

**TITLE:** Recruitment and Retention in Longitudinal Research on Children and Families: A Quantitative and Qualitative Analysis

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### **Introduction**

Failures in recruitment and retention in longitudinal studies on child health and development can gradually reduce promising scientific discovery to unusable data if the sample becomes biased beyond the boundaries of reasonable correction. This literature analysis examines longitudinal studies of child health and development, focusing on practices that promote or interfere with successful recruitment and retention. Our goals are to: identify relevant studies; calculate and examine recruitment and retention rates for families; rank studies on their effectiveness in these areas; explore practices associated with effectiveness; use this information to develop formative research questions and guide the NCS Main Study.

### **Method**

We identified relevant studies through published and “gray” literature, abstracted information about recruitment and retention rates and practices, and verified the information with the studies’ investigators. We then conducted both quantitative and qualitative analyses of the recruitment and retention data.

### **Results and Conclusions**

Recruitment success was negatively affected by operational procedures that unintentionally limited contact opportunities, or created opportunities for families to misunderstand, doubt, or dismiss the participation request. Successful studies created an upfront sense of trust and belonging. Factors important to retention included child age at recruitment, burden during the early years, involvement of both the parents and children in data collection, and (within the U.S.) incentives. Tracing and tracking plans were essential to retention, but were strained by special populations with less residential stability. These findings will be used to develop formative research studies, whose results will be used to guide the NCS Main Study.

**Table 1: Studies reviewed for recruitment and retention**

<b>STUDY NAME</b>	<b>COUNTRY</b>
1958 National Child Development Study [NCDS]	UK
1970 British Cohort Study [BCS]	UK
Australian Aboriginal Birth Cohort Study [AABC]	Australia
Avon Longitudinal Study of Parents and Children [ALSPAC] <sup>1</sup>	UK
Birth to Twenty Study <sup>1</sup>	South Africa
Chicago Longitudinal Study [CLS]	U.S.
Danish National Birth Cohort [DNBC]	Denmark
Durham Child Health and Development Study [Durham]	U.S.
Early Childhood Longitudinal Study-Birth Cohort [ECLS-B]	U.S.
Early Head Start Research and Evaluation Project [EHSRE] <sup>1</sup>	U.S.
ELFE Longitudinal Study Pilot	France
Family and Community Health Study [FACHS]	U.S.
Fragile Families and Child Wellbeing Study	U.S.
Framingham Heart Study - Third Generation Cohort	U.S.
Fullerton Longitudinal Study <sup>1</sup>	U.S.
Growing Up in Australia [AU]	Australia
Gulf Coast Child and Family Health Study [G-CAFH]	U.S.
Infant Health and Development Program [IHDP]	U.S.
Lifeways Study	Ireland
Millennium Cohort Study	UK
National Longitudinal Survey of Youth 1997 [NLSY97]	U.S.
National Longitudinal Transition Study - 2 [NLTS-2]	U.S.
National Survey of Child and Adolescent Well-Being [NSCAW]	U.S.
National Youth Survey - Family Study [NYSFS]	U.S.
Norwegian Mother and Child Cohort Study [MoBa]	Norway
Ontario Child Health Study	Canada
Panel Study of Income Dynamics Child Development Supplement/Transition to Adulthood [PSID-CDS/TA]	U.S.
Pittsburgh Girls Study	U.S.
Pittsburgh Youth Study – Youngest Cohort	U.S.
Social Support and Family Health Study UK [SSFHS - UK]	UK
Study of Early Childcare and Youth Development [SECCYD]	U.S.
Three City Study	U.S.
Wisconsin Study of Families and Work [WSFW] <sup>1</sup>	U.S.

<sup>1</sup> These studies were included based only on review of published and gray literature; little or no PI feedback was received.

