
Article:
Kaelin, V.C. orcid.org/0000-0003-1290-9441, Bosak, D.L. orcid.org/0000-0001-7486-2912, Saluja, S. orcid.org/0009-0007-8515-1746 et al. (3 more authors) (2025) Representation of child and youth participation within the Unified Medical Language System (UMLS). Disability and Rehabilitation, 47 (1). pp. 114-119. ISSN 0963-8288

https://doi.org/10.1080/09638288.2024.2338191

Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/idre20

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To cite this article: Vera C. Kaelin, Dianna L. Bosak, Shivani Saluja, Denis Newman-Griffis, Andrew D. Boyd & Mary A. Khetani (10 Apr 2024): Representation of child and youth participation within the Unified Medical Language System (UMLS), Disability and Rehabilitation, DOI: 10.1080/09638288.2024.2338191

To link to this article: https://doi.org/10.1080/09638288.2024.2338191

Published online: 10 Apr 2024.

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2024.2338191

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RESEARCH ARTICLE

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Representation of child and youth participation within the Unified Medical Language System (UMLS)

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ABSTRACT

Purpose: To examine (1) how much participation is represented in the benchmark Unified Medical Language System (UMLS) resource, and (2) to what extent that representation reflects the definition of child and youth participation and/or its related constructs per the family of Participation-Related Constructs framework.

Materials and methods: We searched and analysed UMLS concepts related to the term "participation." Identified UMLS concepts were rated according to their representation of participation (i.e., attendance, involvement, both) as well as participation-related constructs using deductive content analysis.

Results: 363 UMLS concepts were identified. Of those, 68 had at least one English definition, resulting in 81 definitions that were further analysed. Results revealed 2 definitions (2/81; 3%; 2/68 UMLS concepts) representing participation "attendance" and 18 definitions (18/81; 22%; 14/68 UMLS concepts) representing participation "involvement." No UMLS concept definition represented both attendance and involvement (i.e., participation). Most of the definitions (11/20; 55%; 9/16 UMLS concepts) representing attendance or involvement also represent a participation-related construct.

Conclusion(s): The representation of participation within the UMLS is limited and poorly aligned with the contemporary definition of child and youth participation. Expanding ontological resources to represent child and youth participation is needed to enable better data analytics that reflect contemporary paediatric rehabilitation practice.

IMPLICATIONS FOR REHABILITATION

- The representation of participation within the Unified Medical Language System (UMLS) is limited and poorly aligned with the contemporary definition of child and youth participation.
- From a contemporary paediatric rehabilitation perspective, using the current UMLS concepts for data analytics might result in misrepresentation of child and youth participation.
- There is need to expand ontological resources within the UMLS to fully and exclusively represent participation dimensions (attendance and involvement) in daily life activities to enable better data analytics that reflect contemporary paediatric rehabilitation practice.

ARTICLE HISTORY
Received 4 April 2023
Revised 25 March 2024
Accepted 28 March 2024

KEYWORDS
Rehabilitation; attendance; involvement; health informatics; artificial intelligence; knowledge representation

The adoption of health informatics approaches, including artificial intelligence, to derive insights from health data, is transforming clinical decision-making and service management across various care components. Despite its potential, existing barriers in current health data collection and management approaches have hindered implementation of informatics in rehabilitation [1,2]. One way to bolster informatics in rehabilitation is through efforts focused on extracting and standardising information about rehabilitation interventions and outcomes from free-text health data. However, achieving this standardisation has long proven difficult in rehabilitation disciplines [3–5]. Effective health data standardisation is often highly reliant on the use of biomedical ontologies, well-organised resources which support mapping diverse health measures and observations to systematic, computer-readable categories [2]. However, there is a lack of evidence on the capacity of ontologies to capture key information in rehabilitation, and little is known about challenges for effectively representing rehabilitation outcomes (e.g., participation) with ontology concepts.

