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SCOPING REVIEW

Common data elements of cerebral palsy registries in Arabic-speaking countries: A scoping review

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Abstract

Aim: To (1) identify and extract common data elements (CDEs) reported in registry- and population-based cerebral palsy (CP) studies in Arabic-speaking countries (ASCs), (2) compare reporting across study designs to ensure consistency of extraction and comparability of CDEs, (3) classify reporting consistency of the CDEs across six categories of frequency of reporting, and (4) assess the alignment of CDEs with data elements from international registry networks.

Method: The review was conducted using the JBI methodology for scoping reviews and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines. The Rayyan web application was used as a screening tool. Thirty-eight studies from 11 ASCs were analyzed. CDEs were extracted and grouped by frequency and thematic domains. Fisher's exact test and Cohen's kappa (κ) measured agreement across study types and with three international CP registry networks.

Results: Across 38 studies, core demographic and clinical CP classification data (age, sex, motor type, and topographical distribution) and birth-related characteristics (gestational age, birthweight, and mode of delivery) were consistently reported. Functional classifications, parental demographics, socioeconomic status, and rehabilitation services were less frequently included, particularly in population-based studies. Agreement with international registries was fair with the Australian Cerebral Palsy Register ($\kappa = 0.26$) and Global Low and Middle Income Cerebral Palsy Registers ($\kappa = 0.24$), but only slight with the Surveillance of Cerebral Palsy in Europe ($\kappa = 0.17$). Twelve elements were consistently reported across ASC studies and all three registry networks, covering demographic, perinatal, and core functional classifications.

Interpretation: ASC studies capture core CP data but remain inconsistent in reporting functional classifications, family context, and rehabilitation services. Establishing a harmonized minimum data set and registry network for ASCs would strengthen data quality, guide evidence-informed policy, and enhance both regional and global research impact.

Cerebral palsy (CP) is a neurodevelopmental disorder with a global birth prevalence estimated at around 2 per 1000 live births, with higher prevalence reported in some low- and middle-income countries and an estimated prevalence of 1.8 per 1000 live births in Arabic-speaking countries (ASCs).[1–3] Traditionally defined as a group of permanent disorders of movement and posture caused by non-progressive disturbances in the developing brain,[4] CP is

Abbreviations: ACPR, Australian Cerebral Palsy Register; ASC, Arabic-speaking country; CDE, common data element; GLM-CPR, Global Low and Middle Income Cerebral Palsy Register; MACS, Manual Ability Classification System; SCPE, Surveillance of Cerebral Palsy in Europe.

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further clarified by the Surveillance of Cerebral Palsy in Europe (SCPE) as a permanent but not unchanging motor disorder resulting from a non-progressive lesion in the immature brain.[5] A recent update to the description of CP by Dan et al.[6] emphasizes CP as a lifelong, early-onset condition with diverse motor phenotypes and associated impairments that affect participation and functioning. These evolving definitions highlight the complex and heterogeneous nature of CP and reinforce the need for comprehensive, population-based registries aligned with international standards.

Registry studies are key to understanding CP, particularly when designed to capture all eligible cases in a defined population. As a type of population-based study, they generate findings representative of a specific region.[7] Population-based studies, including registries, cross-sectional surveys, and whole-population cohorts, help describe CP prevalence, distribution, and determinants.[8] Recent evidence shows that such studies have informed the development of common data elements (CDEs) used in CP registries, supporting the inclusion of these studies in this review.[9–11] Registry studies systematically collect standardized data, often on the basis of predefined CDEs covering demographics and clinical characteristics.[12] This enables long-term surveillance, trend analysis, and regional comparisons.[13] Together, these studies support planning and improve CP clinical management.

CP registries in ASCs are notably limited; a global survey identified only one active registry in the region—the Cerebral Palsy Follow-Up Registry in Jordan—among 57 established CP registries worldwide.[14,15] This gap reflects region-specific challenges, including limited resources, fragmented data systems, and insufficient advocacy for disability surveillance.[16] These difficulties are compounded by the diversity of healthcare systems across the 22 member states of the Arab League, which further hinders coordinated data collection efforts. At the global level, inconsistencies in the data collected by existing CP registries also pose a barrier to collaboration. A comparison of three major networks—the Global Low and Middle Income Cerebral Palsy Register (GLM-CPR), the SCPE, and the Australian CP Register (ACPR)—found that only 25% of data elements were shared across all three registries.[5,17,18] Together, these regional and global gaps emphasize the urgent need to standardize CDEs to support the establishment of a CP registry network in ASCs and enable meaningful collaboration with international CP registry networks.

To address this gap, this scoping review examines how CDEs are reported in CP registries and population-based studies conducted in ASCs. It aims to (1) identify and extract CDEs reported in CP registry- and population-based studies in ASCs, (2) compare reporting across study designs to ensure methodological consistency and avoid heterogeneity in extraction, (3) classify reporting consistency of the CDEs across six categories of frequency of reporting (very high, high, moderate, variable, low, and little to no reporting), and (4) assess the alignment of CDEs with data elements from international registry networks using Cohen's kappa (κ) to quantify agreement. Grounded in the lead author's direct experience establishing the Cerebral Palsy Follow-Up Registry in Jordan and supporting emerging CP registry initiatives across the region, this review ensures contextual relevance and feasibility. Its findings will inform efforts to standardize CDEs, inform the development of a coordinated CP registry network in ASCs, and strengthen collaboration with international registry networks.

