ICF Core Sets for the assessment of functioning of adults with cerebral palsy

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ABBREVIATIONS

| ICF | International Classification of |
|-----|---------------------------------|
| | Functioning, Disability and |
| | Health |
| WH0 | World Health Organization |

AIM To report on the results of the online international consensus process to develop the comprehensive and brief International Classification of Functioning, Disability and Health (ICF) Core Sets for adults with cerebral palsy (CP).

METHOD An online iterative decision-making and consensus process involved 25 experts, including clinicians and researchers working with adults with CP, an adult with CP, and the parents of adults with CP from all six regions of the World Health Organization. The most relevant categories were selected from a list of 154 unique second-level candidate categories to develop the ICF Core Sets for adults with CP. This list resulted from evidence gathered during four preparatory studies, that is, a systematic literature review, a qualitative study, an expert survey, and an empirical study.

RESULTS The consensus process resulted in the comprehensive ICF Core Set containing 120 second-level ICF categories: 33 body functions; eight body structures; 50 activities and participation; and 29 environmental factors, from which the most essential categories, 33 in total, were selected for the brief ICF Core Set. For body functions, most of the categories were mental functions and neuromusculoskeletal and movement-related functions. Body structures were mostly related to movement. All the chapters of the activities and participation component were represented, with mobility and self-care as the most frequently covered chapters. For environmental factors, most of the categories addressed products and technology and services, systems, and policies.

INTERPRETATION The comprehensive and brief ICF Core Sets for adults with CP were created using a new online version of an established ICF Core Set consensus process. These Core Sets complement the age-specific ICF Core Sets for children and young people with CP and will promote standardized data collection worldwide.

Cerebral palsy (CP) is one of the most common causes of childhood-onset physical disability, with a prevalence of 2 to 2.5 per 1000 live births in high-income countries.^{1–3} The non-progressive impairment of the developing fetal or infant brain causes atypical development of movement and postural control, resulting in activity limitation.⁴ Motor disorders are often accompanied by disturbances of cognition, communication, and behaviour. Many individuals with CP experience the long-term consequences of the condition, requiring health care services to support their functioning.⁵

Many individuals (approximately 75%) with CP are adults because of an increase in life expectancy.^{6,7} In the

long term, adults with CP experience deterioration of functioning and health, such as in mobility and self-care activities, an increase in pain⁸ and fatigue,^{9,10} and an increased risk for a range of comorbidities (e.g. hypertension and diabetes).¹¹ Previously, research and health care for CP primarily focused on children and young people; however, in the past decades, attention has broadened towards a lifespan perspective on the impact of CP.¹²

Adults with CP present with a broad spectrum of functioning aspects and disability involving body functions, activities, and participation. Factors that impact an individual's level of functioning are a combination of motor

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functioning problems and intellectual disability¹³ that interact with contextual factors, for example, environmental accessibility and use of technical devices.¹⁴ Over the past 20 years, research on adults with CP has focused increasingly on contextual factors,¹² highlighting the importance of a comprehensive approach to functioning and disability in research and clinical practice. The International Classification of Functioning, Disability and Health (ICF)¹⁵ fosters this approach while also facilitating a comprehensive understanding of functioning and disability (henceforth referred to as 'functioning'). The use of the ICF can improve health care service delivery as shown in clinical rehabilitation practice.¹⁶

The ICF is the internationally accepted reference for assessing and reporting functioning. It reflects a comprehensive biopsychosocial model¹⁵ of functioning and can be used in clinical care,^{16–19} for example, for goal-setting or intervention planning. Functioning is described by the components body functions (b), body structures (s), and activities and participation (d); contextual factors address the components environmental (e) and personal factors. ICF categories in each component are represented by a letter (b, s, d, e) and a numeric code and are structured hierarchically according to different levels: chapter-level (e.g. b2 sensory functions and pain); second-level (e.g. b280 sensation of pain); third-level (e.g. b2801 pain in body part); or fourth-level (e.g. b28015 pain in lower limb), with increasing specificity from chapter-level to fourth-level. Personal factors are not yet classified in the ICF.¹⁵