**Table 2: Baseline contact rates in ranked order**

<b>STUDY NAME</b>	<b>BASELINE CONTACT RATE</b>
<b>UPPER QUARTILE</b>	
National Youth Survey - Family Study	100%
1958 National Child Development Study	100%
Infant Health and Development Program	99%
Pittsburgh Girls Study	96%
Millennium Cohort Study	92%
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Early Childhood Longitudinal Study-Birth Cohort	91%
Growing Up in Australia	89%
ELFE Longitudinal Study Pilot	85%
Social Support and Family Health Study UK	83%
Framingham Heart Study - Third Generation Cohort	83%
Chicago Longitudinal Study	78%
National Survey of Child and Adolescent Well-being	73%
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<b>LOWER QUARTILE</b>	
Study of Early Childcare and Youth Development	72%
Wisconsin Study of Families and Work	67%
Birth to Twenty	60%
Australian Aboriginal Birth Cohort Study	55%
Gulf Coast Child and Family Health Study	48%
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**Table 3: Baseline cooperation rates in ranked order**

<b>STUDY NAME</b>	<b>BASELINE COOPERATION RATE</b>
<b>UPPER QUARTILE</b>	
Australian Aboriginal Birth Cohort Study	100%
1958 National Child Development Study	99%
Chicago Longitudinal Study	93%
Panel Study of Income Dynamics - Child Development Supplement/Transition to Adulthood	88%
Pittsburgh Girls Study	85%
Early Childhood Longitudinal Study - Birth Cohort	85%
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Millennium Cohort Study	84%
National Survey of Child and Adolescent Wellbeing	84%
National Longitudinal Transition Study-2	82%
Infant Health and Development Program	76%
Framingham Heart Study - Third Generation Cohort	75%
Wisconsin Study of Families and Work	75%
National Youth Survey - Family Study	73%
Gulf Coast Child and Family Health Study	68%
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<b>LOWER QUARTILE</b>	
ELFE Longitudinal Study Pilot	65%
Growing Up in Australia	64%
Study of Early Child Care and Youth Development	63%
Social Support and Family Health Study	58%
Norwegian Mother and Child Cohort Study	37%

**Table 4: Studies Included in Retention Subgroup Analyses**

<b>STUDY SUBGROUPS AND NAMES</b>	
<b>U.S. Studies Only</b>	
Chicago Longitudinal Study	National Survey of Child and Adolescent Well-Being
Durham Child Health and Development Study	National Youth Survey - Family Study
Early Childhood Longitudinal Study-Birth Cohort	Panel Study of Income Dynamics Child Development Supplement/ Transition to Adulthood
Early Head Start Research and Evaluation Project	Pittsburgh Girls Study
Family and Community Health Study	Pittsburgh Youth Study
Fragile Families and Child Well-being Study	Study of Early Childcare and Youth Development
Framingham Heart Study - Third Generation	Three City Study
Fullerton Longitudinal Study	Wisconsin Study of Families and Work
Gulf Coast Child and Family Health Study	
Infant Health and Development Program	
National Longitudinal Survey of Youth 1997	
National Longitudinal Transition Study-2	
<b>Recruitment at Birth Only</b>	
1958 National Child Development Study	Infant Health and Development Program
1970 British Cohort Study	Study of Early Childcare and Youth Development
Australian Aboriginal Cohort Study	Birth to Twenty Study
Danish National Birth Cohort	Fullerton Longitudinal Study
ELFE Longitudinal Study Pilot	Social Support and Family Health Study
Fragile Families and Child Wellbeing Study	
<b>Prenatal Recruitment Only</b>	
Avon Longitudinal Study of Parents and Children	Norwegian Mother and Child Study
Lifeways Study	Wisconsin Study of Families and Work
<b>U.S. Special Populations Only</b>	
Family and Community Health Study	Gulf Coast Child and Family Health Study
Three City Study	National Survey of Child and Adolescent Well-Being
Fragile Families and Child Wellbeing Study	National Longitudinal Transition Study-2
Chicago Longitudinal Study	Pittsburgh Youth Study
Early Head Start Research and Evaluation Project	
Infant Health and Development Program	
Pittsburgh Girls Study	

