

Data Analysis Legend (adopted from de Loe 1995)¹

CONSENSUS—A measure of the degree to which the group was able to agree on *support* (strong, weak etc).

High	70% of ratings in 1 category, or 80% in 2 contiguous categories
Med	60% of ratings in 1 category, or 70% in 2 contiguous categories
Low	50% of ratings in 1 category, or 60% in 2 contiguous categories

SUPPORT—Support indicates where the group's support lay when there was *consensus*. Categories include:

SS—Strong support

SS-ws—Strong, to weak support

ws—Weak support

WS-wo: Weak support to weak opposition

WO—Weak opposition

wo-SO: Weak, to strong opposition

SO—Strong opposition

When consensus is 'none', support is always 'ambiguous'. It can also be 'ambiguous' when:

(1) the level of consensus is 'low' and the ratings are divided equally between two categories (e.g. rating distributions of 10 0 0 10, or 10 0 10 0);

(2) the ratings are distributed in a pattern such as: 4 10 4 2. In this case, consensus would be considered 'medium' but the point of support could be either of 'SS-WS' or 'WS-WO'.

POLARITY*—Measures whether the group's ratings were polarized (e.g. 10 0 0 10 is a strongly polarized distribution). Categories include strong, weak, none. Polarity is determined using the variance of the distribution.

	De Loe 1995	Rahimzadeh 2018
Strong	Higher than 1.5	Higher than 1.1
Weak	Between 1.2 and 1.5	Between 0.8976 and 1.1
None	Less than 1.2	Less than 0.8976

*modified from de Loe; transformed 80th percentile categories based on highest variance of the distribution calculated in the Round 1 dataset (1.122)

	DIMENSION	RATING				CONSENSUS	SUPPORT	POLARITY
		1	2	3	4			
1. The best interest of children are primary	Relative Importance	7	2	1	0	High	Strong support	None (0.488)
	Feasibility	2	6	2	0	High	Strong to Weak support	None (0.444)
2. Children should be listened to, and involved in decision-making processes related to genomic and associated clinical data sharing in developmentally appropriate ways	Desirability	1	8	1	0	High	Weak support	None (0.222)
	Feasibility	0	7	3	0	High	Weak support	None (0.233)
3. Parents should be informed in a transparent manner how their child's genomic and associated clinical data will be securely managed and used.	Relative Importance	8	2	0	0	High	Strong support	None (0.177)
	Confidence	1	7	2	0	High	Weak support	None (0.322)
4. In a research context, data sharing infrastructures should enable children to withdraw consent to continued sharing of their genomic and associated clinical data when possible upon reaching the age of majority.	Desirability	2	8	0	0	High	Strong support to weak support	None (0.177)
	Feasibility	1	2	7	0	High	Weak opposition	None (0.488)
5. Parental authorization for ongoing, or future unspecified research should include the provision of information related to existing data governance.	Relative Importance	6	2	2	0	High	Strong support to weak support	None (0.711)
	Desirability	5	4	0	1	High	Strong support to weak support	Weak (0.9)
6. Values conveyed by family, legal guardians or primary care givers should be respected when possible.	Relative Importance	5	3	2	0	High	Weak support	None (0.677)
	Feasibility	2	2	4	2	Low	Weak opposition	Strong (1.155)
7. All professionals involved in processes of data sharing and data-intensive research have the responsibility to balance potential benefits and risks and discuss these with parents at the time of consent.	Desirability	5	3	1	1	High	Strong support to weak support	Weak (1.06)
	Feasibility	2	4	2	2	Low	Weak support-weak opposition	None (0.5)
8. The decision to share pediatric genomic and associated clinical data should be supported by an evaluation of realistic risks and benefits.	Feasibility	6	3	1	0	High	Strong support	None (0.5)
	Confidence	4	5	1	0	High	Weak support	None (0.455)

9. Duplicative collection of genomic research data involving pediatric patients should be avoided.	Desirability	6	3	1	0	High	Strong to weak support	None (0.5)
	Feasibility	0	7	2	1	High	Weak support-weak opposition	None (0.488)
10. Anonymized pediatric data should be made available via publicly accessible databases.	Desirability	4	3	2	1	High	Weak support to weak opposition	Strong (1.11)
	Feasibility	3	4	3	0	High	Weak support to weak opposition	None (0.66)
11. Identifiable pediatric genomic and associated clinical data should be coded and made available through a controlled or registered access process.	Desirability	7	1	1	1	High	Strong support	Strong (1.115)
	Feasibility	4	5	0	1	High	Weak support	Weak (0.844)
12. Providing children and their parents the opportunity to share genomic and associated clinical data is an obligation of those who generate such data.	Desirability	4	3	2	1	High	Strong support to weak support	Strong (1.11)
	Feasibility	3	2	4	1	Low	Weak opposition	Strong (1.122)