KIDS Policy Delphi
Round 2 Data Analysis (See Appendix A)

I. Re-ratings

POLICY DELPHI ITEM	DIMENSION	RATING[i] 1	2	3	4	CONSENSUS	SUPPORT	POLARITY
Parental authorization for ongoing, or future unspecified research should include the provision of information related to existing data governance.	Relative Importance	7	4	1	0	High	SS-ws	None (0.42)
	Desirability	8	4	0	0	High	SS-ws	None (0.22)
Values conveyed by family, legal guardians or primary care givers should be respected when possible.	Relative Importance	5	7	0	0	High	ws	None (0.24)
	Feasibility	1	4	7	0	High	wo	None (0.42)
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	7	4	1	0	High	SS-ws	None (0.42)
	Feasibility	3	6	2	1	Med	ws	None (0.74)
Anonymized pediatric data should be made available via publicly accessible databases.	Desirability	5	2	3	2	Low	ws-wo	Strong (1.31)
	Feasibility	5	3	4	0	Med	ws-wo	None (0.74)
Identifiable pediatric genomic and associated clinical data should be coded and made available through a controlled or registered access process.	Desirability	8	1	1	2	Med	SS	Strong (1.35)
	Feasibility	4	5	2	1	Med	SS-ws	None (0.83)
Providing children and their parents the opportunity to share genomic and associated clinical data is an obligation of those who generate such data.	Desirability	8	1	2	1	Med	SS	Weak (1.06)
	Feasibility	3	2	5	2	Low	wo	Weak (1.08)

[i] **Rating of 1** = Very important, Very desirable, Definitely feasible; **Rating of 2** = Somewhat important, somewhat desirable, possibly feasible; **Rating of 3** = Unimportant, Somewhat undesirable, Possibly not feasible; **Rating of 4** = Unimportant, Very undesirable, Definitely not feasible

Incidental (secondary) findings of clinically actionable, validated genomic results should be made available.	Desirability	6	4	2	0	High	SS-ws	None (0.41)
	Feasibility	0	9	2	1	High	ws	None (0.64)

II. Amendments

AMENDED STATEMENT	AGREE	DISAGREE	DECISION
Professionals involved in consent processes related to data sharing and data-intensive research have the responsibility to balance potential benefits and risks. A trained designate should be available to discuss these with parents at the time of consent.	9 (75%)	3 (25%)	Adopt amendment
Anonymized pediatric data should be made available via publicly accessible databases.	6 (50%)	6 (50%)	Undecided
Identifiable pediatric genomic and associated data should be coded and made available through a controlled access process.	6 (50%)	6 (50%)	Undecided
Providing children and their families the opportunity to share their genomic and associated data is an obligation of researchers.	5 (42%)	7 (58%)	Reject amendment
Incidental (secondary) findings of clinically actionable, validated genomic results should be made available.	8 (67%)	4 (33%)	Adopt new statement

IN YOUR VIEW, WHAT (IF ANYTHING) COULD BE DONE TO ENHANCE THE FEASIBILITY OF THE FOLLOWING STATEMENTS?	
Statement	**Main themes after thematic coding**
Values conveyed by family, legal guardians or primary care givers should be respected when possible	• No barriers to feasibility beyond those associated with the consent process [1]
	• Improve ability to assess values [2] via → standardization of questionnaires [1] → tools [1]
	• Differentiate the need to assess values between research and clinical contexts [1]
	• Include family/caregivers at the time of consent [1]
	• Allow data sharing choices that → are not conditional on research participation [1] → restrict future unspecific uses of data [1] → mandates reconsent for each use [1]
	• Improve bidirectional communication [1]
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	• Basic requirement as per ethics principles → informed consent [2] → responsible conduct of research [1]
	• Ensure standards for consent process via → verifying the process is commensurate with levels of risk the data sharing poses [1] → improving readability of consent wording
	• Barriers to feasibility are technical aspects of data security and quality which prevent realistic understandings of risks and benefits within the research enterprise
	• Feasibility of balancing unrealistic after consent due to other clinician demands • Limit the obligation to some, but not all health professionals because → of an inability to discuss potential benefits risks or consent families [1] → infrequent or indirect contact with families [3] → the obligation is too extensive [1]
	• Enhance researcher education/knowledge on data sharing benefits and risks [2]
Providing children and their parents the opportunity to share genomic and associated	• Improve data infrastructures and adequate funding resources to support them [3] → specifically multicentre databases [1]
	• Feasibility strengthened by a rights-based or ethics principle that supports the statement [1]

clinical data is an obligation of those who generate such data	• Establish a common information sharing platform
	• Specify types of sharing that can be expected e.g. return of material findings
	• There is no such obligation
	• Additional human and material resources needed

Appendix A—Non-parametric thresholds for consensus, polarity and support used in Rounds 1 and 2*

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 1995; transformed 80th percentile categories based on highest variance of the distribution calculated in the Round 1 dataset (1.122)