The guiding question is the following: in registry- and population-based studies of children with CP conducted in ASCs, how are CDEs reported, how consistent is their inclusion across study types, and to what extent do they align with the CDEs used in international CP registry networks?

What this paper adds

- Data elements such as the child's age, sex, motor type, and topographical distribution of cerebral palsy were consistently reported.
- Functional classification systems (e.g. GMFCS, MACS) were underreported, particularly in population-based studies.
- Socioeconomic, family, and rehabilitation-related data elements were inconsistently captured across studies.
- Common data elements (CDEs) reported in Arabic-speaking country studies shared fair agreement with the ACPR and GLM-CPR.
- CDEs reported slight agreement with SCPE, highlighting strong alignment with Australian and LMIC registries.

METHOD

The review was conducted in full accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines, with no deviations.[19] The protocol was prospectively registered with JBI and is publicly available online (https://jbi.global/sites/default/files/2025-04/PROTOCOL%20REGISTRATION%20%5B39%5D.pdf).

Ethical considerations

This systematic review did not involve primary data collection and therefore did not require ethical approval. However,

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ethical considerations related to data privacy and confidentiality were adhered to when reporting the findings.

Search strategy

A comprehensive literature search was conducted in May 2024, December 2024, and updated in March 2025. The search included academic databases, gray literature, and government/non-governmental documents. Manual searches of the reference lists of included studies were conducted to identify additional relevant studies. The databases searched were Scopus, Web of Science, Google Scholar, PubMed, Embase, and CINAHL. No time limits were applied.

Major search terms combined key concepts related to 'cerebral palsy', 'prevalence', 'population-based studies', 'registries', and the names of the 22 ASCs. Boolean operators (AND, OR) were used to link terms specific to each database. The complete search strings for population- and registry-based studies are presented in Appendix S1.

Eligibility criteria

Inclusion criteria

There were five inclusion criteria. (1) Studies published any time before December 2024. (2) Different types of CP prevalence and registry study conducted in ASCs where Arabic was the official or co-official language (primarily situated in North Africa and Western Asia) were included in the review. For this review, ASCs were defined as the 22 member states of the Arab League, all of which recognize Arabic as an official language, while also acknowledging the presence of other co-official or widely spoken languages (e.g. French, English, Kurdish, Somali, Berber). Member states currently include: Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen.[20] (3) Studies that reported CDEs related to the description, classification, or surveillance of children with CP in ASCs were included. This encompassed registry-based studies using data from regional or national CP registries or surveillance programs, as well as population-based studies reporting epidemiological or clinical data from defined populations. Population-based studies were defined broadly to include cross-sectional, case–control, cohort (retrospective or prospective), and hospital-based studies when they reflected data from a defined regional population (e.g. referral centers or systematically sampled populations). (4) Peer-reviewed journal articles, conference proceedings, and gray literature reports with no restrictions on publication dates for ongoing or continuously updated registries were included in the review. (5) Studies published in any language and with no time limitations were eligible for inclusion. While all included articles were in English or Arabic, we had planned to arrange translation for non-English/Arabic articles if necessary.

Exclusion criteria

There were five exclusion criteria. (1) Studies that were not primary, such as commentaries, letters to the editor, perspectives, and related communications. (2) Studies that did not include original data, such as review articles (scoping reviews, systematic reviews, meta-analyses, and narrative reviews). (3) Registry-based studies on the general population that were not specifically linked to CP. (4) Studies that included children with progressive neurological disorders (e.g. muscular dystrophies, leukodystrophies) or conditions not primarily resulting from disturbances in the developing brain (e.g. spinal cord injuries, peripheral neuropathies, orthopedic deformities) were excluded, as they fell outside the accepted definition of CP. (5) Inability to access the full text of a study.

Study selection

The Rayyan application[21] and PRISMA guidelines[22] were used to guide the selection of relevant articles. To minimize bias, a three-stage procedure was implemented after importing all the studies from the different databases into Rayyan: (1) manually removing duplicates by the researcher, (2) title/abstract screening, and (3) full-text review for inclusion/exclusion criteria. Two reviewers independently screened all 947 records. Interrater reliability during screening was calculated using Cohen's kappa, which was 0.91, indicating almost perfect agreement. Discrepancies ($n = 5$) were resolved through discussion and consensus. This approach ensured a comprehensive summary of existing research.

Data extraction

A preliminary set of CDEs was identified on the basis of a comprehensive review of CP registries in Jordan, Sweden, and Australia. The Jordanian registry[14]—the first in the region—was developed in collaboration with the Swedish registry,[23] and the Australian registry has also informed a proposed registry initiative in Saudi Arabia.[18] This set of common elements was used to develop an initial data coding form. Both authors piloted the form using 11 registry-based studies and iteratively refined it over multiple meetings to ensure shared understanding, consistency, and completeness. On the basis of discussions and feedback during this pilot phase, several modifications were made to the structure, definitions, and organization of the coding categories before finalization. This ensured the inclusion of relevant variables found in the registries in ASCs. Once the researchers finalized the data coding form, the two reviewers performed data extraction independently (Appendix S2). Each study

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was coded independently by each reviewer, noting which CDEs were included in the studies, how the investigators described these features, and where the features were found in the manuscripts (e.g. page numbers, table numbers). Interrater agreement averaged 95% before disagreements were discussed. Disagreements between reviewers were resolved through discussion until 100% consensus was reached for all core elements. Consistent with the PRISMA-ScR guidelines, no critical appraisal of included sources was conducted, as the purpose of this scoping review was to map existing literature rather than assess the quality of individual studies.

