

APPENDIX 1: DELPHI ROUND 1

Table i. Respondent background.

Respondent background	Total (n = 42), n (%)
Consultant orthopaedic surgeon	28 (67)
Orthotist	2 (5)
Physiotherapist	5 (12)
Parent/carer	7 (17)

Table ii. Consensus criteria.

Consensus in	75% or more participants scored it as 'critical for inclusion', and less than 25% of participants scored it as 'not important for inclusion' *
Consensus out	75% or more participants scored it as 'not important for inclusion', and less than 25% of participants scored it as 'critical for inclusion' *
No consensus	Anything else not included in the other two categories. *

^{*}Participants selecting 'unable to answer' for a question were not included in this assessment.

Table iii. Descriptive analysis of participant response to importance of outcomes in relation to the ambulatory and non-ambulatory child.

Variable	n	1 to 3, n (%)	4 to 6, n (%)	7 to 9, n (%)	Median	IQR
The ambulatory child						
1. The child (if age appropriate) is independent with activities of	41	1 (2)	4 (10)	36 (88)	9	8 to 9
daily living	4.4		, ,			
2. The child's ability to walk unaided	41	2 (5)	17 (41)	22 (54)	7	5 to 9
3. An improvement in gait (walking pattern) perceived by patient or family	41	3 (7)	11 (27)	27 (66)	7	6 to 9
4. A symmetrical rotational profile (feet facing forward as the child walks)	41	5 (12)	24 (59)	12 (29)	5	5 to 7
5. Foot position in standing/when using standing frame	42	5 (12)	20 (48)	17 (40)	6	5 to 7
6. The child's ability to walk barefoot	41	12 (29)	17 (41)	12 (29)	5	3 to 7
7. The child's ability to climb the stairs	42	5 (12)	18 (43)	19 (45)	6	5 to 8
8. The child's ability to walk with 'splints'	41	3 (7)	7 (17)	31 (76)	7	7 to 8
9. The child's ability to undertake independent transfers	40	1 (3)	3 (8)	36 (90)	9	8 to 9
10. The child's tolerance of splints	40	1 (3)	7 (18)	32 (80)	7	7 to 9
11. A reduction in the child's use of/ reliance on splints	40	12 (30)	12 (30)	16 (40)	6	3 to 7
12. The child's ability to wear normal footwear	42	8 (19)	16 (38)	18 (43)	6	5 to 7
13. Range of motion in the hip	41	3 (7)	21 (51)	17 (41)	6	5 to 7
14. Range of motion in the knee	41	3 (7)	17 (41)	21 (51)	7	6 to 7
15. Range of motion in the ankle	41	5 (12)	19 (46)	17 (41)	6	5 to 7
16. Residual deformity/ stiffness in the hip	41	2 (5)	17 (41)	22 (54)	7	5 to 7
17. Residual deformity in the foot and ankle	39	2 (5)	15 (38)	22 (56)	7	6 to 7.5
18. Coronal and sagittal lower limb alignment (the legs look straight from the front and side)	42	5 (12)	20 (48)	17 (40)	6	5 to 7
19. Equal leg lengths	42	7 (17)	20 (48)	15 (36)	6	4.25 to 7
20. Balanced symmetrical spine and pelvic alignment/position	42	2 (5)	10 (24)	30 (71)	7	6 to 8
21. Stable hips that are in joint	42	5 (12)	8 (19)	29 (69)	7.5	6 to 8.75
22. The foot position when resting on wheelchair plates (if they have a wheelchair)	42	1 (2)	12 (29)	29 (69)	7	6 to 8
23. The child's seating position in their wheelchair (if they have a wheelchair)	42	1 (2)	5 (12)	36 (86)	8	7 to 9
24. Maintaining muscle strength	42	3 (7)	9 (21)	30 (71)	7	6 to 8
25. Absence of pain	42	1 (2)	0 (0)	41 (98)	9	8.25 to 9
26. Absence of pressure sores	41	0 (0)	1 (2)	40 (98)	9	8 to 9
27. Good wound healing	42	2 (5)	6 (14)	34 (81)	8	7 to 9