This study investigates the representation of participation, particularly child and youth participation, in the Unified Medical Language System (UMLS) [6]. The UMLS is a large ontology widely used in healthcare data analysis [7]. It combines over 200 health and biomedical vocabularies into a single resource containing over 3 million unique concepts. The UMLS is used, for example, to link health information across different computer systems (e.g.,

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electronic health records) such as those of the physicians and hospitals to enhance communication between these systems [8,9]. Additionally, the UMLS is commonly used to structure text data and support classification tasks [8]. In participation-focused paediatric research, this approach has been explored for classifying participation-focused caregiver strategies according to their targeted focus (i.e., a child's or youth's environment/context, activity competencies, sense of self or preferences) [10]. Caregiver strategies were linked to relevant UMLS concepts to support the prediction of their targeted focus through natural language processing. However, the inclusion of the UMLS did not enhance automated classification, raising doubts about the utility of the UMLS in its current form in participation-focused research and applications. While representing participation is not the main focus of vocabularies within the UMLS, elements of participation are included. For example, the International Classification of Functioning, Disability and Health (ICF) [11] and its version for children and youth (ICF-CY) [12] are common rehabilitation classification systems [13] that are integrated into the UMLS ontology and include an "Activity and Participation" chapter [11,12]. However, the definition of participation within the ICF and ICF-CY has been widely critiqued due to its limited focus on the subjective dimension of participation and the overlap of participation and activity concepts [14,15].

The family of Participation-Related Constructs (fPRC) [14] framework is based on a systematic literature search to further conceptualise child and youth participation and its related but distinct participation-related constructs (i.e., environment/context, preferences, sense of self, activity competence) [14,16,17]. In the fPRC, participation consists of two dimensions: "attendance" and "involvement." Attendance is defined as "being there" [14] (p.18) (e.g., frequency of attending, and/or the range or diversity of activities), and involvement is described as "the experience of participation while attending" [14] (p.18). The extent to which participation concepts within the UMLS align with this contemporary definition of child and youth participation (i.e., attendance and involvement) is unknown, although crucial when applying computer-based analyses (e.g., artificial intelligence) in participation-focused paediatric rehabilitation.

Therefore, our objective was to understand (1) how much the concept of participation is represented in the UMLS and (2) to what extent that representation reflects the contemporary definition of child and youth participation and/or its related concepts per the fPRC.

Methods

Study design

We conducted descriptive analyses of a subset of publicly available data extracted from the UMLS database [6], employing methods akin to those used in descriptive reviews for comparing definitions across scholarly resources [18,19].

Data source

The 2022AA version of the UMLS database (accessed June 2022) includes 4,553,796 unique medical concepts, 14,276,639 distinct text names for these concepts, and expert-written definitions for 259,573 concepts, drawn from a set of 222 source vocabularies. Unique medical concepts incorporated within the UMLS link various text names denoting the same concept across different vocabularies, such as the ICF [11] and the Nursing Outcome Classification (NOC) [20]. We searched the 2022AA UMLS version using their interface browser (https://uts.nlm.nih.gov/uts/umls/home) for the term "participation" and extracted all identified UMLS concepts and definitions (if present) to a Microsoft Excel spreadsheet, together with their source vocabularies.

Data analyses

For Aim 1, we used frequency count to represent UMLS concepts pertaining to any type of participation across their corresponding vocabularies. For Aim 2, we extracted the expert-written definitions for the subset of these concepts where the UMLS included definitions, filtering out concepts without a definition provided and excluding duplicates. Each unique definition was independently rated by two research assistants (DB, SS) using deductive content analysis [21] and with a focus on child and youth participation. More specifically, raters first excluded non-English definitions and rated the remaining according to whether child and youth participation (i.e., "attendance," "involvement," or both) was represented, per the fPRC (see Figure 1). Inter-rater credibility was established through pilot rating of 25% of the UMLS concept definitions, together with a third rater (VK) with prior experience using the UMLS in participation-focused paediatric rehabilitation research. Remaining data were independently analysed (DB, SS) in three additional rounds (25% data per round), while applying investigator triangulation (key informant VK) in each round to settle discrepancies using the "majority rule." Overall inter-rater percentage agreement was 88.37%.

UMLS concept definitions rated as representing "attendance" and/or "involvement" were further screened for indication of additional representation of participation-related construct(s) (i.e., the child or youth's environment, activity competence, preferences, and/or sense of self) [14] to examine potential overlap.

UMLS concept definitions not representing "attendance" and/or "involvement" were further screened and grouped into one of two categories: (1) participation-related construct(s) [14], or (2) other (e.g., definitions including the term "participation" but without any additional context provided).