Data synthesis

The data coding for this review involved several steps to synthesize CDEs reported in both CP registry- and population-based studies in ASCs. Given this variability, CDEs were grouped by frequency of reporting to identify consistently used elements across the studies. We focused on four domains: child and family demographics, birth-related data, CP types and functions, and medical and rehabilitation services.

The frequency of reporting CDEs in CP registry- and population-based studies from ASCs was compared using Fisher's exact test to assess whether reporting patterns differed significantly between the two study types. This analysis was conducted to evaluate the consistency across the two primary data sources and to determine the appropriateness of combining data from both study types to generate the list of CDEs. Significant differences would indicate non-comparability between the two sources, requiring standardization before data could be pooled, whereas no differences would support the validity of generating a unified CDE list across both study types.

The CDEs identified from both CP registry- and population-based studies in ASCs were categorized according to frequency of reporting across all studies. Five reporting frequency categories were applied: very high (80–100%), high (60–79%), moderate (40–59%), low (20–39%), and little to none (0–19%). These thresholds, adapted from consensus guidelines used in scoping reviews and Delphi studies, differentiate between well-established, emerging, and under-reported CDEs. Given the limited number of registry-based studies in ASCs, this approach allowed a more comprehensive assessment of regional reporting patterns to inform standardization of CDEs.[24]

The agreement between CDEs reported in ASC studies and those reported in international CP registry networks (ACPR, GLM-CPRs, SCPE) was assessed using Cohen's kappa. For each of the 85 CDEs identified by Goldsmith et al.,[15] reporting in the three international CP registry networks was extracted directly from published sources (Appendix S3), whereas reporting in ASCs was independently coded by two researchers, with consensus reached on discrepancies. Each CDE was coded as 'reported = 1' or 'not reported = 0', serving as the subject, while ASC studies and each registry acted as the two raters. Agreement was interpreted as 0.01 to 0.20 = slight, 0.21 to 0.40 = fair, 0.41 to 0.60 = moderate, 0.61 to 0.80 = substantial, and 0.81 to 1.00 = almost perfect.[25] We report kappa, its standard error, 95% confidence interval (CI), standardized κ, and percentage agreement for each 'ASC–registry network' comparison. We also identified the subsets of CDEs that were consistently reported across ASCs and all three registry networks.

RESULTS

Study selection

The initial search identified 1925 articles. After removing duplicates, 947 articles remained. Titles and abstracts were screened, which narrowed the number of relevant papers to 30 articles for full-text review. Applying the inclusion and exclusion criteria further refined the selection to 27 studies. Additionally, a manual search of the reference lists from related reviews and articles identified 11 more studies, which were also included in the review (Figure S1). A summary of the aims, methods, and key results of the 38 studies is included in Appendix S4.

Table 1 summarizes the key characteristics of the 38 included studies, which were conducted in 11 ASCs. Most studies were conducted in Egypt (26.3%), Jordan (23.7%), and Saudi Arabia (21.1%), while only single studies were reported from Kuwait, Oman, Tunisia, Palestine, Morocco, and Libya. There was an almost equal distribution of papers between population-based (52.6%) and registry-based (47.4%) studies. While the studies varied in design and objectives, all met the inclusion criteria, and the synthesis focused on identifying commonly reported elements across the different types of study. Regarding sample size, the most frequent categories were studies with 101 to 150 participants (21.1%) and those with more than 300 participants (21.1%). For child age, more than a quarter of studies (26.3%) focused on children aged 0 to 5 years, followed by 16 to 20 years (21.1%) and 6 to 10 years (18.4%).

Identification and comparison of CDEs reported in ASC studies

Table 2 provides a comparative summary of the number and percentage of registry- and population-based studies that reported each CDE, with p-values for statistical significance. For 88% of the CDEs (33 elements), no statistically significant differences in reporting frequency were observed between study types. Child demographic data were the most consistently reported CDEs, with child age and sex appearing in nearly all studies. In contrast, information related to parents' ages, education, and socioeconomic status was less frequently reported, particularly in registry-based studies. A statistically significant difference was observed in reporting parents' ages, which was reported in 50%

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TABLE 1 Selected characteristics of studies and study participants included in the review.

Study characteristics	*n*	%
Country		
Egypt	10	26.3
Jordan	9	23.7
Saudi Arabia	8	21.1
Iraq	3	7.9
Sudan	2	5.3
Libya	1	2.6
Morocco	1	2.6
Palestine	1	2.6
Tunisia	1	2.6
Oman	1	2.6
Kuwait	1	2.6
Type of study		
Registry-based	18	47.4
Population-based	20	52.6
Number of participants		
0–50	2	5.3
51–100	5	13.2
101–150	8	21.1
151–200	5	13.2
201–250	5	13.2
251–300	3	7.9
301+	8	21.1
Not specified	2	5.3
Child's sex (male)		
50–54%	5	13.2
55–60%	17	44.7
61–65%	7	18.4
66%+	2	5.3
Not specified	7	21.1
Child's age		
0–5 years	10	26.3
6–10 years	7	18.4
11–15 years	5	13.2
16–20 years	8	21.1
Not specified	8	21.1

of population-based studies compared with only 17% of registry-based studies ($p = 0.04$).