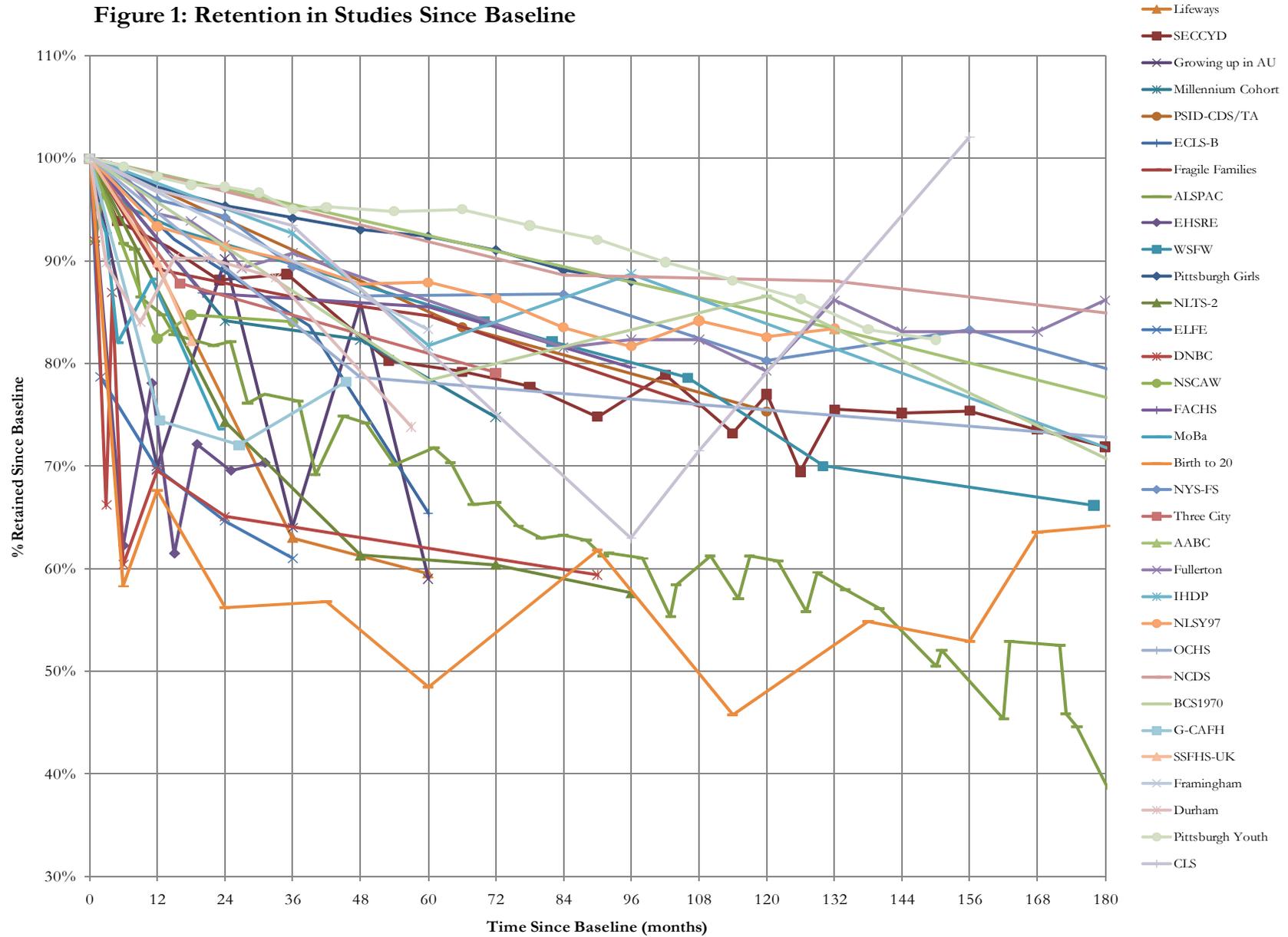
**Table 5. Estimated mean and median retention since baseline**