Results

Representation of participation in the UMLS

A total of 363 UMLS concepts were identified in relation to "participation" (e.g., patient participation, community participation and social participation) across 51 UMLS vocabularies, with these vocabularies most represented: Logical Observation Identifiers Names and Codes (LOINC) terminology ($n = 92$), Metathesaurus Names (MTH) ($n = 60$), and NOC ($n = 49$).

Reflection of the contemporary definition of child and youth participation and/or its related concepts

Of the 363 UMLS concepts about participation, 295 (81%) had no expert definition beyond their text names and therefore were not further analysed. Of the remaining 68 UMLS concepts with definitions, 24 UMLS concepts had multiple definitions ($n = 2$-7) from different vocabularies, 5 definitions were duplicates, and 8 included non-English definitions. This resulted in 81 definitions (covering 68 unique UMLS concepts) that were further analysed according to their representation of participation "attendance" and/or "involvement" (see Figures 1 and 2).

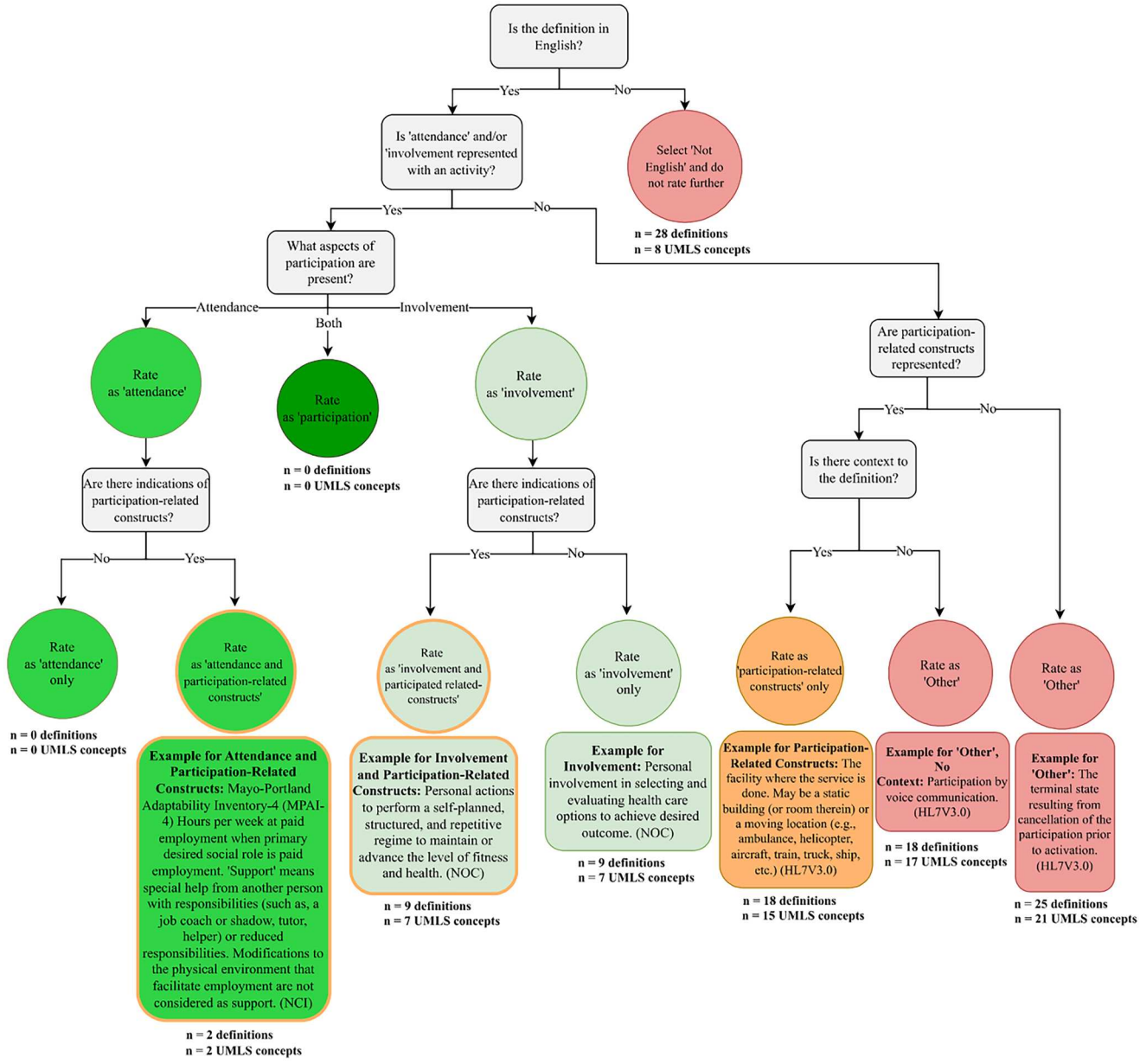

Figure 1. Data analysis process for UMLS concepts about child and youth participation, with examples per category. NCI: National Cancer Institute; NOC: Nursing Outcomes Classification; HL7V3.0: Health Level Seven Vocabulary, Version 3.0 OR HL7 Version 3.0; UMLS: Unified Medical Language System.

A total of 20 out of 81 definitions (25%; 16 UMLS concepts) explicitly represented either "attendance" or "involvement." Specifically, 2 of 81 definitions (3%; 2 UMLS concepts) explicitly represented participation "attendance" in "paid employment" and "other than