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Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy

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Abstract

Aim. Children with cerebral palsy (CP) often experience communication difficulties. We aimed to identify a classification system for communication of children with CP suitable for epidemiological surveillance.

Method. Systems to classify the communication of children with CP were identified. The Communication Function Classification System (CFCS), Functional Communication Classification System (FCCS) and Viking Speech Scale (VSS) were chosen for further investigation and translated. They were administered to 160 children aged 4-13 years with CP (across all motor severity levels) from eight European countries. Children's parents/carers, speech therapists and other health professionals applied the systems through direct observation. Other professionals applied them from case notes only. The systems were assessed for agreement, stability, ease and feasibility of application.

Results. Test-retest stability was moderate-to-high for VSS (k 0.66-0.88), CFCS (k uncomputed-0.91) and FCCS (k 0.52-0.91). Overall inter-rater agreement was fair to very good for every classification system. VSS achieved the best agreement between parents/caretakers and speech therapists. VSS was considered the easiest instrument to apply.

Interpretation. Due to its ease of use by a range of healthcare professionals, the VSS should be considered for CP registers which intend to survey speech intelligibility. For a wider assessment of communication, the CFCS or FCC should be considered.

Key words: cerebral palsy, surveillance, register, communication, children, classification

Short title: Classifying communication for cerebral palsy surveillance

What this paper adds

- VSS is valid to document speech intelligibility for CP registers
- FCCS and CFCS are valid to document communication for CP registers

- Parents and professionals found FCCS and CFCS more difficult to use than the VSS

Cerebral palsy (CP) is a permanent but not unchanging disorder of movement, posture and motor function¹, “often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder”.² Surveillance programmes monitor trends in CP prevalence and its determinants, and record the functional severity of associated impairments.³

Surveillance registers of CP share similar inclusion and exclusion criteria but vary in their methods of data collection.⁴ Classification systems of the severity of impairment of gross motor function (GMFCS)⁵ and fine manual function (BFMF, MACS)^{6,7} are now frequently used in surveillance registers,^{8,9} enabling the severity of impairments to be reliably compared across time and regions.^{10,11,12} Most classification systems have been validated to be applied from the age of four years, because this age allows both a reliable confirmation of the condition and the assessment of the child’s function.^{1,13} However, it is recognised that the development of the functions classified is rarely complete at this age.

The WHO International Classification of Function, Disability and Health - Children and Youth Version (2007), characterizes *Communication* in the *Activities and Participation* domain with subcodes d310 to d329 for *Receiving Communication* and d330 to d349 for *Producing Communication*.¹⁴ Classifying both components of communication is important and complex, as the motor disorders of CP can impair the production of speech and gesture; and the disorders of cognition and sensation may affect the development of both expressive and receptive communication. Systems to describe the speech^{15,16} and communication by multiple modes¹⁷ have been developed but their use for surveillance registers has not been evaluated.

This study was part of the SCPE-NET project, which aims to promote best practice in describing children with CP and to document variations in access to health care and in health outcomes (<http://www.scpenetwork.eu>). The study aimed to identify classification systems suitable to describe the communication of children with CP for epidemiological surveillance, either as a full activity or some of its components. To be considered suitable, the classification system should have acceptable content

validity, reliability and applicability using different sources of information, such as direct observation of the child and retrieving information from case records.

Methods

A systematic review of the literature was undertaken to identify classification systems of communication in children with CP. Medline, CINAHL, EMBASE, PsychInfo, Web of Knowledge, Scopus, First Search, ERIC, Linguistics and Language Behaviour Abstracts and DARE, were searched up until June 2010 using the terms “communication”, “speech production measurement”, “speech articulation tests”, “speech disorders”, “articulation disorders”, “communication disorders” or “dysarthria”. Key journals were also hand-searched from their inception or from 1980 until end March 2010.

Classification systems identified in the search were assessed by 12 experts from 8 countries (speech and language therapists [SLTs], occupational therapists, neurodevelopmental paediatricians, paediatric neurologists and epidemiologists) using a pre-established set of construct, validation and effectiveness parameters (Supplemental Table 1).

The selected classification systems were translated into Danish, Latvian, Lithuanian, Norwegian, European Portuguese, European Spanish and Swedish, following international guidelines that included two independent translators, discussions on phrasing and terminology by two focus-groups (parents and health professionals) and back translation, to ensure retention of original concepts and meaning.¹⁸ Translations were made of the classification systems, the instructions and any examples provided. Back translations were checked and approved by the first author of the classification system.

To assess the comparative effectiveness of the classification systems, parents (or caretakers), SLTs and other healthcare professionals applied them to classify the communication of children with CP and rated their experience of applying the systems.