28. Avoidance of a fracture	42	2 (5)	6 (14)	34 (81)	8	7 to 9
29. Presence of a normal body fat percentage/ MI	42	3 (7)	15 (36)	24 (57)	7	5 to 7
30. Recurrence or relapse of initial need for intervention	40	1 (3)	9 (23)	30 (75)	7	6.75 to 8
31. Recurrent surgery or interventions for the same indication/problem	41	1 (2)	9 (22)	31 (76)	8	7 to 8
32. The child's emotional well-being concerning their condition	41	0 (0)	2 (5)	39 (95)	9	8 to 9
33. The child attends school regularly	41	2 (5)	3 (7)	36 (88)	9	7 to 9
34. Participation in sport or activities/has a hobby	42	2 (5)	9 (21)	31 (74)	7	6.25 to 9
35. Socialises with peer group	42	2 (5)	5 (12)	35 (83)	8.5	7 to 9
The non-ambulatory child						
36. The child's ability for independent transfers	42	3 (7)	5 (12)	34 (81)	8	7 to 9
37. The child's tolerance of splints	42	4 (10)	17 (40)	21 (50)	6.5	5 to 8
38. A reduction in the child's use of /reliance on splints	42	12 (29)	19 (45)	11 (26)	5	3 to 6.75
39. The child's ability to wear normal footwear	42	9 (21)	19 (45)	14 (33)	5.5	4 to 7
40. Range of motion in the hip	42	5 (12)	23 (55)	14 (33)	5.5	4 to 7
41. Range of motion in the knee	42	7 (17)	23 (55)	12 (29)	5	4 to 7
42. Range of motion in the ankle	41	7 (17)	22 (54)	12 (29)	5	4 to 7
43. Residual deformity in the hip	42	7 (17)	26 (62)	9 (21)	6	4.25 to 6
44. Residual deformity in the knee	41	7 (17)	27 (66)	7 (17)	6	4 to 6
45. Residual deformity in the foot and ankle	42	7 (17)	27 (64)	8 (19)	6	4.25 to 6
46. Equal leg lengths	41	16 (39)	14 (34)	11 (27)	5	3 to 7
47. Balanced symmetrical spine and pelvic alignment/position	42	3 (7)	8 (19)	31 (74)	7	6.25 to 8
48. Stable hips that are in joint	42	12 (29)	14 (33)	16 (38)	5	3 to 7
49. Balanced pelvis (both hips dislocated or both hips enlocated	42	6 (14)	7 (17)	29 (69)	7	6 to 8.75
50. The child's ability to use a standing frame	42	5 (12)	20 (48)	17 (40)	6	5 to 7.75
51. The child's ability to crawl or bottom shuffle	42	4 (10)	14 (33)	24 (57)	7	5.25 to 8
52. Foot position in standing/when using standing frame	42	3 (7)	17 (40)	22 (52)	7	5.25 to 8
53. Foot position when resting on wheelchair plates	42	4 (10)	16 (38)	22 (52)	7	5.25 to 8
54. The child's seating position in their wheelchair	41	1 (2)	4 (10)	36 (88)	8	7 to 9
55. Maintaining muscle strength	42	5 (12)	16 (38)	21 (50)	6.5	4 to 7
56. Absence of pain	41	1 (2)	1 (2)	39 (95)	9	8 to 9
57. Absence of pressure sores	41	1 (2)	2 (5)	38 (93)	9	8 to 9
58. Absence of poor wound healing	41	2 (5)	5 (12)	34 (83)	8	7 to 9
59. Avoidance of a fracture	41	3 (7)	4 (10)	34 (83)	8	7 to 9
60. Presence of a normal body fat percentage/BMI	42	3 (7)	19 (45)	20 (48)	6	5 to 7