The ICF is extensive, consisting of more than 1400 categories, which makes its use in clinical care and research cumbersome. Given this, the World Health Organization (WHO) and ICF Research Branch (www.icf-researchbranch.org) introduced the ICF Core Sets;²⁰ these are shortlists of the most relevant categories for specific health conditions selected from the full classification. These ICF Core Sets can serve as an international standard for the assessment and reporting of functioning. ICF Core Sets have been created for several health conditions, such as multiple sclerosis,²¹ traumatic brain injury,²² stroke,²³ and children and young people with CP,24 but not yet for adults with CP. Considering that children and young people with CP naturally grow into adult roles,²⁵ there is a shift of relevant outcomes for individuals with CP when they are adults; for example, other participation areas might be important, such as employment or intimate relationships, and the ICF Core Sets for children and young people with CP might not fully apply to adults. Therefore, we conducted a study to create both a comprehensive and brief ICF Core Set for adults with CP based on the specific experiences and expertise of adult-age persons with CP and the health professionals and researchers working with them.

The comprehensive ICF Core Set should include sufficient categories to comprehensively describe the functioning profile of adults with CP, yet concise enough to be practical for routine assessments. The brief ICF Core Set

What this paper adds

- Almost half of the categories of the comprehensive and brief ICF Core Sets represented the activities and participation component.
- Environmental factors and body functions were also well represented.
- Consensus process participants placed as much value on environmental factors as body functions.
- Some aspects of functioning may be underrepresented in the brief ICF Core Set as a result of the chosen 27% cut-off.

should include the fewest possible categories while still capturing the most essential categories to serve as a minimum international standard for assessing and reporting the functioning of adults with CP. The objective of this study was to reach an international consensus on the first version of the comprehensive and brief ICF Core Sets for adults with CP.

METHOD

The methodology of the WHO and ICF Research Branch was followed to develop the first version of the ICF Core Sets for adults with CP.²⁰ This scientific process involved conducting several preparatory steps, such as a systematic literature review,²⁶ a qualitative study,²⁷ an expert survey,²⁸ and an empirical study,²⁹ and included direct involvement of adults with CP and their families in defining what matters most to them.^{27,29} The results of these studies provided the evidence base for a consensus process to establish the first version of the ICF Core Sets. Due to the COVID-19 pandemic, we pioneered an online version of the original face-to-face consensus conference.²⁰

Preparatory studies

The four preparatory studies were conducted to generate an aggregated list of 'candidate' second-level ICF categories to serve as the basis for deciding on the ICF Core Sets for adults with CP and ensure that the ICF Core Sets reflected the different perspectives of the relevant stakeholders: adults with CP and their families, researchers, and health professionals treating adults with CP as well as other experts. The systematic literature review identified 72 categories in the most commonly used outcome measures reported in studies on adults with CP published between 2000 and 2017.26 The qualitative study, which involved six focus groups with adults with CP without intellectual disability and seven individual interviews with adults with CP with intellectual disability and their caregivers, identified 132 categories.²⁷ While 63 categories were identified in the survey of 126 health professionals and researchers from 32 countries across all six WHO regions,²⁸ the empirical study pinpointed 104 categories reflecting common functioning problems experienced by adults with CP with and without intellectual disability visiting health care services in the Netherlands. Thailand, Sweden, and USA.29

Altogether, the aggregated list of candidate categories consisted of 154 categories (48 body functions, nine body structures, 56 activities and participation categories, and 41 environmental factors).

Participants

The inclusion criteria for participants in the consensus process were at least 5 years of experience in working with and/or conducting research with adults with CP (aged $\geq 18y$) and fluency in English. We invited potential participants from all six WHO regions and a wide range of professional backgrounds, for example, physical medicine and rehabilitation, neurology, orthopaedics, physical therapy, occupational therapy, speech and language therapy, nursing, psychology, and other experts with experience with adults with CP and intellectual disability. We also strove for a good distribution of clinicians versus researchers. Moreover, an adult with CP and the parents of adults with CP were invited to participate.

The pool of participants from the expert survey²⁸ was used as a source to identify and invite potential participants to the consensus process. This consensus participant pool was supplemented with persons from international study consortia on adults with CP and members and former members of the Lifespan Care Committee of the American Academy of Cerebral Palsy and Developmental Medicine. From the responding experts, the project team preselected available key experts in the field of adults with CP; some experts were selected to ensure different countries of origin. A sample was drawn from the remaining respondents who accepted the invitation and met the inclusion criteria, thereby ensuring the aforementioned representation of WHO region, professional background, and CP representatives.

Decision-making process

The comprehensive and brief ICF Core Sets for adults with CP were developed using a two-part process: the comprehensive version in part one and the brief version in part two. The online decision-making and consensus process was conducted via Zoom, a cloud-based videoconferencing platform (https://zoom.us/), over a 4-week period with 1- to 3-hour sessions per week (Fig. 1).