An international, multicentre sample of children with CP aged four to thirteen years was purposively sampled by local clinicians from clinical caseloads of seven registers members of Surveillance of Cerebral Palsy in Europe (SCPE) (North of England, Portugal [Lisbon and Oporto], Latvia, Lithuania, Norway, Spain [Madrid], Western Sweden). Target sample size was 30 children per centre, covering all CP types (bilateral and unilateral spastic, dyskinetic, and ataxic), gross motor function (GMFCS levels I-V) and cognition (IQ \geq 70; 50-69; <50).

The communication of each child was rated by four types of raters: 1) parents/caretakers applying the systems from their knowledge of their child; 2) SLTs and 3) other healthcare professional by direct observation of the child; and 4) another healthcare professional retrieving information from case notes. These notes were usually those held by the paediatrician but such notes usually include letters from SLTs describing communication. The communication of Norwegian children was rated by special educators with expertise in language and communication rather than SLTs but, for ease of reporting, we refer to them as SLTs. Video-recording facilities were not available in every centre or clinic and are not used in routine data collection for the registers involved in SCPE, so it was not used in this assessment.

Raters applied the classification systems in their first language. No training on the classification systems was provided. At least four weeks later, children's communication was rated again by rater types 2-4 specified in the paragraph above. Parent reassessment was not required. Each rater classified children's communication blind to other raters' assessments and to their original rating.

To investigate the construct validity of the systems, respondents were asked to rate how well each system described for each child "full activity of communication (both receiver and producer)", "ability to perform as an emitter" and "ability to produce speech", using Likert scales (1 = very well; 5 = very badly).

For each classification system, raters were also asked to rate "How easy did you find the application of this classification system in this particular child?" using a Likert scale (1=very easy; 5= very difficult).

Agreement was estimated with the complete agreement rate (CAR) between rater types, with 95% confidence intervals (95%CI). Inter-rater reliability and intra-rater reliability were estimated with Cohen's adjusted Kappa (standard error). Kappa was interpreted as suggested by Landis and Koch.¹⁹

Ratings of ease of use and understanding of construct were compared between the three classification systems and between the four groups of raters using the Friedman Test. As every child was not assessed by every group of raters, missing values were managed variablewise for the analysis. Analysis used SPSS 15.0 (SPSS Inc., 2006) and OpenEpi 2.3.1 (www.OpenEpi.com).

Parents gave written consent to participate and for their child's communication to be rated for the purpose of the study. Ethics permission was obtained by each of the participating centres.

Results

From the systematic review of the literature, eight classification systems were identified (Supplemental Table 2) and five were selected by the expert group for further analysis based on their scope, validation assessment and actual use. In order to improve discriminative power and ease of application, we proposed to the developers of the Communication Function Classification System (CFCS)¹⁷ that the three sublevels of level 4 (which differentiate difficulties in sending, receiving or both), should also be applied to level 2; this proposal was agreed and the revised instrument, which lacks specific validation, was called CFCS-SCPE. The developers of the Verbal Expression Scale (abstract presented at the 2009 European Society for Paediatric Research Conference, personal communication), the Speech Production Rating Scale (SPRS)¹⁵ and the Norwegian classification system¹⁰ were invited to merge their three scales into a single, consensual classification system, the Viking Speech Scale (VSS)¹⁶. Table 1 summarises the description of the three classification systems finally chosen by the expert group for comparative assessment: the Functional Communication Classification System (FCCS), the CFCS-SCPE and the VSS. The full scales are provided as supplementary material (Supplemental Tables 3 to 5).

The sample included 151 children (91 boys) aged 4 to 13 years (mean 6, SD 1.1). Most children had spastic CP (n=118, 76.1%; bilateral n=78); 30 (19.4%) had dyskinetic type and 7 (4.6%) had ataxic CP. The results of their functional assessment are shown in Table 2. All children used multiple modes of communication. The most frequently recorded modes were: speech (n=107, 69.0%); vocalisation (n=64, 41.3%) and gesture (n=40, 25.8%). Many children used augmentative and alternative communication (AAC) to supplement their natural forms of communication. Twenty four used manual sign (15.5%); 33 (21.3%) used low technology AAC book; and 18 (11.6%) used high tech AAC (electronic devices, usually with speech output).

Overall, 134 children were rated by their parents (106 [79.1%] mothers; 20 [14.9%] fathers; 2 [1.5%] other relative; 6 [4.5%] other caretaker). The communication of 143 children was rated by SLTs; 139 by other healthcare professionals from direct observation (26 [17.8%] physiotherapists; 63 [43.2%] paediatricians, 57 [39.0%] other healthcare professionals) and 141 were rated using case notes (1 [0.7%] physiotherapist; 1 [0.7%] nurse; 127 [84.7%] paediatricians, 22 [14.0%] other health professionals). Of those rating children using case notes, 32 (20.6%) stated that they had previous knowledge of the child. The tables with the distribution of the rates given by each group using the three classification systems are provided as supplementary material (Supplemental Tables 6 to 8).