SUBGROUP/ TIME POINT	NUMBER OF STUDIES	PERCENT SAMPLE RETAINED		
		MEAN (SD)		MEDIAN
<b>ALL STUDIES</b>				
12 months	33	89.86	(7.39)	92.40
60 months	26	80.87	(10.85)	85.50
120 months	15	78.16	(8.71)	81.00
180 months	10	69.92	(11.03)	74.45
<b>U.S. STUDIES ONLY</b>				
12 months	20	92.12	(5.19)	93.20
60 months	16	83.98	(7.83)	85.95
120 months	9	79.97	(4.64)	81.60
180 months	4	72.13	(5.94)	74.85
<b>BIRTH RECRUITMENT ONLY</b>				
12 months	11	87.67	(9.86)	90.70
60 months	9	81.88	(11.42)	85.90
120 months	7	77.69	(10.19)	79.90
180 months	7	70.83	(10.71)	73.90
<b>PRENATAL RECRUITMENT ONLY</b>				
12 months	4	88.43	(4.42)	87.60
60 months	3	72.43	(12.01)	75.60
120 months	2	68.45	(4.85)	68.45
180 months	1	51.60	(N.A.)	51.60
<b>U.S. SPECIAL POPULATIONS ONLY</b>				
12 months	11	90.8	(6.48)	92.80
60 months	8	84.09	(8.19)	84.90
120 months	3	81.23	(5.76)	81.60
180 months	1	62.00	(N.A.)	62.00

**Table 6: Estimated slopes of best fit retention lines in ranked order**

<b>STUDY NAME</b>	<b>SLOPE COEFFICIENT</b>
<b>UPPER QUARTILE</b>	
Fullerton Longitudinal Study	-0.0601
1958 National Child Development Study (NCDS)	-0.0722
Birth to Twenty	-0.0732
National Youth Survey – Family Study (NYSFS)	-0.0837
Chicago Longitudinal Study (CLS)	-0.0856
1970 British Cohort Study (BCS)	-0.0909
Pittsburgh Youth Study - Youngest Cohort (PYS)	-0.1089
Ontario Child Health Study (OCHS)	-0.1124
National Longitudinal Survey of Youth 1997 (NLSY97)	-0.1125
Pittsburgh Girls Study (PGY)	-0.1149
Study of Early Child Care and Youth Development (families)	-0.1313
Australian Aboriginal Birth Cohort Study (AABC)	-0.1316
Infant Health and Development Program (IHDP)	-0.1527
Family and Community Health Study (FACHS)	-0.1786
Wisconsin Study of Families and Work (WSFW)	-0.1856
Fragile Families and Child Wellbeing	-0.1885
Panel Study of Income Dynamics - Child Development Supplement/Transition to Adulthood(PSID-CDS/TA)	-0.2073
Avon Longitudinal Study of Parents and Children (ALSPAC)	-0.2487
Three City Study	-0.2552
Danish National Birth Cohort (DNBC)	-0.2718
Framingham Third Generation Cohort (Framingham)	-0.2784
Durham Child Health and Development Study (Durham)	-0.3095
Millennium Cohort Study	-0.3231
National Survey of Child and Adolescent Wellbeing (NSCAW)	-0.3784
<b>LOWER QUARTILE</b>	
Gulf Coast Child and Family Health Study (G-CAFH)	-0.4028
National Longitudinal Transition Study-2 (NLTS-2)	-0.4112
Growing Up in Australia (AU)	-0.4368
Early Childhood Longitudinal Study – Birth Cohort (ECLS-B)	-0.5502
Early Head Start Research and Evaluation Project (EHSRE)	-0.5915
Lifeways Study	-0.7346
ELFE Longitudinal Study Pilot	-0.8593
Social Support and Family Health Study UK (SSFHS-UK)	-0.9674
Norwegian Mother and Child Cohort Study (MoBa)	-0.9702

**Figure 1: Retention in Studies Since Baseline**



**Figure 2: Linear Estimates of Retention in Upper and Lower Slope Quartile Studies Since Baseline**