Birth-related characteristics such as birthweight, gestational age, and mode of delivery were reported in both study types, with no significant differences observed. Similarly, both study types frequently reported the type of CP, defined by the predominant motor impairment (spastic, dyskinetic, or ataxic) and topographical distribution (hemiplegia, diplegia, or quadriplegia). In contrast, significant differences were found in reporting functional classification systems: registry-based studies reported the Gross Motor Function Classification System (GMFCS) level in 100% of cases compared with only 25% of population-based studies ($p < 0.001$). The Manual Ability Classification System (MACS) level was also more frequently reported in registry-based studies (61% vs 5%, $p < 0.001$), as was the Viking Speech Scale, which was reported only in registry-based studies (39% vs 0%, $p = 0.003$).

Reporting on medical and rehabilitation service elements was generally inconsistent across studies. Physical therapy was more frequently documented in registry-based studies, although this difference did not reach statistical significance. Other services—such as occupational therapy, speech-language pathology, and orthotics and prosthetics—were rarely reported in either type of study.

Classification of CDEs reported in ASC studies

Table 3 summarizes the CDEs by frequency of reporting across all included studies, highlighting patterns rather than implying clinical importance or priority. A high frequency of reporting (≥80%) was observed for core variables such as child age (97%), child sex (95%), motor type of CP (85%), and topographical distribution (82%). These elements were the most consistently used across both population- and registry-based studies.

Moderately high frequency of reporting (60–79%) was observed for key birth-related characteristics, including gestational age (74%), birthweight (69%), and mode of delivery (64%), indicating that these variables were frequently prioritized.

Several elements showed moderate frequency of reporting (40–59%), such as the GMFCS (59%), associated health conditions (59%), and complications during delivery (54%). This indicates recognition of their clinical value, although their inclusion was not consistent across studies.

Lower frequency of reporting (20–39%) was found for several important but underreported variables. These included parents' ages (33%), socioeconomic status (31%), and MACS level (31%). Physical therapy services were also underreported (26%), limiting insights into intervention exposure.

Finally, there was little to no reporting (<20%) for a wide range of clinical, therapy-related, and classification variables. These include the Viking Speech Scale (18%), maternal age (18%), and services such as occupational therapy (15%), speech–language pathology (10%), and orthotics and prosthetics (13%). The Communication Function Classification System (8%) and respiratory therapy (3%) were the least commonly reported.

Agreement between CDEs in ASC studies and international registries

Table 4 summarizes the agreement between CDEs reported in ASC studies and those reported in the three international

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TABLE 2 Comparative reporting of common data elements between registry- and population-based studies in Arabic-speaking countries.

Common data elements	Population-based studies, *n* (%)	Registry-based studies, *n* (%)	Fisher's exact test (*p*)
Child and family demographics			
Child date of birth	1 (5)	5 (28)	0.08
Child sex	20 (100)	17 (94)	0.47
Child age	20 (100)	17 (94)	0.47
Parents' age	10 (50)	3 (17)	**0.04**[a]
Parents' education	7 (35)	3 (17)	0.28
Socioeconomic status	8 (40)	4 (22)	0.31
Birth-related characteristics			
Maternal age	5 (25)	2 (11)	0.41
Consanguinity	9 (45)	8 (44)	1.00
Place of birth	12 (60)	6 (33)	0.12
Multiple births	11 (55)	6 (33)	0.21
Birthweight	15 (75)	12 (67)	0.72
Mode of delivery	14 (70)	11 (61)	0.73
Gestational age	17 (85)	12 (67)	0.26
Complications during delivery	14 (70)	7 (39)	0.10
Types and classification of cerebral palsy			
Motor type of cerebral palsy	17 (85)	16 (89)	1.00
Topographical distribution	16 (80)	16 (89)	0.66
Gross Motor Function Classification System	5 (25)	18 (100)	**<0.001**[a]
Manual Abilities Classification System	1 (5)	11 (61)	**<0.001**[a]
Viking Speech Scale	0 (0)	7 (39)	**0.003**[a]
Communication Function Classification System	0 (0)	3 (17)	0.10
Associated health conditions	13 (65)	10 (56)	0.74
Medical and rehabilitation services			
Neurology conditions	11 (55)	5 (28)	0.11
Neurology medications	3 (15)	4 (22)	0.69
Neurology investigations	4 (20)	1 (6)	0.34
Neurology surgeries	2 (10)	0 (0)	0.49
Orthopedic conditions	2 (10)	2 (11)	1.00
Orthopedic medications	2 (10)	2 (11)	1.00
Orthopedic surgeries	3 (15)	1 (6)	0.61
Physical therapy	3 (15)	7 (39)	0.14
Occupational therapy	3 (15)	3 (17)	1.00
Speech and language pathology	3 (15)	1 (6)	0.61
Orthotics and prosthetics	3 (15)	2 (11)	1.00
Respiratory therapy	0 (0)	1 (6)	0.47

[a]The *p*-values in bold type indicate the statistical significance of the differences between the population- and registry-based studies for each variable.

registry networks. Fair agreement was observed with the ACPR ($\kappa = 0.26$; 95% CI 0.07–0.44) and GLM-CPRs ($\kappa = 0.24$; 95% CI 0.11–0.37), whereas only slight agreement was found with the SCPE ($\kappa = 0.17$; 95% CI −0.04 to 0.37). These findings indicate closer alignment with Australian and low- and middle-income country registries than with European reporting practices. Table 5 shows the 12 CDEs consistently reported across ASC studies and all three registry networks, covering basic demographic, perinatal, and core clinical elements such as date of birth, sex, birthweight, gestational age, and functional classifications (GMFCS, MACS). However, several domains were underreported in ASC studies, including vital status, neonatal indicators (e.g. Apgar score, care in neonatal intensive care unit), and long-term functional outcomes such as education, sensory impairments, and comorbidities, emphasizing areas where alignment with international CP registry networks remains limited (see Appendix S3).