The agreement and reliability analysis are presented on Table 3. For statistical purposes, the performance of the CFCS-SCPE was assessed for both the full version with nine categories (5 levels, two of them with 3 sublevels) and considering only its five main levels, to allow comparability with the classification systems with only four (VSS) or five levels (FCCS).

The inter-rater agreement was moderate for the FCCS and fair to moderate for the CFCS-SCPE (also considering the five main levels of CFCS-SCPE only). The inter-rater agreement for the VSS was moderate to good; the agreement between SLTs rating by direct observation of the child, healthcare professionals rating based on case notes and the ratings given by parents or caretakers was virtually the same.

The intra-rater agreement (test-retest reliability) was assessed in a smaller sample of children (69 to 104 depending on rater group). It was moderate to very good for the FCCS, good to very good for the VSS and the CFCS-SCPE (moderate to very good considering only its five main levels).

The agreement of score between the CFCS-SCPE considering its five main levels and FCCS has a wide variation (Kappa 0.53 to 0.85), the highest agreement being achieved for scores given by healthcare professionals rating children through access to case notes (data not shown). The correlations between the scores given by the CFCS-SCPE considering its five main levels and the VSS are good (Spearman r 0.795 to 0.89) and very good between the FCCS and the VSS (Spearman r 0.85 to 0.92), the highest correlation being achieved for scores given by healthcare professionals rating children through access to case notes.

The comparative assessment of the construct validity of the classification systems is presented in Table 4. The CFCS-SCPE achieved the highest rating for classifying communication comprehensively by every group of raters; it did so “well” or “very well” in a majority of the reports. The FCCS achieved the highest rating for classifying “communication as an emitter” by caretakers and by health professionals (other than SLTs) using it either by direct assessment or through clinical notes, but not by SLTs. Most raters considered that the VSS described the child’s speech well or very well: 66.4% of parents, 74.1% of SLTs, 77.3% of healthcare professionals rating through direct observation of the child and 70.9% of healthcare professionals rating children through access to case notes. The VSS was seldom judged to assess well the child’s communication (both receiver and producer) or producing communication (as an emitter).

The VSS was considered as the easiest classification system to apply by every group of raters, including those using case notes. Every group of raters except the SLTs considered the FCCS easier to apply than the CFCS-SCPE. The percentage of raters judging the classification system as difficult or very difficult to apply was small in every rater group, but smaller (Friedman Test, $p < 0.001$) for the VSS (0% to 9.3%) than for the FCCS (4.5% to 15.2%) and the CFCS-SCPE (0% to 21.8%). The highest

percentage of raters that considered the classification systems difficult or very difficult to apply was found amongst healthcare professionals rating children through access to case notes (VSS 9.3%, FCCS 15.2%, CFCS-SCPE 21.8%) (Friedman Test, $p < 0.001$) and the lowest amongst healthcare professionals rating through direct observation of the child (VSS 0%, FCCS 4.5%, CFCS-SCPE 0%) (Friedman Test, $p < 0.001$).

Discussion

The assessment of communication in epidemiological surveillance of children with CP is important, as communication difficulties are a frequent cause of activity limitation and impact on children, their families, and society.²⁰ This project aimed to identify systems to classify communication which were easy to use, valid and reliable.

Three classification systems were compared in the field. The CFCS was developed to classify the full activity of communication in five levels, with sublevels for some differentiation between producing and receiving communication; it was validated for children with CP aged 2-18 years.¹⁷ The FCCS was developed to classify the activity of the production of communication in five levels; it was validated for children with CP aged 4-6 years. The VSS was developed to classify the intelligibility of speech in four levels; it does not assess the receptive activity of communication and does not consider other forms of production of communication; it was validated for children with CP aged 4-13 years.¹⁶

Barely half of the respondents in each rater group considered the CFCS-SCPE a good descriptor of the ability to communicate either as both a producer and a receiver (45.3% - 58.7%) or as a producer only (54.5% - 58.1%). The FCCS was considered by every group of raters as a good or very good descriptor of the ability to communicate as a producer (58.8% - 79.0%). Thus, many raters, even SLTs, thought that neither the FCCS nor the CFCS-SCPE described adequately the full communication abilities of the children they rated.

The construct of the VSS was correctly understood by a large majority in every group of raters (66.4% - 77.3%). Each rater group classified this system as able to describe correctly the ability to speak intelligibly. The VSS scored consistently highly in ease of application across every rater group (76.1% - 85.3%). Particularly, it was the classification system that healthcare professionals who rated children's communication from case notes found the most easy to apply (84.2%). These data are relevant, as many registers of CP rely mostly on data retrieved from case notes. Detail in case notes will of course vary but a register seeks complete ascertainment and reproducibility, rather than great detail; it is reassuring that this study shows there was sufficient detail for case notes review to be as informative as direct observation.