61. Recurrence or relapse of initial need for intervention	40	4 (10)	8 (20)	28 (70)	7	5.75 to 8
62. Recurrent surgery or interventions for the same indication/problem	41	4 (10)	9 (22)	28 (68)	7	6 to 8
63. The child's emotional well-being about their condition	42	2 (5)	2 (5)	38 (90)	9	8 to 9
64. The child (if age appropriate) is independent with activities of daily living	41	1 (2)	6 (15)	34 (83)	8	8 to 9
65. The child attends school regularly	41	0 (0)	2 (5)	39 (95)	9	8 to 9
66. Participation in sport or activities/has a hobby	41	2 (5)	8 (20)	31 (76)	8	7 to 9
67. Socialises with peer group	42	1 (2)	2 (5)	39 (93)	9	8 to 9

Outcomes gaining "Consensus in" (75%)
Outcomes gaining "Consensus Out" (75%)

Table iv. Healthcare professional responses on optimal follow-up and COS collection.

Period	Total Respondents (n = 35), n (%)				
What is the minimum follow-up following an intervention in a ch	required before a COS collection				
1 year	18 (51)				
2 years	9 (26)				
3 years	4 (11)				
4 years	0 (0)				
5 Years	3 (9)				
Other	1 (3)				
	1.'Depends on age of child. Probably till skeletal maturity'				
For children that have had interv please choose the most appropri (Select one or more option)					
Age at which some children will walk (12 to 18 months)	12 (34)				
Starting school (5 years)	30 (86)				
End of primary school (11 to 12 years)	21 (60)				
Skeletal maturity	21 (60)				
Other	2 (6)				
	1.'I didn't really understand this question, and it does depend on the intervention '				
	2.'Over 2 when most children have found their feet and stabilized '				

Table v. Descriptive analysis of the importance of investigations as scored by healthcare professionals.

		Healthcare	Professionals			
	n	1 to 3	4 to 6	7 to 9	Median	IQR
1. Achieving the goals of surgery as agreed with the parents/carers	35	1 (3)	3 (9)	31 (89)	9	8 to 9
2. Gait analysis	35	7 (20)	14 (40)	14 (40)	6	4 to 7
3. Electromyography (EMG)	33	18 (55)	11 (33)	4 (12)	3	1 to 5
4. Plain radiographs of the pelvis	35	3 (9)	13 (37)	19 (54)	7	5.5 to 7.5
5. Plain radiographs of the spine	34	4 (12)	10 (29)	20 (59)	7	5.25 to 7
6. Measurements of the lordosis, and/or scoliosis, and/or kyphosis	34	2 (6)	16 (47)	16 (47)	6	5 to 7
7. Plain radiographs of the foot and ankle	35	7 (20)	14 (40)	14 (40)	6	4 to 7
8. Measurement of Reimers migration percentage	32	7 (22)	14 (44)	11 (34)	6	4 to 7.25
9. Other measurements of hip morphology (e.g. Shenton line, acetabular index)	33	5 (15)	14 (42)	14 (42)	6	4 to 7

Outcomes gaining "Consensus in" (75%)
Outcomes gaining "Consensus Out" (75%)

Table vi. Outcome measurement tools analyzed by healthcare professionals' regular use in practice.

	Healthcare professionals, n (%)					
Variable	Yes	No	Unable to answer			
Hoffer Functional Ambulation Scale	7 (20)	27 (77)	1 (3)			
Medical Research Council (MRC) grading	18 (51)	15 (43)	2 (6)			
Dimeglio	1 (3)	32 (91)	2 (6)			
Pirani	23 (66)	11 (31)	1 (3)			
Classification system of Scott et al	0 (0)	33 (94)	2 (6)			
Grading system of Neto, Dias & Gabrieli	2 (6)	31 (89)	2 (6)			
Criteria of Dias et al	4 (11)	29 (83)	2 (6)			
Criteria of King et al	0 (0)	32 (91)	3 (9)			
Grading system of Legaspi et al	1 (3)	32 (91)	2 (6)			
International Clubfoot Study Group (ICFSG) and Bensahel	1 (3)	32 (91)	2 (6)			
Quality of life Paediatric Outcomes Data Collection Instrument (PODCI) (2 to 10; 11 +)	11 (31)	22 (63)	2 (6)			
PedsQL	13 (37)	19 (54)	3 (9)			

APPENDIX 2: DELPHI ROUND 2

Table i. Respondent background.