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TABLE 3 Common data elements reported in registry- and population-based studies in Arabic-speaking countries, grouped by reporting frequency and thematic domains.

Common data elements	Domain of common data elements	Both types of study
Very high frequency of reporting (80–100%)		
Child age	Demographic characteristics	97
Child sex	Demographic characteristics	95
Motor type of cerebral palsy	CP types and functions	85
Topographical distribution	CP types and functions	82
High frequency of reporting (60–79%)		
Gestational age	Birth-related data	74
Birthweight	Birth-related data	69
Mode of delivery	Birth-related data	64
Moderate frequency of reporting (40–59%)		
Gross Motor Function Classification System	CP types and functions	59
Associated health conditions	CP types and functions	59
Complications during delivery	Birth-related data	54
Place of birth	Birth-related data	46
Consanguinity	Birth-related data	44
Multiple births	Birth-related data	44
Neurology conditions	Medical and rehabilitation services	41
Low frequency of reporting (20–39%)		
Parents' age	Demographic characteristics	33
Socioeconomic status	Demographic characteristics	31
Manual abilities classification system	CP types and functions	31
Parents' education	Demographic characteristics	26
Physical therapy	Medical and rehabilitation services	26
Little to no reporting (0–19%)		
Maternal age	Birth-related data	18
Viking Speech Scale	CP types and functions	18
Neurology medications	Medical and rehabilitation services	18
Child date of birth	Birth-related data	15
Occupational therapy	Medical and rehabilitation services	15
Neurology investigations	Medical and rehabilitation services	13
Orthotics and prosthetics	Medical and rehabilitation services	13
Orthopedic conditions	Medical and rehabilitation services	10
Orthopedic medications	Medical and rehabilitation services	10
Orthopedic surgeries	Medical and rehabilitation services	10
Speech and language pathology	Medical and rehabilitation services	10
Communication Function Classification System	CP types and functions	8
Neurology surgeries	Medical and rehabilitation services	5
Respiratory therapy	Medical and rehabilitation services	3

DISCUSSION

This scoping review found that while core demographic and clinical CDEs were consistently reported in ASC studies, variability remained across other domains. Functional classifications differed between study types, perinatal and risk factor data were inconsistently captured, and socioeconomic and family indicators were rarely included. Rehabilitation-related CDEs showed very low reporting, and motor type and distribution were documented mainly through traditional categories rather than SCPE-aligned systems. Benchmarking with ACPR, GLM-CPRs, and SCPE demonstrated only fair to slight agreement, with just 12 CDEs consistently shared across all data sets.[15,26] Longitudinal and outcome-related elements, such as education, participation, and follow-up health indicators,

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TABLE 4 Agreement between the frequency of reporting common data elements in ASC studies and international CP registry networks.

	Agreement with ASCs (%)	Weighted kappa	95% CI	Standardized kappa
ACPR	62.35	0.26	0.07–0.44	2.72
GLM-CPRs	55.29	0.24	0.11–0.37	3.72
SCPE	61.18	0.17	−0.04 to 0.37	1.57

Abbreviations: ACPR, Australian Cerebral Palsy Register; ASC, Arabic-speaking country; CI, confidence interval; CP, cerebral palsy; GLM-CPRs, Global Low and Middle Income Cerebral Palsy Registers; SCPE, Surveillance of Cerebral Palsy in Europe.

TABLE 5 CDEs reported across ASC studies and all three international CP registry networks.

Domain	CDEs consistently reported
Child information	Date of birth; sex
Parent information and history	Mother's age at time of delivery
Delivery	Place of birth/delivery (e.g. hospital); gestational age; birthweight; multiple birth
Diagnosis and clinical information	MRI; PNN-CP; epilepsy; GMFCS; MACS

Abbreviations: ASC, Arabic-speaking country; CDEs, common data elements; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; MRI, magnetic resonance imaging; PNN-CP, postneonatal cause of cerebral palsy.

were seldom reported, further limiting comparability and long-term evaluation. These findings point to clear priorities for strengthening CDE reporting and advancing CP registry development in ASCs.

Functional classification systems were the only CDEs with significantly different reporting frequencies between registry- and population-based studies, highlighting the need to standardize their reporting in ASC studies. GMFCS level was reported in 100% of registry-based studies, compared with only 25% of population-based studies. Similarly, MACS level was reported in 61% of registry-based studies, but in just 5% of population-based studies. This disparity probably reflects the clinician-led nature of CP registries in ASCs, which focus more on clinical outcomes and benefit from greater medical infrastructure.[15,27] In contrast, population-based studies often aim to estimate prevalence and may lack the clinical expertise or resources to apply functional classification systems.[28,29] Despite this difference, most other CDEs, including demographic, diagnostic, and perinatal data, were consistently reported across study types. This supports the decision to include both types of study and confirms that the findings reflect a coherent data set.[9–11] Bridging classification system gaps through targeted training and investment will improve the comparability and clinical utility of the CP registry network in ASCs.

