

## Weighted outcomes of importance to parents

Outcome Measure	Ranked most important by parents	Ranked 2 <sup>nd</sup> most important by parents	Ranked 3 <sup>rd</sup> most important by parents	Total number of parents	Weighted score
Functioning bowel	P3; P6; P7; P8; P9; P11; P13; P15; P17; P18; P20; P21; P22; P23 (n=14/23 <sup>+</sup> ; 61%)	P2; P12 (n=2/23; 9%)	P24 (n=1/23; 4%)	17	47
Weight/Growth	P2; P10; P11; P12; P16; P17; P19; P20; P24 (n=9/23; 39%)	P5; P8; P15 (n=3/23; 13%)	P4; P6 (n=2/23; 9%)	14	35
Feeding	P2; P3; P7; P10; P11, P12, P13; P19; P20 (n=9/23; 39%)	P16; P18 (n=2/23; 9%)	P4 (n=1/23; 4%)	12	32
Child quality of life (includes social outcomes for child)	P4; P10; P11; P18; P23 (n=5/23; 22%)	P14; P19 (n=2/23; 9%)		7	19
Length of hospital stay		P7; P19; P24 (n=3/23; 13%)	P5; P11 (n=2/23; 9%)	5	8
No. of operations and procedures (No surgical complications or more procedures)	P17; P21; P22 (n=3/23; 13%)		P2; P14 (n=2/23; 9%)	5	11
Survival	P5; P14; P22 (n=3/23; 13%)			3	9
Chronic lung disease overlapping with days of invasive ventilation		P6 (n=1/23; 4%)	P14 (n=1/23; 4%)	2	3
Days on central line			P15; P16 (n=2/23; 9%)	2	2
Parent quality of life (includes couple and wider family relationships, grandparents not being able to meet the baby)		P19; P22 (n=2/23; 9%)		2	4
Cognitive ability		P4 (n=1/23; 4%)		1	2
<p><b>Key</b>  <sup>+</sup> 23 parents out of 24 ranked the outcomes of importance to them. (P1 ended their interview before ranking outcomes.)  Only 7 parents could separate the ranking of outcomes, demonstrating how overlapping 16 parents (P2; P3; P4; P7; P10; P11; P12; P13; P14; P17; P18; P19; P20; P21; P22; P23) thought the outcomes are.</p>					