A limitation of the VSS is that children with CP may be unable to produce any intelligible speech due to cognitive as well as motor impairments. The reason for unintelligibility is not clear from the scale alone. Thirty-one percent of this sample did not use speech for communication and had to be classified as grade IV, in spite of their eventual ability to produce communication by other means.

The agreement on the classifications given by each group of raters seems to be higher for the VSS than for the CFCS-SCPE or the FCCS, but the confidence intervals of the CAR frequently overlap and it is difficult to state the significance of the difference in the values of Cohen's kappa²¹ as the levels of agreement could be considered either different or similar depending on the criteria.^{19,22,23} The criteria most frequently cited in the literature were followed.¹⁹

The stability of the three classification systems on test-retest was virtually the same.

Training and increased familiarity with classification systems, such as the GMFCS, improves their usefulness.²⁴ This may suggest that while the VSS is easy to apply, even by those not familiar with it or using case notes, FCCS and/or CFCS-SCPE may become easier to use with increasing practice.

The main strengths of this study are: inclusion of both published and "grey literature"²⁵ in the review; rigour provided by the research protocol; balanced

distribution of clinical types of CP, IQ and communication abilities in the participating children; varied professional backgrounds of raters; and different sources of information used for rating children. Moreover, its multinational design provides culturally validated versions of the classification systems in eight different European languages and lays the groundwork for their use in international surveillance of CP.

The relatively small sample of children and their cultural heterogeneity are weaknesses of the study. Each centre aimed to recruit 30 children to the study, but for some centres this was not possible for reasons relating either to time or financial constraints. Also, in some centres, the professionals rating the children from case notes had previous knowledge of the children and this may have created bias.

In spite of the careful cultural adaptation during translation, the reliability assessment of the classification systems could differ between countries and languages; our sample size did not allow this to be investigated but further research could address this.

It has to be acknowledged that the CFCS-SCPE version of CFCS has been approved by the developers of CFCS but has yet to be specifically validated. The FCCS was applied to a sample that included children older than those used by its developers for the validation. The VSS was validated using the same sample reported in this study.¹⁶

It is possible to classify communication in the setting of epidemiologic surveillance of CP with the instruments that already exist.

Their ease to use is different, reflecting the complexity of their purposes and constructs. They all are valid and reliable. Choosing between the three assessed instruments depends mainly on the sources of information and characteristics of the reporters and on the surveillance priorities of each register (balancing areas of special interest with the length of the data collection forms). Classifications of the disorders of cognition and sensation that may affect both expressive and receptive communication and of the motor disorders that can impair the production of gesture are already usually collected by registers. On the other hand, as speech is not

generally described, there is a lack of information on the most frequent and important form to produce communication.

We recommend the VSS be adopted as the single measure of speech in epidemiological surveillance, supplemented with additional information on cognition, sensation, and manual ability. The FCCS or CFCS may be used in addition to the VSS to obtain a broader classification of communication.

Collaborators

The following SCPE centres collected data for this study: Denmark (led by Gija Rackauskaite), Latvia (led by Andra Greitane), Lithuania (led by Audrone Prasauskiene), Norway (led by Guro L. Andersen), Portugal (Lisbon and Oporto, led by Maria da Graça Andrada), Spain (Madrid, led by Javier de la Cruz), Sweden (Western Sweden, led by Kate Himmelmann), UK (North of England, led by Karen Horridge). The data analysis was performed with the assistance of the Epidemiology and Statistics Office of the Research Unit of the Centro Hospitalar de Lisboa Central (Lisbon, Portugal).

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Table 1. Summary description of the classification systems selected by the expert group for comparative assessment.

Classification System	Assessed activity	Rating levels	Use in epidemiologic surveillance	Published reference
Communication Function Classification System (CFCS)	producing and receiving communication	5 (3 sublevels on level 4)	recommended by the authors	17
Functional Communication Classification System (FCCS)	producing communication	5	recommended by the authors	Barty and Caynes, 2009 ICPC proceedings
Verbal Expression Scale (VES)	producing communication	5	used in Portuguese CP register	Andrada et al., 2009 ESPR proceedings
Speech Production Rating Scale (SPRS)	speech	5	none	15
Andersen, Mjøen & Vik	speech	4	used in Norwegian CP register	10
Viking Speech Scale (VSS)	speech	4	recommended by the authors	16

CP: cerebral palsy. ESPR: European Society for Paediatric Research. ICIC: International Cerebral Palsy Conference.