CDEs related to perinatal and risk factors showed high to moderate reporting across ASC studies. Birth-related variables such as gestational age, birthweight, and mode of delivery were frequently reported, whereas other pre- and perinatal risk factors such as parental consanguinity, neonatal intensive care, maternal complications, place of birth, and multiple births were reported in fewer than 60% of studies. This contrasts with CP surveillance systems in high-income settings, where detailed perinatal data are systematically linked to neonatal and obstetric records.[12] In ASC studies, the limited reporting of these risk factors probably reflects fragmented data systems and weak integration between maternal and child health services.[30] Moreover, CP etiology in ASCs is multidimensional, involving both genetic and preventable factors. Studies from Saudi Arabia and Palestine have identified parental consanguinity, congenital anomalies, low birthweight, preterm birth, and perinatal hypoxia as key risk factors.[31,32] Expanding and standardizing the collection of perinatal and genetic data is therefore essential for strengthening CP surveillance, supporting prevention strategies, and guiding early intervention efforts across the ASCs.

CDEs related to socioeconomic and family contexts showed low reporting frequencies in ASC studies, limiting equity-focused analysis. Variables such as parents' ages, education level, and household income were included in fewer than 40% of studies, which is lower than the reporting rates observed in high-income CP registry settings.[7,33] This gap may reflect structural and cultural barriers in ASCs, including limited access to reliable family data and concerns about the sensitivity of socioeconomic information. Without these contextual elements, it is difficult to interpret outcomes in a broader social framework or assess disparities in access to care. Addressing this gap through the inclusion of family and socioeconomic indicators in future minimum data sets is essential to support equity analyses and inform policy development.

Rehabilitation-related CDEs showed very low reporting frequency across ASC studies, despite their central relevance to CP management. Data on services such as respiratory therapy, speech-language pathology, and orthotics and prosthetics were reported in fewer than 15% of studies. This underreporting probably reflects both gaps in service provision and in the limited integration of rehabilitation indicators in research designs, rather than a lack of clinical importance.[14,30] Global frameworks, such as the World Health Organization's International Classification of Functioning, Disability and Health, emphasize the need to monitor access to and outcomes of rehabilitation services.[34] The underreporting of these elements in ASC studies restricts the evaluation of care pathways, resource allocation, and system responsiveness. Future CP registry networks in ASCs should prioritize capturing rehabilitation-related data to guide

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health system planning and support advocacy for equitable service access.

CDEs related to motor type and topographical distribution were consistently reported across ASC studies, although most used traditional categories such as spastic, dyskinetic, and ataxic CP, alongside unilateral or bilateral. These classifications reflect longstanding clinical practice in ASCs, where motor type and distribution are documented separately, but they are not aligned with international registry network standards. In contrast, the SCPE classification system used in many international registries integrates motor type and distribution into unified categories such as spastic unilateral and spastic bilateral, enhancing consistency and comparability. A gradual shift towards SCPE-aligned classification in ASC studies and future registry networks is recommended to promote data harmonization and strengthen international comparability.

CDE benchmarking showed only fair agreement between ASCs and ACPR and GLM-CPRs, and slight agreement with SCPE, consistent with the global variability in reporting described by Goldsmith et al.[15] The fair agreement with ACPR and GLM-CPRs may reflect shared emphasis on core perinatal and clinical variables, whereas the weaker alignment with SCPE probably relates to its broader inclusion of follow-up and outcome-based indicators that require more advanced registry infrastructures. These patterns may also reflect the heterogeneity of socioeconomic contexts across ASCs, which range from high- to middle- to low-income settings, influencing the feasibility of collecting longitudinal and outcome-oriented data. Importantly, 12 CDEs, including basic demographic, perinatal, and functional classification measures (e.g. date of birth, sex, gestational age, birthweight, magnetic resonance imaging, GMFCS, MACS), were consistently reported across ASC studies and all three international registry networks, providing a small but concrete foundation for global harmonization. Given that most ASC studies focused on prevalence and basic clinical profiling, these results suggest that benchmarking should be seen less as a process of enforcing uniformity and more as a means to identify feasible entry points for harmonization. The gaps, particularly in domains such as vital status, neonatal indicators, and long-term outcomes, highlight opportunities to strengthen alignment with international standards. A phased strategy may be most realistic, beginning with core elements where agreement already exists and gradually moving towards the inclusion of outcome-oriented elements with the development of the registry network for ASCs.

Finally, CDEs related to longitudinal and outcome domains were rarely reported in ASC studies, with few capturing variables such as education, participation, functional communication, or follow-up health indicators.[14] This gap limits the ability to assess the long-term impact of CP and to evaluate the effectiveness of interventions. Longitudinal data are increasingly recognized as essential for health system responsiveness and disability-inclusive policy development.[35] Strengthening follow-up systems and embedding outcome monitoring in the future registry network in ASCs will therefore be crucial to support evidence-based care and service planning across the lifespan.