Before starting the consensus process, participants were asked to become familiar with the ICF by completing the ICF e-learning tool provided by the WHO (https://www. icf-elearning.com/) and viewing voiced-over presentations on the preparatory studies and consensus and voting process. They also received a short summary of the presentation content during the first plenary session. The list of 154 candidate categories was also sent to participants along with the request to select for themselves the categories they thought were essential to include in the comprehensive ICF Core Set for adults with CP. The study team decided beforehand that only second-level categories would be included in the ICF Core Sets because second-level categories cover several third- and/or fourth-level categories. ICF Core Sets with second-level categories enable flexibility of use since users can take the more detailed categories corresponding to the second-level ICF Core Set category if needed.

The process for developing the comprehensive ICF Core Set consisted of a working group and a plenary session, including votes A and B respectively. Participants were allocated to three working groups of eight or nine voting participants each with a balanced representation of WHO regions, a person with CP or family of an adult with CP, professional disciplines, and sex, wherever possible. Each working group was led by a moderator (WS, ER-B, DT) and a working group assistant (LT, MR, SN).

In the working group session, participants discussed the pros and cons of including each candidate ICF category in the comprehensive ICF Core Set and voted (vote A) directly after the discussion of each specific category. For the discussion and vote, participants were asked to consider the results of the preparatory studies, commonality between some categories, relevance of a category for adults with CP with and without intellectual disability based on participants' experience, clinical utility, and cultural applicability. If a candidate category was included by at least 75% of participants, it was automatically included in the comprehensive ICF Core Set for adults with CP. Categories garnering less than 40% positive votes were automatically excluded. Categories were considered 'ambiguous' if 40% or more but less than 75% of participants affirmed inclusion of the category.

The results of vote A were presented in plenary session 2; as in the working group session, participants discussed and voted whether to include each ambiguous category (vote B). In this round, categories receiving more than 50% positive votes were added to the comprehensive ICF Core Set for adults with CP. The votes of two participants for 20% of the categories were missing due to the night-time hours of the sessions because of a 9-hour time difference.

The comprehensive version was the basis for developing the brief ICF Core Set. To prepare for this process, a voiced-over presentation briefed participants on the ranking process for developing the brief ICF Core Set, followed by a summary in plenary session 3. Two ranking rounds took place offline.

Participants were provided with an Excel file containing the comprehensive ICF Core Set categories listed in individual spreadsheets according to the ICF components. They were asked to rank the top 10 most essential ICF categories within each ICF component from 10 to 1 (with '10' being the most essential) and provide brief arguments for the top 5 categories to include and the 5 categories to definitely exclude. The ranking results were analysed using descriptive statistics to generate a common ranking (rank A). For the second ranking round, an Excel file with the newly ordered list of categories according to rank A was sent to participants with a summary of the aforementioned arguments for each category. Considering these arguments, participants again ranked the top 10 most essential ICF categories for each component to produce rank B. Striving for a feasible number of categories in the brief ICF Core Set, the study team decided a priori on a cut-off of 27% for the number of categories included in the comprehensive ICF Core Set. The team also reconfirmed the 27%



Figure 1: Decision-making process. ICF, International Classification of Functioning, Disability and Health.

cut-off with the consensus conference participants before finalizing the brief version. For transparency's sake, participants were shown several brief versions of ICF categories with cut-offs of 20%, 25%, 27%, and 33%. In the interest of feasibility in clinical practice and research and to be in line with the proportion of categories included in the brief ICF Core Set for children and young people with CP (14-18y) compared to the corresponding comprehensive version, participants decided on a 27% cut-off. The ICF Core Set for 14 to 18 year olds with CP includes 37 (27%) of the 135 categories included in the comprehensive ICF Core Set for children and young people with CP.²⁴

RESULTS

Participants

Of 421 experts invited to participate in the consensus process, 143 accepted the invitation and 89 met the inclusion criteria. From the 89 persons in the pool of experts, 25 (18 females, seven males) participated in the consensus process, representing 11 different professional backgrounds, 15 countries (Argentina, Australia, Brazil, Canada, France, Germany, Hong Kong, India, Morocco, the Netherlands, South Africa, Spain, Sweden, Turkey, USA), and all six WHO regions (Table 1).