paid employment," and 18 of 81 definitions (22%; 14 UMLS concepts) represented participation "involvement" in one of these 5 ways: 1) research studies ($n = 5$; 3 UMLS concepts), 2) decision-making ($n = 4$; 4 UMLS concepts), 3) community activities ($n = 3$; 2 UMLS concepts), 4) "an activity" not otherwise specified ($n = 4$; 3 UMLS concepts); or 5) "service event" or "repetitive regimes" ($n = 2$; 2 UMLS concepts). None of the 81 definitions (68 UMLS concepts) represented both "attendance" and "involvement."

Both definitions representing participation "attendance" also represented the participation-related construct of "environment/context," and 9 of 18 definitions representing participation "involvement" (50%; 7 UMLS concepts) also represented one or more participation-related constructs (i.e., 7 definitions (5 UMLS concepts) included "activity competence" only and 2 definitions (2 UMLS concepts) included multiple participation-related constructs).

Eighteen of 61 definitions that neither represent "attendance" nor "involvement" (30%; 15 UMLS concepts) were found to contain content representing one or more of the 4 participation-related constructs, and 43 of 61 (71%; 38 UMLS concepts) were labelled as "other." Figure 2 illustrates the percentages of analysed UMLS concept definitions representing child and youth participation and/or its related constructs per the fPRC [14] in relation to the total UMLS concept definitions for participation (n=81).

Discussion

Understanding participation—and participation restrictions—is key to effective paediatric rehabilitative care [11,14]. Reliable computer-readable representations of participation concepts are