This scoping review provides the first comprehensive mapping of CDEs in CP research across ASCs, combining elements from both registry- and population-based studies and benchmarking findings against international CP registry networks to offer novel insights into reporting consistency, alignment with global standards, and priorities for future harmonization. The inclusion of studies from 11 ASCs, representing both clinical and epidemiological perspectives, strengthens the breadth and regional relevance of the findings.

However, several limitations should be acknowledged. Most ASCs lack fully developed national CP registries except for Jordan,[14] which limits the ability to evaluate registry operations, data governance, and quality assurance. The review assessed whether CDEs were reported but did not evaluate the completeness, consistency, or accuracy of reporting in individual studies. Variation in study objectives may also have influenced whether certain CDEs were included, making it difficult to distinguish study-specific scope from systemic reporting gaps. In addition, heterogeneity in registry structures, definitions, and purposes—both in ASCs and across international networks—may have affected agreement levels. Finally, this review did not include individuals with lived experience of CP, as the objective was to map and synthesize published research. Their engagement will be essential in the next phase through stakeholder workshops with families, clinicians, and policy-makers to co-develop a regionally relevant registry network that reflects ASC priorities and supports inclusive, person-centered care.

For research, the consistent reporting of core CDEs such as child age, sex, motor type, and topographical distribution demonstrates the feasibility of establishing a standardized minimum data set across ASC studies. These core elements should serve as a foundation for future registry network development and regional collaborations. Further research is needed to promote the standardized use of functional classifications (GMFCS, MACS), strengthen reporting of socioeconomic, perinatal, and rehabilitation-related data, and expand inclusion of longitudinal outcomes such as education, participation, and quality of life.

For policy, the variability in reporting across domains emphasizes the need for ministries of health and policymakers to embed CDEs in national health information systems and CP registries. Prioritizing the inclusion of socioeconomic and service-related indicators, such as parental education, household income, and access to rehabilitation, will enable monitoring of equity, inform prevention strategies, and guide early intervention. Developing an Arabic CP registry network can further support harmonization with global standards while reflecting regional realities.

For practice, the limited use of functional classification systems in population-based studies and the underreporting of rehabilitation-related indicators highlight the need for investment in training and consistent clinical documentation. Integrating caregiver-reported outcomes and lived

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experience data into registries will strengthen the relevance of information for clinical decision-making, service planning, and person-centered care.

CONCLUSIONS

This scoping review mapped CDEs reporting in CP research across ASCs, highlighting both progress and gaps. Core elements such as child age, sex, motor type, and topographical distribution were consistently reported, supporting the feasibility of developing a regional minimum data set. In contrast, socioeconomic indicators, rehabilitation services, functional outcomes, and longitudinal measures were underreported, reflecting broader challenges in fragmented health systems.

Agreement analysis showed fair alignment with the ACPR and GLM-CPRs and only slight alignment with the SCPE, emphasizing the need for a unified minimum data set that balances global standards with regional realities. Adoption of such a data set would strengthen epidemiological monitoring, service planning, and collaborative research, enabling ASCs to contribute more effectively to international CP registry networks. Achieving this requires commitment from clinicians, researchers, and policy-makers to prioritize data-driven decision-making and invest in sustainable registry infrastructure. Strengthening these systems will enhance the evidence base for children with CP and position ASCs as key partners in the global CP knowledge ecosystem.

DATA AVAILABILITY STATEMENT

Data is available upon request from the authors.

