gender Identity, Health Insurance Coverage, Sex Assigned at Birth, Sexual Orientation), and inclusion of social drivers was classified using five protocols (Access to Health Services, English Proficiency, Food Insecurity, Health Literacy, Occupational Prestige). See Supplementary Appendix 2 for the data extraction table.

The methods and results sections of the included articles were reviewed to extract information about the groups of stakeholders involved in the development of health CDE sets. Data included Review article ID, authors, year, DOI, title, abstract, study goal, therapeutic area, geographic application, total number of involved experts, sources of CDE sets, and final consensus-based SDOH-related CDE sets (see Supplementary Appendix 2). All eligible studies were included in the scoping review. The critical appraisal of evidence was not conducted due to the scoping nature of the systematic review reported in this article.

Results

A total of 384 studies matching the search string were identified, 167 duplicates were removed, and 217 were screened. Reasons for exclusion during the full-text review are shown in Fig. 1. After the screening, 22 articles were deemed eligible for inclusion.

The earliest included article was published in 2013 [23], with more articles published in 2021, 2022, and 2023. The complete list of included studies is available in Supplementary Appendix 2.





No publication date limitations were applied to the search. Geographically, CDE development projects addressed USA (n = 8), international (n = 8), Canada-specific (n = 5), and Switzerland-specific (n = 1) health contexts. The health focus of the reviewed articles covered a variety of therapeutic areas (e.g. cerebral palsy [24], epilepsy [25], spinal cord injury [8]), medical professions (e.g. nursing [23], surgery [26, 27]), and population groups (e.g. pediatric patients [28–31]) frail adults [32].

Stakeholder groups represented in Delphi-based clinical CDE sets

The data in Delphi studies come from expert input. The studies included in this review involved between 5 and 272

experts (M = 53.6, SD = 69.0). The studies with the smallest number of experts involved were part of more extensive data harmonization efforts for spinal cord injury [8] and pediatric sepsis [30] CDE sets. Another 14 studies involved less than 50 experts [23–25, 29, 31, 33–41]. Finally, 6 studies involved 59–272 experts [26–28, 32, 42, 43].

All studies involved experts with health or medical expertise directly relevant to the developed CDE set. Most studies did not distinguish between clinician scholars and researchers. However, several studies specifically differentiated and listed research ("researcher scientist") and clinician ("PICU physician and nurse," allied health practitioners) participants [24, 28, 32, 37, 40, 42, 43]. Other stakeholder groups involved in the CDE sets development included experts in health services and population health management [25, 28, 33, 34, 39] standards and accreditation [23, 33, 37, 40, 43], information technology and informatics [34, 36, 40] industry [42, 43], and project management [28, 32, 38]. Finally, six studies included the participation of health consumers [24, 28, 32, 43], caregivers [32], and patient advocacy groups [26, 42, 43]. These six projects represented the Delphi CDE set efforts involving a more significant number of experts. The exception to this group of studies is the study by Hirji et al. [27], who engaged 60 subject-matter experts and 137 participants from an Annual Multidisciplinary Cardiovascular and Thoracic Critical Care Conference, none of whom were reported to represent health consumers.

Sources of SDoH variables in Delphi-based clinical CDE sets

Most studies (n = 14, 63%) used literature reviews [23–26, 28–30, 32, 33, 35–37, 42, 43], but only six reported that their reviews were systematic [24–26, 29, 37, 42]. The second largest reported source of data elements was expert input (n = 9, 41%) [28, 32–34, 36, 38, 39, 41, 42]. One study further differentiated between expert and provider input [28]. Regulatory requirements guided several studies (n = 4, 18%) [36, 40], existing protocols, 522 postmarket surveillance [43], and data standards [33]. Two studies (9%) used administrative [23] and clinical [43] real-world data. Finally, six studies were reported involving health consumers in the development of CDE sets [24, 26, 28, 32, 42, 43]. Only two of them (9%) integrated patient perspectives by consulting patient-reported outcomes instruments [42] and direct input from a patient advisory group [26].