Comprehensive ICF Core Set for adults with CP

In the comprehensive ICF Core Set for adults with CP, 120 of the 154 second-level ICF categories were included: 33 (27%) body functions; eight (7%) body structures; 50 (42%) activities and participation; and 29 (24%) environmental factors (Table S1, online supporting information). For body functions, most of the categories were mental functions (b1, e.g. emotional, intellectual) and neuromusculoskeletal and movement-related functions (b7, e.g.

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| Table I. Fallicipalits of the | consensus process according t | о мпо тедіон, со | unitry, and professional t | uscipiine |

| Working group 1 | Working group 2 | Working group 3 | Sex | Profession or experience | Country | WHO region |
|--------------------|--------------------|--------------------|------------------|--|---------------------|---|
| | 1 | | Male | Adult with CP and researcher | The Netherlands | European Region |
| 1 | | | Female | Parent of adult daughter with CP | Canada | Region of the Americas |
| | | 1 | Female | Parent of adult son with CP and medical doctor in public health | India | South-East Asian Region |
| | | | Male | Parent of adult son with CP, orthopaedic surgeon, director of CP centre | USA | Region of the Americas |
| | 1 | | Female | Orthopaedic surgeon and researcher | Brazil | Region of the Americas |
| | | | Female | Specialist in PMR | Turkey | European Region |
| | | 1 | Female | Specialist in PMR | Argentina | Region of the Americas |
| | | 1 | Male | Specialist in PMR and researcher | France | European Region |
| | | | Female | Specialist in PMR and researcher | The Netherlands | European Region |
| | 1 | | Female | Specialist in PMR and researcher | USA | Region of the Americas |
| | 1 | | Male | Specialist in PMR, pain medicine and researcher | Morocco | Eastern Mediterranean Region |
| | | 1 | Male | Specialist in PMR with expertise in persons with intellectual disability | Canada | Region of the Americas |
| | | | Female | Physical therapist | India | South-East Asian Region |
| | | 1 | Female | Physical therapist and researcher | USA | Region of the Americas |
| | 1 | | Male | Physical therapist and researcher | Hong Kong | Western Pacific Region |
| | 1 | | Female | Physical therapist and researcher | Sweden | European Region |
| | | | Female | Physical therapist and researcher | Australia | Western Pacific Region |
| | | 1 | Female Female | Physical therapist and researcher Occupational therapist and researcher | South Africa USA | African Region Region of the Americas |
| | | 1 | Female | Occupational therapist and director of reintegration centre | The Netherlands | European Region |
| | | | Female | Speech and language therapist and researcher | Germany | European Region |
| | | | Male | Nurse practitioner and researcher | USA | Region of the Americas |
| | | 1 | Female | Endocrinologist and researcher | Australia | Western Pacific Region |
| | 1 | | Female | Neurological gerontologist rehabilitation researcher | USA | Region of the Americas |
| | 1 | | Female | Clinical neuropsychologist and researcher | Spain | European Region |

WHO, World Health Organization; CP, cerebral palsy; PMR, physical medicine and rehabilitation.

muscle tone, control of voluntary movement). Body structures were mostly related to movement (s7, e.g. structure of the upper and lower extremities). All chapters of the activities and participation component were represented, with mobility (d4, e.g. fine hand use, walking) and self-care (d5, e.g. dressing, eating) as the most frequently covered chapters. For environmental factors, most of the categories addressed products and technology (e1, e.g. products for mobility, accessibility of buildings) and services, systems, and policies (e5, e.g. transportation, health services).

Brief ICF Core Set for adults with CP

Agreeing with the 27% cut-off, participants included 33 ICF Categories in the brief ICF Core Set for adults with CP: nine (27%) body functions; two (6%) body structures; 14 (42%) activities and participation; and eight (24%)

environmental factors (Fig. 2). The most frequently covered chapters for body functions and body structures were the same as for the comprehensive ICF Core Set, while eight out of nine activities and participation chapters were covered. Besides chapters e1 and e5, support and relationships (e3, e.g. support of family, support of personal care providers) were also represented.