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REFERENCES

1. Jensen A. Cerebral palsy – brain repair with stem cells. J Perinat Med. 2023;51(6):737–51.
2. Paton MCB, Finch-Edmondson M, Fahey MC, London J, Badawi N, Novak I. Fifteen years of human research using stem cells for cerebral palsy: a review of the research landscape. J Paediatr Child Health. 2021;57(2):295–6.
3. Mushta SM, King C, Goldsmith S, Smithers-Sheedy H, Badahdah AM, Rashid H, et al. Epidemiology of cerebral palsy among children and adolescents in Arabic-speaking countries: a systematic review and meta-analysis. Brain Sci. 2022;12(11):1515.
4. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M. A report: the definition and classification of cerebral palsy, April 2006. Dev Med Child Neurol Suppl. 2007;109:8–14.
5. Cans C. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol. 2000;42(12):816–24.
6. Dan B, Rosenbaum P, Carr L, Gough M, Coughlan J, Nweke N. Proposed updated description of cerebral palsy. Dev Med Child Neurol. 2025;67(6):700–9.
7. Hollung SJ, Given J. Insights from the epidemiology of cerebral palsy: navigating the advantages and limitations of registry versus administrative health data. Paediatr Perinat Epidemiol. 2023;38(1):31–3.
8. Kirby RS. Providing a population-based perspective on the perinatal factors associated with cerebral palsy. Dev Med Child Neurol. 2014;56(8):710–1.
9. Lidbeck C, Häbel H, Martinsson C, Pettersson K, Löwing K. Motor development in children with cerebral palsy in Sweden: a population-based longitudinal register study. Children (Basel). 2023;10(12):1990.
10. Gray C, Leonard H, Cooper MN, Rai D, Glasson EJ. The application of population data linkage to capture sibling health outcomes among children and young adults with neurodevelopmental conditions: a scoping review. Int J Popul Data Sci. 2025;10(1):2002.
11. Kim S, Steffen K, Gottschalk-Henneberry L, Miros J, Leger K, Robichaux-Viehoever A, et al. Standardized clinical data capture to describe cerebral palsy. medRxiv [Internet]. 2024 Aug 9 [cited 2025 Jul 14]. Available from: https://pubmed.ncbi.nlm.nih.gov/39211855/
12. Arnaud C, Ehlinger V, Perraud A, Kinsner-Ovaskainen A, Klapouszczak D, Himmelmann K, et al. Public health indicators for cerebral palsy: a European collaborative study of the Surveillance of Cerebral Palsy in Europe network. Paediatr Perinat Epidemiol. 2023;37(5):404–12.
13. Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. Dev Med Child Neurol. 2013;55(6):509–19.
14. Almasri NA, Saleh M, Abu-Dahab S, Malkawi SH, Nordmark E. Development of a cerebral palsy follow-up registry in Jordan (CPUP-Jordan). Child Care Health Dev. 2018;44(1):131–7.
15. Goldsmith S, Smithers-Sheedy H, Almasri N, Andersen GL, Diviney L, Gincota EB, et al. Cerebral palsy registers around the world: a survey. Dev Med Child Neurol. 2024;66(6):765–77.
16. Hassanein SMA, El-Sobky TA. Towards creation of national cerebral palsy registries in Arab countries: what is missing? World J Pediatr. 2022;18(3):222–4.
17. Jahan I, Muhit M, Hardianto D, Laryea F, Chhetri AB, Smithers-Sheedy H, et al. Epidemiology of cerebral palsy in low- and middle-income countries: preliminary findings from an international multi-centre cerebral palsy register. Dev Med Child Neurol. 2021;63(11):1327–36.
18. Smithers-Sheedy H, McIntyre S, Gibson C, Meehan E, Scott H, Goldsmith S, et al. Findings from the Australian Cerebral Palsy Register, birth years 1993–2006. Dev Med Child Neurol. 2016;58 Suppl 2:5–10.
19. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–73.
20. Wikipedia contributors. Arab League. Wikipedia [Internet]. 2025 Jan 6 [cited 2025 Jan 7]. Available from: https://en.wikipedia.org/w/index.php?title=Arab_League&oldid=1267830852
21. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan: a web and mobile app for systematic reviews. Syst Rev. 2016;5(1):210.
22. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med. 2009;151(4):264–9.
23. Alriksson-Schmidt AI, Arner M, Westbom L, Krumlinde-Sundholm L, Nordmark E, Rodby-Bousquet E, et al. A combined surveillance program and quality register improves management of childhood disability. Disabil Rehabil. 2017;39(8):830–6.
24. Diamond IR, Grant RC, Feldman BM, Pencharz PB, Ling SC, Moore AM, et al. Defining consensus: a systematic review recommends methodologic criteria for reporting of Delphi studies. J Clin Epidemiol. 2014;67(4):401–9.
25. McHugh ML. Interrater reliability: the kappa statistic. Biochem Med (Zagreb). 2012;22(3):276–82.
26. Katangwe TJ, Kruger M, Chimowa T, Maposa I, Van Toorn R, Solomons R, et al. Variables included in cerebral palsy registries globally: a scoping review. Dev Med Child Neurol. 2024;66(9):1148–56.

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27. Paul S, Nahar A, Bhagawati M, Kunwar AJ. A review on recent advances of cerebral palsy. Oxid Med Cell Longev. 2022;2022:2622310.
28. Atia A, Abogrein A, Alssoghaiar M, Akroush M, Alsagheer M. Birth incidence of cerebral palsy in Tripoli, Libya: a population-based study. Khalij-Libya J Dent Med Res. 2021;5(1):1–5.
29. Kissani N, Ouadika RJB, Arabi H, Khalfaoui S, Abdelfettah Y. Cerebral palsy in Morocco: state of affairs and challenges. Rom J Pediatr. 2022;71(2):182–7.
30. Hassanein SMA, El-Sobky TA. Towards creation of national cerebral palsy registries in Arab countries: what is missing? World J Pediatr. 2022;18(3):222–4.
31. Al-Rajeh S, Bademosi O, Awada A, Ismail H, Al-Shammasi S, Dawodu A. Cerebral palsy in Saudi Arabia: a case-control study of risk factors. Dev Med Child Neurol. 1991;33(12):1048–52.
32. Daher S, El-Khairy L. Association of cerebral palsy with consanguineous parents and other risk factors in a Palestinian population. East Mediterr Health J. 2014;20(7):420–6.
33. Schiariti V, Fowler E, Brandenburg JE, Levey E, McIntyre S, Sukal-Moulton T, et al. A common data language for clinical research studies: the NINDS and AACPDM cerebral palsy common data elements version 1.0 recommendations. Dev Med Child Neurol. 2018;60(10):976–86.
34. World Health Organization. International classification of functioning, disability and health: ICF. Geneva: WHO; 2010.
35. Zwicker J, Oskoui M. Addressing heterogeneous needs using cerebral palsy registers. Dev Med Child Neurol. 2017;59(5):458–9.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Complete search strategy for population-based and registry-based studies.

Appendix S2: Coding form for ascertaining core cerebral palsy registry elements.

Appendix S3: Benchmarking of common data elements reported in Arabic-speaking countries against three international cerebral palsy registry networks.

Appendix S4: Summary of studies included in the scoping review.

Figure S1: PRISMA-ScR flow diagram illustrating the identification, screening, eligibility, and inclusion of studies in the scoping review.

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