Respondent background	Total respondents (n = 39), n (%)
Consultant orthopaedic surgeon	26(67)
Orthotist	2 (5)
Physiotherapist	4 (10)
Parent/carer	7 (18)

Table ii. Consensus criteria.

Consensus in	75% or more participants scored it as 'critical for inclusion', and less than 25% of participants scored it as 'not important for inclusion' *
Consensus out	75% or more participants scored it as 'not important for inclusion', and less than 25% of participants scored it as 'critical for inclusion' *
No consensus	Anything else not included in the other two categories. *

^{*}Participants selecting 'unable to answer' for a question were not included in this assessment.

Table iii. Descriptive analysis of participant response to the importance of outcomes in relation to the ambulatory and non-ambulatory child.

	All participants, n (%)					
	n	1 to 3	4 to 6	7 to 9	Median	IQR
The Ambulatory child			·		<u>.</u>	
2. The child maintains their walking potential.	38	0 (0)	3 (8)	35 (92)	9	8 to 9
3. An improvement in gait (walking pattern) perceived by patient or	37	0 (0)	6 (16)	31 (84)	8	7 to 9
family.						
4. Feet face forward as child walks.	37	3 (8)	25 (68)	9 (24)	5	5 to 6
5. Foot is plantigrade in standing / when using standing frame.	37	0 (0)	12 (32)	25 (68)	7	6 to 8
6. The child's ability to take some steps barefoot.	37	8 (22)	17 (46)	12 (32)	5	4 to 7
7. The child's ability to climb stairs independently.	36	2 (6)	14 (39)	20 (56)	7	6 to 8
12. The child's ability to wear off the shelf footwear.	38	4 (11)	15 (39)	19 (50)	6.5	5 to 7
13. Passive ROM in hip joint.	39	1 (3)	24 (62)	14 (36)	6	5 to 7
14. Passive ROM in Knee joint.	39	0 (0)	14 (36)	25 (64)	7	6 to 8
17. Residual deformity in the foot and ankle.	38	0 (0)	12 (32)	26 (68)	7	6 to 8
19. Equal leg lengths.	39	5 (13)	20 (51)	14 (36)	6	5.5 to 7
20. Balanced symmetrical spine and pelvic alignment/position.	38	0 (0)	5 (13)	33 (87)	8	7 to 8
21. Stable hips that are in joint.	39	5 (13)	6 (15)	28 (72)	8	6 to 9
24. Maintaining muscle strength.	39	0 (0)	2 (5)	37 (95)	8	7 to 9
29. Avoid obesity.	39	0 (0)	6 (15)	33 (85)	8	7 to 9
34. Participation in sport or activities/has a hobby.	39	0 (0)	5 (13)	34 (87)	8	7 to 9
The non-ambulatory child		·		·	<u>.</u>	
37. The child's tolerance of splints.	39	2 (5)	11 (28)	26 (67)	8	6 to 8
39. The child's ability to wear off-the-shelf footwear.	37	5 (14)	16 (43)	16 (43)	6	5 to 7
40. Passive ROM of the hip.	38	3 (8)	19 (50)	16 (42)	6	5 to 7
41. Passive ROM of the knee joint.	39	3 (8)	25 (64)	11 (28)	6	5 to 7
45. Residual deformity in the foot and ankle.	39	1 (3)	24 (62)	14 (36)	6	5 to 7
46. Equal leg lengths.	39	14 (36)	17 (44)	8 (21)	5	2.5 to 6
47. Balanced symmetrical spine and pelvic alignment/position.	38	1 (3)	4 (11)	33 (87)	7.5	7 to 8
48. Stable hips that are in joint.	39	13 (33)	14 (36)	12 (31)	5	3 to 7
49. Balanced pelvis (both hips dislocated or both hips enlocated).	39	3 (8)	6 (15)	30 (77)	8	7 to 8
50. The child's ability to maintain their use of a standing frame.	37	4 (11)	17 (46)	16 (43)	6	5 to 7
51. The child's ability to maximise their potential to move	38	0 (0)	4 (11)	34 (89)	8	7 to 9
independently eg crawling or bottom shuffling.						