Types of SDoH variables included in Delphi-based clinical CDE sets

PhenX SDoH Core collection domains were used to extract the data about demographic and social driver domains included in the consensus-based CDE sets. Demographic SDoH domains covered by PhenX include Annual Family Income, Birthplace, Current Address, Current Age, Current Employment Status, Educational Attainment-Individual, Ethnicity and Race, Gender Identity, Health Insurance Coverage, Sex Assigned at Birth, Sexual Orientation and social driver domains include Access to Health Services, English Proficiency, Food Insecurity, Health Literacy, Occupational Prestige. Overall, nine studies (41%) reported including only demographic SDoH CDE sets [24-26, 28, 30, 33, 34, 36, 43], six studies (27%) also included both demographic and social driver domains [32, 35, 37, 38, 41, 42], and seven studies (32%) did not report the inclusion of any demographic variables in the CDE sets [8, 23, 27, 29, 31, 39, 40]. On average, studies included 4.5 demographic domains (Min = 2, Max = 8) and 1.2 social driver domains (Min = 1, Max = 2).

Each demographic SDoH domain was included in at least one study. Age and Sex Assigned at Birth were two domains included in each of the 15 studies that considered SDoH CDE sets. In addition to Sex Assigned at Birth, five studies (23%) also included the domain of Gender Identity [28, 32, 33, 35, 43], and one study included the domain of Sexual Orientation [32]. Race and Ethnicity were included in 10 studies (45%) [28, 32–36, 38, 41–43]. Employment was included in seven (32%) studies [32, 35, 37, 38, 41–43]. Current Address was included in four (18%) studies [28, 33, 34, 41], and Educational Attainment was included in four (18%) studies [32, 33, 37, 42]. Income [38, 41], Health Insurance [32, 34], and Birthplace [24, 41] were covered by two studies (9%) each.

For the social driver domains, four studies (18%) included the Occupational Prestige domain [35, 38, 41, 42], two studies (9%) reported including Access to Health Services [32, 37], and one study included Food Insecurity [32]. The inclusion of English/Language Proficiency and Health Literacy was not reported by any study.

Discussion

This study reported a systematic scoping review of the application of the Delphi technique as a consensus development method for constructing CDE sets. This review shows that the application of consensus methods provides transparency and opportunities for systematically comparing the methodologies used in CDE selection. This review contributes to the growing body of literature on consensus-based CDE set development and stands to inform future design considerations related to stakeholder, source, and type choices specific to the SDoH variables.

For stakeholder considerations, the current study showed that the studies under review identified and involved diverse stakeholder groups in developing CDE sets. Predominantly, healthcare professionals and translational scientists constituted the most frequently engaged groups. Most CDE set efforts did not involve patients or patient advocacy groups, which risks missing an opportunity to support patientcentered research and clinical practice [44, 45]. The CDE set development efforts that involved more experts were poised to have representation from patients, caregivers, and industry groups. However, given the number of experts involved in these efforts, the extent to which patients' voices were fully heard should be carefully considered and evaluated. The very definition of expert warrants a rigorous conceptual explication and operational definition. Clinical and research staff are only some of the best sources of expertise that can inform the development process of CDE sets. Instead, patients, caregivers, and other primary support groups are best suited for this endeavor. Individuals and patient advocacy groups have lived and health system interaction experiences [46] that can effectively contribute to the research process as community advisors or citizen scientists. The Delphi technique is a rigorous and recognized data collection method among experts, and future research is needed to identify the domains of expertise and characteristics of experts who should be involved in patient-, practitioner-, and community-centered CDE efforts. Future CDE set development studies should consider including patients or patient advocates who can bring the lived experience and contribute their expertise to identify SDoH variables that are core to their health conditions.