Table 2. Characteristics of children with cerebral palsy who participated in the comparative assessment study [numbers (%)] by motor function, assigned to levels of GMFCS, BFMF and MACS, cognition, vision and hearing impairment.

Function	Classification system	Level					
		I	II	III	IV	V	Unknown
Gross motor function	GMFCS	35 (22.6%)	19 (12.3%)	30 (19.4%)	27 (17.4%)	38 (24.5%)	6 (3.8%)
Fine motor function	BFMF	25 (16.2%)	29 (18.8%)	27 (17.4%)	20 (13.0%)	25 (16.2%)	28 (18.2%)
Fine motor function	MACS	19 (12.3%)	38 (24.7%)	27 (17.5%)	21 (13.6%)	25 (17.5%)	22 (14.3%)
		No impairment	Impaired, but not severely	Severe impairment		Unknown	
Cognition	IQ	62 (40.0%)	28 (18.1%)	44 (28.4%)		21 (13.5%)	
Vision	VA	78 (50.3%)	54 (34.8%)	18 (11.6%)		5 (3.2%)	
Hearing	Not stated	136 (87.7%)	6 (3.9%)	3 (1.9%)		10 (6.5%)	

GMFCS: The Gross Motor Function Classification System. BFMF: The Bimanual Fine Motor Function classification system. Hearing: audition acuity (no handicap; not severe handicap; severe handicap; unknown). IQ: Intellectual Quotient (≥ 70 ; 50-69; < 50). MACS: The Manual Ability Classification System. VA: Vision Acuity ($\geq 6/6$; 5-2/6 ; $< 2/6$) in better eye.

Table 3. Intra-rater reliability in each rater group and inter-rater reliability and agreement between rater groups for each classification system.

Rater groups	Intra-rater reliability and agreement	CFCS-SCPE (full)	CFCS-SCPE (5 main levels)	FCCS	VSS
DOSLT (n=104)	%CAR (95%CI) Kappa (SE)	79 (70.2-85.9) 0.74 (0.047)	82 (73.4-88.3) 0.77 (0.048)	83 (74.5-89.1) 0.78 (0.047)	90 (83.5-95.0) 0.86 (0.040)
DOAHP (n=79)	%CAR (95%CI) Kappa (SE)	57 (45.9-67.5) not computed	65 (53.6-74.5) 0.55 (0.067)	62 (51.0-72.2) 0.52 (0.068)	76 (65.6-84.4) 0.66 (0.067)
CN (n=69)	%CAR (95%CI) Kappa (SE)	93 (84.7-97.3) 0.91 (0.038)	96 (88.6-98.9) 0.94 (0.031)	93 (84.7-97.3) 0.91 (0.039)	91 (82.8-96.4) 0.88 (0.047)
Pairs of rater groups	Inter-rater reliability and agreement	CFCS-SCPE (full)	CFCS-SCPE (5 main levels)	FCCS	VSS
DOSLT vs. DOAHP (n=128)	%CAR (95%CI) Kappa (SE)	48 (39.1-56.3) 0.37 (0.051)	52 (43.7-60.9) 0.40 (0.055)	54 (44.8-62.1) 0.42 (0.056)	66 (57.1-73.5) 0.51 (0.057)
DOSLT vs. CN (n=140)	%CAR (95%CI) Kappa (SE)	56 (47.1-63.6) 0.46 (0.048)	63 (54.45-70.6) 0.53 (0.051)	68 (59.8-75.2) 0.59 (0.049)	77 (69.6-83.5) 0.67 (0.048)
DOSLT vs. Pct (n=128)	%CAR (95%CI) Kappa (SE)	57 (48.3-65.4) 0.48 (0.049)	63 (54.7-71.3) 0.53 (0.052)	60 (51.5-68.4) 0.49 (0.054)	77 (69.0-83.7) 0.68 (0.050)
DOAHP vs. CN (n=137)	%CAR (95%CI) Kappa (SE)	49 (40.1-57.0) 0.39 (0.048)	58 (49.0-65.6) 0.47 (0.053)	60 (51.15-67.6) 0.49 (0.053)	67 (60.5-76.0) 0.55 (0.055)
DOAHP vs. Pct (n=119)	%CAR (95%CI) Kappa (SE)	46 (37.4-55.2) 0.36 (0.050)	54 (44.8-62.6) 0.42 (0.055)	53 (44.4-62.2) 0.41 (0.057)	67 (57.8-74.8) 0.53 (0.058)
CN vs. Pct (n=131)	%CAR (95%CI) Kappa (SE)	53 (44.5-61.6) 0.44 (0.049)	63 (53.9-70.6) 0.53 (0.052)	58 (49.3-66.25) 0.46 (0.053)	72 (63.9-79.3) 0.61 (0.052)

95%CI: 95% confidence interval. **CAR:** complete agreement rate. **CFCS-SCPE:** The Communication Function Classification System, SCPE version. **CN:** Classification through case notes. **DOAHP:** Direct observation of the child by another health professional. **DOSLT:** Direct observation of the child by a speech and language therapist. **FCCS:** The Functional Communication Classification System. **Pct:** Classification by parent or caretaker. **VSS:** The Viking Speech Scale.