DISCUSSION

In this consensus process, a group of 25 international participants representing a variety of backgrounds and experience decided on the first version of the comprehensive and brief ICF Core Sets for adults with CP taking into consideration the evidence collected in the preparatory steps, that is, the systematic literature review,²⁶ qualitative study,²⁷ expert survey,²⁸ and empirical study.²⁹ This specific ICF



Figure 2: International Classification of Functioning, Disability and Health (ICF) framework including the ICF categories from the brief ICF Core Set for adults with cerebral palsy (Appendix S1, online supporting information). The checklist summarizes the functioning profile of an adult with cerebral palsy using the brief ICF Core Set. The extent of the problems can be rated using the ICF qualifiers: (0) no impairment or difficulty; (1) mild impairment or difficulty; (2) moderate impairment or difficulty; (3) severe impairment or difficulty; (4) complete impairment or difficulty. Environmental factors can be rated as barriers (from mild to complete; 1–4), facilitators (from +1 to +4), or no barriers or facilitators (0).¹⁵

Core Set consensus process was the first to be conducted online.

It is not surprising that the comprehensive ICF Core Set consists of a large number and wide range of ICF categories since the adult population with CP is heterogeneous and presents with different degrees of gross motor functioning and/or cognitive deficits.⁴ Although almost half of the categories (42%) of the comprehensive and brief ICF Core Sets represent the activities and participation component, environmental factors and body functions were also well represented with 24% and 27% of the 120 categories respectively. This distribution of factors follows a trend observed in health care that is shifting from a mainly biomedical approach towards a more comprehensive client-centred approach that also considers personal, social, and environmental aspects.³⁰ Especially telling is that the consensus process participants placed as much value on environmental factors (n=29 environmental factors and n=33 body functions in the comprehensive version and n=8 environmental factors and n=9 body functions in the brief version) as body functions. This is also reflected in some of the preparatory studies, for example, n=21 environmental factors and n=20 body functions in the expert survey.²⁸

While the comprehensive ICF Core Set is wide-ranging, some aspects of functioning may be underrepresented in the brief ICF Core Set as a result of the 27% cut-off. For example, only the body structures of the upper and lower extremities were included, although many participants argued that structures of the brain and trunk are highly relevant in adults with CP. In the activities and participation component, categories such as moving around using equipment (e.g. wheelchairs or crutches) or hand and arm use did not meet the cut-off but may be particularly relevant for specific adults with CP. Nevertheless, the experts agreed that the brief list of categories should be considered important when assessing the functioning of adults with CP.

This ICF Core Sets for adults with CP will complement the ICF Core Sets developed for children and young people with CP,²⁴ including a comprehensive ICF Core Set, a common brief ICF Core Set, and three age-specific brief ICF Core Sets (<6y, 6-13y, 14-18y). A comparison of the two comprehensive sets reveals that they share 98 secondlevel categories (e.g. intellectual functions, pain, muscle tone functions, walking, toileting, products for mobility, and health care services), 22 categories unique to adults and 36 categories unique to children and young people. Since 82% of the categories in the comprehensive ICF Core Set for adults with CP are also included in the comprehensive ICF Core Set for children and young people with CP, this will facilitate continuity of use. The differences between these Core Sets can be partially explained by the use of the ICF standard version to develop the ICF Core Sets for adults with CP, whereas the children and young people version of the ICF was used for the ICF Core Sets for children and young people with CP;³¹ there are eight categories in the comprehensive ICF Core Set for children and young people that are in the ICF children and young people version but not in the ICF. In comparing the brief ICF Core Sets of adults with CP and the agespecific set for young people aged 14 to 18 years, only half of the categories were shared. The children and young people categories address issues important to teenagers, for example, e320 friends and e420 individual attitudes of friends, whereas the adult version highlights topics important to adults, for example, d177 making decisions, d230 carrying out daily routine, or d770 intimate relationships. This may be due to the more autonomous functioning of adults with CP in daily life, for example, decision-making that affects major life areas, such as work, performing daily routines independently, and intimate relationships of adults with CP. Furthermore, support provided by personal assistants and health professionals and social security were included as essential environmental factors in the brief set for adults with CP but not in the ICF Core Set for young people aged 14 to 18 years; these factors may be understood as important for enabling autonomy in adult life. The comparison of the adult and children and young people versions confirms the added value of the ICF Core Sets for adults with CP since it underscores the importance of functioning categories that reflect the specific needs of those with CP older than 18 years.