52. Foot position plantigrade when standing or using a standing	38	1 (3)	10 (26)	27 (71)	7	6 to 8
frame.						
53. Foot position plantigrade when resting on wheelchair plates.	39	2 (5)	15 (38)	22 (56)	7	6 to 8
55. Maintaining muscle strength.	38	3 (8)	10 (26)	25 (66)	7	5.25 to 8
60. Avoid obesity.	39	0 (0)	5 (13)	34 (87)	7	7 to 8.5
61. Recurrence or relapse of initial need for intervention.	35	0 (0)	10 (29)	25 (71)	7	6 to 7
62. Recurrent surgery or interventions for the same	38	1 (3)	12 (32)	25 (66)	7	6 to 7
indication/problem.						

Outcomes gaining "Consensus in" (75%)
Outcomes gaining "Consensus Out" (75%)

Table iv. Descriptive analysis of the importance of outcomes as scored by healthcare professionals.

		Healthcar	Healthcare Professionals, n (%)			
Variable	n	1 to 3	4 to 6	7-9	Median	IQR
1. Gait analysis	31	3 (10)	7 (23)	21 (68)	7	5.5 to 7.5
2. Electromyography (EMG)	30	24 (80)	6 (20)	0 (0)	2	1 to 3
3. Plain radiographs of the pelvis assessing hips enlocated	31	1 (3)	5 (16)	25 (81)	7	7 to 8
4. Plain radiographs of the spine assessing the deformity	32	0 (0)	3 (9)	29 (91)	7	7 to 8
5. Plain radiographs of the foot and ankle	32	2 (6)	11 (34)	19 (59)	7	6 to 7.25
6. Measurement of Reimers migration percentage	31	3 (10)	17 (55)	11 (35)	6	5 to 7
7. Other measurements of hip morphology (e.g. Shenton line, acetabular index)	31	4 (13)	12 (39)	15 (48)	6	5 to 7

Outcomes gaining "Consensus in" (75%)
Outcomes gaining "Consensus Out" (75%)

Table v. Outcome measurement tools analyzed by healthcare professionals' regular use in practice.

	Healthcare professionals, n (%)			
Variable	Yes	No	Unable to	
			answer	
Medical Research Council (MRC) grading	19 (59)	13 (41)	0 (0)	
Pirani	16 (50)	16 (50)	0 (0)	
Quality of life Paediatric Outcomes Data Collection	5 (16)	27 (84)	0 (0)	
Instrument (PODCI) (2 to 10; 11 +)				
PedsQL	3 (9)	29 (91)	0 (0)	
Activities Scale for Kids (ASK) Score	0 (0)	32 (100)	0 (0)	
Goal Attainment Scale in Rehabilitation (GAS)	9 (28)	22 (69)	1 (3)	
Spina Bifida Hip Questionnaire (SPHQ) measuring	1 (3)	31 (97)	0 (0)	
physical function in children with dislocated hips				
Spina Bifida Paediatric Questionnaire – QoL	2 (6)	30 (94)	0 (0)	
The F-words Agreement	3 (9)	29 (91)	0 (0)	