For SDoH source decisions, this study suggests that the inclusion of SDoH variables needs to be counterbalanced with the feasibility of collecting and extracting those data from electronic medical records. The missingness of SDoH data in medical records remains high [47, 48]. Furthermore, low-resourced institutions and institutions that serve minoritized and low-income patients will likely face personnel shortages and technical challenges in SDoH data capture.

For the types of SDoH variables, this study showed that individual demographic domains were included in most reviewed studies, and data elements related to social factors, such as health behavior and access to care, were less common. Neighborhood-level data and social vulnerability indices can serve as a relevant proxy for social drivers of health that may affect human health. However, this review also showed that the current address is included in a small subset of data elements. Since current address data are regularly captured at the patient intake and are systematically recorded within the electronic medical records, the systematic inclusion of current address data can help alleviate this gap. Including zip codes can allow future research projects to link individual-level EHR data with existing neighborhood- and national-level statistics on the social conditions of populations within the United States.

In discussing the implications of this study, it is essential to note its focus and limitations. This systematic scoping review focused on and was limited to applying the Delphi method to develop health and clinical CDE sets. Other methods for expert consensus include structured Nominal Group Techniques and unstructured expert panels, but both are used less frequently to develop CDE sets. Furthermore, the review is limited to the studies that developed CDE sets for high-income counties. Similar CDE development efforts occur worldwide, and future reviews inform this practice by expanding the focus to include middle- and low-income countries. Despite these limitations, this scoping review has implications for clinical research and health policy development [49].

This study has implications for future research and policy development. Several US national guidelines call for the development of an infrastructure for health information exchange, data interoperability, and patient access to data. This review revealed that, despite their importance, patients and caregivers often need to be more represented in developing data elements and their inclusion as CDE sets. Therefore, conducting specific studies on implementing policies for patient and caregiver involvement could create better opportunities to promote patient-centered practices in health information exchange and data accessibility. This review also suggests that while SDoH variables are included in most efforts to develop CDE sets, their potential still needs to be fully realized. Thus, this research presents an opportunity for national task forces to develop evidence-based recommendations and SDoH standards. Future CDE set development efforts and national task forces can evaluate the feasibility of including the 16 domains articulated in the PhenX core dataset and provide recommendations for point-of-care data capture. Researchers should also continue to refine the vision for standardized data in research and clinical practice to maximize efficiency, hasten the initial stages of the study by reusing standardized metadata and tools, and reduce the load on data storage for quality and validation. These efforts would ensure more comprehensive inclusion of social drivers of health and broader engagement of stakeholder groups in policy and standards development.

Conclusion

The evolving landscape of technology and healthcare services has amplified the capacity to capture diverse health-related data for clinical and translational research. The translational science perspective that guided this review offers considerations for incorporating SDoH into future CDE sets and engaging stakeholder groups with diverse perspectives. The standardization and inclusion of SDoH as common data elements promise to improve the understanding of patients' individual and social circumstances and their efforts to improve health outcomes. To harness the full potential of these data, standardization through the establishment of CDE sets is crucial. The Delphi technique effectively engages diverse expert groups around the health and SDoH CDE sets. Future studies can benefit from including health consumers as lived experience experts.

Supplementary data

Supplementary data is available at *Translational Behavioral Medicine* online.

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Author Contributions

Y.A.L.S., J.D.N., H.M.W., and X.W. contributed to the edits and literature knowledge of the sections. Y.A.L.S. contributed to the methods, results, and discussion sections. J.D.N., H.M.W., and X.W. contributed to the discussion section. S.M.M. contributed to the revisions and editing of the final manuscript. All authors read and approved the final manuscript.

Transparency Statement

Study Registration: This study was not formally registered. Analytical Plan Preregistration: Not applicable for this study. Data Availability: De-identified data not applicable. Analytical Code Availability: There is not analytical code associated with this study. Materials Availability: Materials for this study is not applicable.

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