The ICF Core Set for adults with CP is an open access tool that can be used as the foundation for the systematic assessment of adults with CP, to standardize data collection worldwide, and support data comparison across studies, disciplines, and settings. Standardized data will enable the creation of individual functioning profiles for goal-setting or treatment planning for adults with CP. These shortlists of ICF categories will serve as a guideline for the systematic assessment of functioning of adults with CP by providing users with a checklist of 'what' to measure. This is illustrated in an example of a functioning profile of an adult with CP in Appendix S1 (online supporting information), using the ICF qualifiers to indicate which body functions, and activities and participation categories, are impaired. A functioning profile is also provided in the publication of the ICF Core Sets for children and young people with CP and implemented in different countries worldwide.32 Such a profile is useful because it provides an easy to understand visual overview of a person's functioning (which aspects of functioning the person is experiencing problems with and which they are not). This profile can ensure that clinicians do not miss any core aspects of functioning that are likely to be relevant for adults with CP.

To promote standardized data collection, it is also important 'how' to measure relevant aspects of functioning. Therefore, it is advisable to select standardized tools, such as patient-reported outcomes measures or clinical assessments that align with the content of the ICF Core Sets for adults with CP, such as the toolbox of multiple item measures developed for children and young with CP.33,34 Before proceeding, it is important to validate the ICF Core Sets for adults in diverse social, cultural, and economic contexts worldwide to identify any gaps in the current version and test its usefulness in clinical care. To facilitate the testing and implementation of the ICF Core Sets globally, we plan to collaborate with the American and European Academies for Cerebral Palsy and Developmental Medicine and other academies for CP worldwide, united in the International Alliance of Academies of Childhood Disability (https://iaacd.net/). Collaboration with the International Alliance of Academies of Childhood Disability will also help ensure that future implementation considers the regional or local context.

The procedures we followed to develop these ICF Core Sets were unique. Due to the COVID-19 pandemic, we had the opportunity to pioneer an online version of the consensus process. Despite adhering as close as possible to the original methodology, concessions were necessary. For example, we decided to have fewer voting rounds and sessions to reduce participant burden. However, this meant less opportunity for discussion and more consideration of the available information. The results of all preparatory studies and previous voting results were carefully considered. From experience in previous ICF Core Set consensus conferences, physical presence and interactions during breaks and meals has been shown to be helpful for interactive exchange. In the present online process, it took longer

for participants to feel comfortable and provide input. Nevertheless, as in previous ICF Core Set conferences, participants engaged quite actively as time passed. Another challenge was the 9-hour spread of time zones across all six WHO regions. We did our best to plan all meetings at the most appropriate time possible considering all different time zones, making it inevitable that, for some participants, meetings started early in the morning and for others late in the evening. An online meeting takes longer than planned due to delays in audio or waiting for people to respond. This led to schedule changes and extension of meeting times. This, in turn, was an added challenge since some participants had to leave the meeting as it was past midnight and some had subsequent appointments; thus, their votes in the last part of a meeting could not be considered. Where appropriate, participants who were unavailable for a session were asked to provide their arguments to be shared during the session. Other efforts were made to promote participant involvement and facilitate individual and shared decision-making, for example, providing summaries of results and brief presentations on the nextsession activities. Despite these challenges, the overall experience was positive and the methodology of this online process can serve as a model for future ICF Core Set consensus processes and similar Delphi procedures in the future. An additional advantage of the online format was a significant reduction of costs and travel time compared to an offline consensus meeting lasting several days.

Study strengths and limitations

Some strengths and limitations should be considered when interpreting the results of this consensus process. A strength of this process was the international group of participants representing a mix of backgrounds and experiences, as well as the inclusion of adults with CP and three parents of adults with CP, of which two were also clinicians. However, some professional backgrounds were underrepresented, for example, experts in neurology, social work, or nursing, which may have influenced the results. Additionally, although all six WHO regions were represented in the preparatory studies and consensus process, most participants were from the region of the Americas (24%) and European region (32%), while only a few participants were from the Eastern Mediterranean and African regions (each 4%). To address this limitation, consensus process participants were regularly asked to consider the applicability of the ICF Core Sets worldwide, including different cultural backgrounds and socioeconomic circumstances, during discussions and when voting.

CONCLUSION

The comprehensive and brief ICF Core Sets for adults with CP were created using a new online version of an established ICF Core Set consensus process. These ICF Core Sets can be applied to clinical care and research. Application will promote standardized data collection worldwide.

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DATA AVAILABILITY STATEMENT

Data available on request from the authors.

SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: The second-level ICF categories included in the comprehensive and brief ICF Core Sets for adults with cerebral palsy

Appendix S1: Checklist summarizing the functioning profile of an adult with cerebral palsy using the brief ICF Core Set.

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