Table 4. Distribution (%) of the levels on a five point Likert scale to the stated questions compared by rater group for each classification system.

“How well do you think the communication systems describe this particular child’s ability to perform the full activity of communication (both receiver and producer)?”				
Likert scale: 1 = very well; 2 = quite well; 3 = acceptable; 4 = badly; 5 = very badly.				
Rater groups classifying the ability to communicate	Likert level	Communication Classification System		
		CFCS-SCPE [‡]	FCCS [#]	VSS [#]
Direct observation of the child by a speech and language therapist (n=143) *	1	17.5	11.9	15.5
	2	32.9	27.3	13.4
	3	30.1	32.9	10.6
	4	17.5	11.2	23.9
	5	2.1	16.8	36.6
Direct observation of the child by another health professional (n=139) *	1	19.6	15.1	18.2
	2	39.1	38.1	22.7
	3	34.1	21.6	31.8
	4	7.2	7.9	18.2
	5	0	17.3	9.1
Classification through case notes (n=151) *	1	10.0	6.0	6.0
	2	35.3	35.8	14.1
	3	34.7	30.5	9.4
	4	15.3	10.6	42.3
	5	4.7	17.2	28.2
Classification by parent or caretaker (n=134) †	1	17.2	14.9	18.0
	2	35.8	32.8	27.8
	3	32.8	27.6	27.1
	4	12.7	7.5	5.3
	5	1.5	17.2	21.8

“How well do you think the communication systems describe this child’s ability to perform the activity of producing communication (as an emitter)?”

Likert scale: 1 = very well; 2 = quite well; 3 = acceptable; 4 = badly; 5 = very badly.				
Rater groups classifying the ability to communicate	Likert rate	Communication Classification System		
		CFCS-SCPE [‡]	FCCS [#]	VSS ^{##}
Direct observation of the child by a speech and language therapist (n=143) *	1	20.3	18.2	21.1
	2	37.8	40.6	21.1
	3	28.0	32.9	15.5
	4	11.2	7.7	17.6
	5	2.8	0.7	24.6
Direct observation of the child by another health professional (n=139) *	1	20.3	21.6	19.4
	2	36.2	55.4	16.5
	3	35.5	19.4	24.5
	4	8.0	3.6	14.4
	5	0	0	25.2
Classification through case notes (n=151) *	1	9.9	11.3	9.3
	2	46.4	47.7	28.8
	3	29.8	29.8	18.7
	4	9.3	6.6	26.8
	5	4.6	4.6	18.0
Classification by parent or caretaker (n=134) †	1	19.4	18.7	20.9
	2	35.1	47.8	29.9
	3	35.1	29.1	23.1
	4	7.5	3.7	5.2
	5	3.0	0.7	20.9

“How easy did you find the application of this scale in this particular child?”

Likert scale: 1 = very easy; 2 = easy; 3 = some doubts; 4 = difficult; 5 = very difficult.

Rater groups classifying the ability to communicate	Likert level	Communication Classification System		
		CFCS-SCPE [#]	FCCS [#]	VSS [#]
Direct observation of the child by a speech and language therapist (n=143) *	1	24.5	20.3	51.7
	2	33.6	38.5	33.6
	3	28.5	31.5	12.8
	4	10.5	7.0	1.4
	5	2.8	2.8	0.7
Direct observation of the child by another health professional (n=139) *	1	20.3	21.6	43.2
	2	37.7	48.2	35.3
	3	35.5	27.3	18.7
	4	6.5	2.9	2.9
	5	0	0	0
Classification through case notes (n=151) *	1	11.3	11.3	36.5
	2	42.4	42.4	47.7
	3	31.1	31.1	16.6
	4	9.9	9.9	4.0
	5	5.3	5.3	5.3
Classification by parent or caretaker (n=134) *	1	20.1	21.8	41.0
	2	35.1	38.3	35.1
	3	32.1	30.8	18.7
	4	10.4	7.5	5.2
	5	2.2	1.5	0

CFCS-SCPE: The Communication Function Classification System, SCPE version. FCCS: The Functional Communication Classification System. VSS: The Viking Speech Scale. * Differences between classification systems: Friedman Test, $p \leq 0.001$. † Differences between classification systems: Friedman Test, $p \leq 0.05$. # Differences between classifying groups: Friedman Test, $p \leq 0.001$. ‡ Differences between classifying groups: Friedman Test, $p \leq 0.005$. †† Differences between classifying groups: Friedman Test, $p \leq 0.05$.

Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy

Supplementary material

Supplemental Table 1. Set of construct, validation and effectiveness parameters used for the description and rating of the classification systems for communication identified in the search. Higher score was given to those tools that have already been submitted to thorough validation process, especially if validated for children with cerebral palsy, and those that are known to be already in use, especially for epidemiologic surveillance purposes. The language in which the identified tools might have been validated was not a main issue.

The activity or function that is evaluated (according to WHO ICF-CY):

“communication” (“producing” + “receiving”) = 3

“producing” = 2

“receiving” = 1

Activity or function non elicited = 0

Clinical validation

yes = 2

no = 1

Age range for which validation has been performed

4 – 6 years old = 3

4 – 8 years old = 2

older than 8 years old = 1

younger than 4 years old = 0

Clinical diagnosis of the individual used for validation

children with cerebral palsy only = 3

children with several disabilities including cerebral palsy = 2

children with other disabilities besides cerebral palsy = 1

children with non-specified disabilities = 0

Complexity of the tool

tool very easy to apply in a surveillance setting = 3

tool fairly easy to apply in a surveillance setting = 2

tool difficult to apply in a surveillance setting = 1

tool impossible to apply in a surveillance setting = 0

Feasibility assessment or known use in epidemiologic surveillance settings

tool very easy to apply in a surveillance setting = 3

tool fairly easy to apply in a surveillance setting = 2

tool difficult to apply in a surveillance setting = 1

tool impossible to apply in a surveillance setting = 0

Number of references the tool already has in the literature

more than 5 references = 3

1- 5 references = 2

none = 1

Supplemental Table 2. The eight classification systems for communication identified in the systematic review of the literature.

The identified tools classifying speech – 4

Pennington and McConachie, Speech Production Rating Scale, 2001

Andrada et al, Verbal Expression Scale, 2009

Barty and Caynes, Functional Communication Classification System (FCCS), 2009

Andersen, Mjøen and Vik, Speech, 2010

The identified tools classifying speech and language – 1

Hustad, Gorton and Lee, Speech and Receptive Language, 2010

The identified tools classifying language – 1

Andersen, Mjøen and Vik, Language Comprehension, 2010

The identified tools classifying communication – 2

Hidecker et al, Communication Function Classification System (CFCS), 2010

Meester-Delver A et al. Capacity Profile in preschool children with cerebral palsy, 2009

Supplemental Table 3. The Communication Function Classification System – SCPE Version (CFCS-SCPE) for Individuals with Cerebral Palsy.

-
- I - **Effective Sender and Receiver with unfamiliar and familiar partners.** The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person’s communication.
-
- II - **Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. **a)** The child may need extra time to produce and understand messages. **b)** The child may need extra time to understand messages but is an effective sender of messages. **c)** The child may need extra time to compose messages and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual success of the person’s communication with both unfamiliar and familiar partners. The child is an effective receiver of messages.
-
- III - **Effective Sender and Receiver with familiar partners.** The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.
-
- IV - **Inconsistent Sender and/or Receiver with familiar partners.** The person does not consistently alternate sender and receiver roles. This type of inconsistency might be seen in different types of communicators including: **a)** an occasionally effective sender and receiver; **b)** an effective sender but limited receiver; **c)** a limited sender but effective receiver. Communication is sometimes effective with familiar partners.
-
- V - **Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a sender and a receiver. The person’s communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is seldom effective even with familiar partners.
-

Supplemental Table 4. The Functional Communication Classification System (FCCS).

I -	An effective communicator in most situations. Can independently communicate a wide variety of messages/topics to familiar and unfamiliar people in most environments.
II -	An effective communicator in most situations, but does need some help. <ul style="list-style-type: none">– Can communicate a variety of messages/topics to familiar people but may experience some difficulties with unfamiliar people/topics and environments.– Needs some help/support with some activities, or situations, where success may depend on environmental factors/context and with unfamiliar communication partners such as:<ul style="list-style-type: none">- prompt questions to initiate with unfamiliar listeners or situations- repetitions (to make themselves understood)- speech loudness- short phrasing for breath control or oral motor control- extra time– An AAC user who requires assistance with set up, and/or programming; and whose listener may need some assistance with orientation/interpretation of AAC strategies. [Note the type of AAC system on the cover page.]
III -	An effective communicator in some situations. Can communicate a small range of messages/topics to most familiar people. <ul style="list-style-type: none">– Effective communicator with familiar people and activities and in familiar settings about their needs and wants, and things that are happening.– Requires assistance with unfamiliar people/topics and environments.– May use “conventional gestures” such as pointing, movements (e.g. waving), eye contact and/or vocalisations (ah, ehya,), to gain attention or start the interaction.– Relies on a familiar communication partner to interpret AAC or speech attempts, and to prepare, set up and support communication.
IV -	Assistance is required in most situations, especially with unfamiliar people and environments. Communicates daily/routine needs and wants with familiar people. <ul style="list-style-type: none">– Can initiate and attract attention but needs a familiar person who is familiar with their routine, recent/significant experiences and likes and dislikes, and to interpret her communication– Responds to familiar voices, sounds, and routines using body movement, facial expression, and vocalisation.– Can anticipate familiar activities and routines.– Accepts, rejects/refuses and/or protests – from offered choices. This may be by using body movements or vocalisations.
V -	Communicates unintentionally with others, using movement and behaviour. <ul style="list-style-type: none">– Daily/routine needs and wants are interpreted by familiar people from observation of the individual’s emotional state, body movement and behaviour.– Needs full assistance from a familiar person to observe, interpret movements and behaviours, anticipate, and problem solve based on their experience, training and observation.