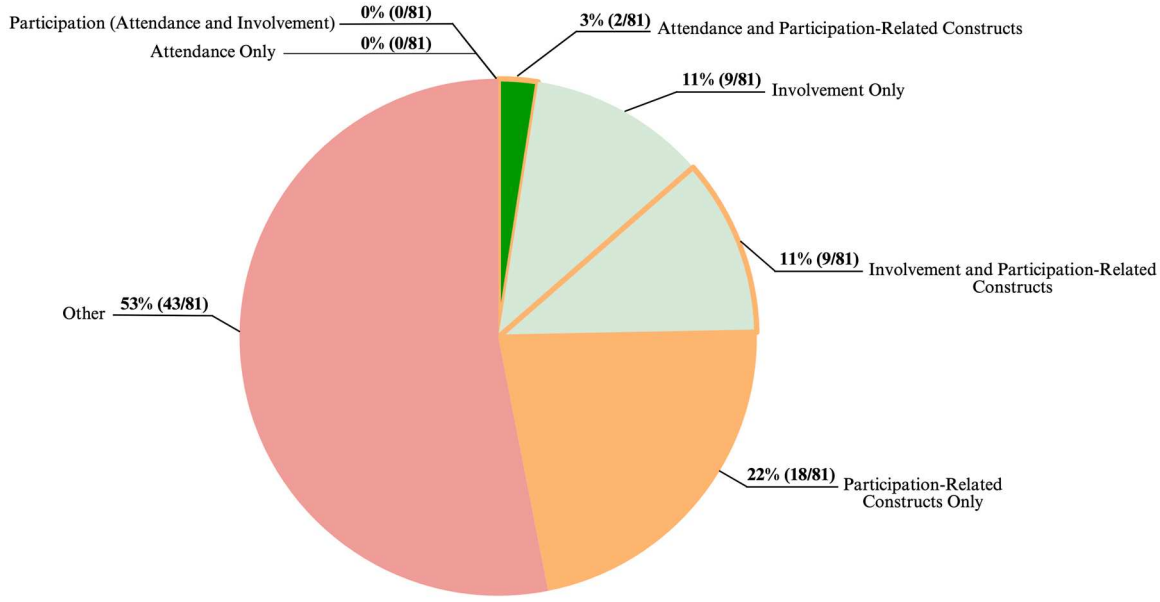

Figure 2. Percentage of analysed UMLS concept definitions representing child and youth participation and/or its related constructs. 81 definitions were analysed for 64 unique concepts whose name(s) included the word "participation."

vital for informing the increased use of artificial intelligence and data analytics in paediatric rehabilitation, and to ensure these efforts align with the participation needs of paediatric rehabilitation clients.

Our study shows that participation as defined in the fPRC is poorly represented in the UMLS, the largest and most widely used ontology in health informatics. Of 81 definitions for UMLS concepts referring to "participation," none represented both attendance and involvement (i.e., participation), only 2 (3%) represented participation "attendance" and 18 (22%) represented participation "involvement." Reflected participation contexts were either broad (e.g., "paid employment") or reflected atypical daily activities (e.g., research activities). Moreover, most of the definitions (11/20 definitions; 55%; 9/16 UMLS concepts) representing a dimension of participation (i.e., attendance or involvement) also represented a participation-related construct (typically "activity competence"). This aligns with prior paediatric rehabilitation and informatics research [14,15], reinforcing the challenge of separating participation dimensions from participation-related constructs. Overlaps between the participation-related concepts (e.g., activity competence) and "participation" hinders comparison across research [14,22] and, together with the low overall coverage of participation, limits the utility of existing UMLS concepts for communicating information related to child and youth participation between computer systems and for classification tasks in participation-focused paediatric rehabilitation [10,22,23]. Our work therefore highlights the need for further development of structured knowledge resources to better capture the specific concepts and expertise of rehabilitation disciplines, similar to a recent example of further extending existing resources to better account for mental functioning [24].

This study focused on appraising the representation of child and youth participation according to the fPRC [14], which is a commonly used contemporary participation-focused framework within paediatric rehabilitation [25]. However, there are other sources which contributed to the definition of child and youth participation [26–29]. Rating UMLS concepts according to other definitions of child and youth participation may lead to different results. In addition, this study was restricted to concepts that explicitly referred to "participation," however it is likely that other UMLS concepts may describe situations that imply participation; identifying these cases is not straightforward but may provide additional understanding of the limits of available resources. Nonetheless, it is clear that robust data analytics for paediatric rehabilitation require expanding existing vocabularies or creating new resources to extend the UMLS with concepts that reflect the contemporary definition of child and youth participation [4,5].

Conclusion

Systematic representations of concepts such as participation are key resources for advancing data reuse and analysis in paediatric rehabilitation. However, the representation of participation within the UMLS is limited and poorly aligned with the contemporary definition of child and youth participation as outlined in the fPRC [14]. Expanding ontological resources, whether within the UMLS or through developing complementary resources, to fully and exclusively represent participation dimensions (attendance and involvement) in daily life activities is needed to enable better data analytics that reflect contemporary paediatric rehabilitation practice.

Acknowledgements

The authors thank the Children's Participation in Environment Research Lab (CPERL) for their critical feedback on our data analyses approach.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the University of Illinois Chicago, in part through their Dean's Scholar Fellowship (PI: V. Kaelin), and with funds from the National Institute on Disability, Independent Living, and Rehabilitation Research (90SFGE0032-01-00, PI: V. Kaelin). NIDILRR is a Centre within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The content of this manuscript does not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

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