Supplemental Table 5. Viking Speech Scale (VSS).

I - Speech is not affected by motor disorder.

- Children in Level I will be following the usual pattern of speech development. They may have some speech immaturities, similar to other children of their age/developmental level.
 - Children in Level II have speech that is affected by their motor disorder. Their speech is usually understandable but is not following the usual pattern of development and does not sound like children of their age/developmental level.
-

II - Speech is imprecise but usually understandable to unfamiliar listeners.

- Loudness of speech is adequate for one to one conversation. Voice may be breathy or harsh sounding but does not impair intelligibility. Articulation is imprecise; most consonants are produced, but deterioration is noticeable in longer utterances. Although difficulties are noticeable, speech is usually understandable to unfamiliar listeners out of context.
- Children in Level II have speech that is affected by their motor disorder. Their speech may sound weak, slushy, slurred or loudness may be inappropriate but is usually understandable without contextual cues.
 - Children in Level III will usually have speech that is severely affected by their motor disorder at multiple levels (e.g. breath control, vocal cord movement/voice, articulation). The severe difficulties that children experience in controlling each level act together to make the children's speech very difficult to understand without contextual cues.
-

III - Speech is unclear and not usually understandable to unfamiliar listeners out of context.

- Difficulties controlling breathing for speech - can produce one word per utterance and/or speech is sometimes too loud or too quiet to be understood. Voice may be harsh sounding; pitch may change suddenly. Speech may be markedly hyper nasal. A very small range of consonants are produced. The severity of the difficulties makes the speech difficult to understand out of context.
- Children in Level III use speech as a method of communication. Their speech may be understandable to unfamiliar adults when they speak in single words or occasional words may be understood within longer phrases.
 - Children in Level IV may produce vocalisations but cannot produce any words or word approximations that unfamiliar listeners can understand out of context.
-

IV - No understandable speech.

The full scale can be found at <http://www.scpenetwork.eu/en/about-scpe/scpe-net-project/harmonisation/communication/>. Explanations of the differences between levels I and II and levels II and III were provided in the scale.

Supplemental Table 6. Classification given by each group of raters using the Communication Function Classification System – SCPE Version (CFCS-SCPE).

Rater groups	CFCS-SCPE level								
	I	IIa	IIb	IIc	III	IVa	IVb	IVc	V
Direct observation of the child by a speech and language therapist (n=143)	41	7	3	10	23	18	2	7	32
Direct observation of the child by another health professional (n=139)	31	9	4	11	26	14	2	8	32
Classification through case notes (n=148)	42	11	3	12	19	14	4	12	31
Classification by parent or caretaker (n=134)	44	7	4	11	23	19	2	9	15

CFCS-SCPE: Communication Function Classification System – SCPE Version.

Supplemental Table 7. Classification given by each group of raters using the Functional Communication Classification System (FCCS).

Rater groups	FCCS level				
	I	II	III	IV	V
Direct observation of the child by a speech and language therapist (n=143)	38	29	25	30	21
Direct observation of the child by another health professional (n=138)	32	31	20	31	24
Classification through case notes (n=151)	46	25	19	35	26
Classification by parent or caretaker (n=134)	41	29	18	27	19

FCCS: Functional Communication Classification System.

Supplemental Table 8. Classification given by each group of raters using the Viking Speech Scale (VSS) classification system.

Rater groups	VSS level			
	I	II	III	IV
Direct observation of the child by a speech and language therapist (n=143)	51	22	18	52
Direct observation of the child by another health professional (n=139)	39	31	12	57
Classification through case notes (n=151)	49	28	15	59
Classification by parent or caretaker (n=132)	49	26	18	39

VSS: Viking Speech Scale.