

## Technical report on the enhancement of Millennium Cohort Study data with linked electronic health records; derivation of consent weights

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### Scope

This document applies to the preparation of a Standard Operating Procedure (SOP) for the Wellcome Trust Data Linkage Project regarding the definition of consent weights for linkage to electronic health records between routinely collected data and data from the Millennium Cohort Study (MCS).

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## Introduction

The Millennium Cohort Study (MCS) is a multidisciplinary survey of over 19,000 children born in the UK in 2000-01 who are followed over time. A disproportionately stratified clustered sampling design was used to over-represent children living in Wales, Scotland and Northern Ireland, disadvantaged areas and areas with high proportions of ethnic minority groups. The first survey took place when the children were aged around 9 months old,<sup>2</sup> and subsequent surveys have taken place when the children were aged around 3 years, 5 years, 7 years, 11 years and 14 years old. The survey collects information from parents covering a range of domains including socio-economic circumstances, parenting, child's activities and behaviour, child and parental health, neighbourhood, relationships, childcare, and child's education and schooling. For further information on the MCS see: [www.cls.ioe.ac.uk/mcs](http://www.cls.ioe.ac.uk/mcs)

At the fourth survey (~ 7 years) parents or carers were asked to give consent to linkage of information collected within MCS to their child's routine electronic health records through to age 14 years. Further information on the consent procedure, including the consent form used and validation of the consents received has been reported by Shepherd (2013). This report describes the steps used to calculate the consent weights that should be used in analyses of linked MCS and electronic health data.

## Consent Analysis

### Productive families at MCS4

There were 13,857 productive families in the 4<sup>th</sup> sweep of the MCS (MCS4), for a total of 14,043 children.

### Consent categories

There were 13,047 children consenting, 996 nonconsenting. Note that there are no missing values for this outcome variable. The outcome variable was named C and coded as 1 (Yes) and 0 (No).

### Predictors of consent

Predictors of consent were initially identified among those used by (Ketende, 2010) to analyse nonresponse at MCS4, and by (Rich et al, 2013) to predict probability to participate to the MCS accelerometry study. Predictors were grouped as follows (Plewis, 2007):

1. UK country.
2. Socio-demographic variables: sex and ethnic group of the cohort member; if the cohort member is singleton or not; cohort member's sweep of MCS entry; main respondent's age at birth of the cohort member, main respondent's highest academic qualification, change of address between sweep 3 and 4.
3. Socio-economic variables: yearly net family income; housing tenure; socio-economic status (NS-SEC), type of accommodation and occupational status of the respondent.
4. Miscellaneous: whether there was a partner in the household, they had been interviewed; number of children in the household; household language; cohort member's longstanding illness; whether the mother had breast-fed the cohort child.

### Statistical models

Predictors of non-consent to data linkage was obtained using logistic regression with  $C$  as a binary outcome variable (reference category: consent:  $C=0$ ). Odds ratios (ORs), adjusted odds ratios (aORs) and 95% confidence intervals (CI) were calculated for the predictors introduced above in both univariable and multivariable regression models. All models were fitted taking into account the complex sampling design used in the MCS (Plewis, 2007).

The final models were defined using the following model selection strategy. For the analysis of whole UK data, we first selected all variables which were significant ( $p < 0.05$ ) in the univariable analyses. These variables were considered in the first multivariable model, and those which remained significant were included in the final multivariate model. In the country-specific analyses, all variables with an OR  $> 1.49$  or OR  $< 0.67$  (i.e. regression coefficient  $> 0.4$  or  $< -0.4$ ) were considered in the first multivariable model. The final model only included those variables which had an odds ratio within these bounds in the adjusted model.

Since there were incomplete cases in some predictors, a sensitivity analysis on the coefficients of the multivariable logistic regression models was performed by using a multiple imputation procedure. The standard error of the models' parameter estimates were obtained from a robust variance estimation procedure. The calculations were carried out on Stata version 13; we used the Stata routines **ice** (Carlin et al 2008) and **mi** (van Buuren 2007) to perform multiple imputation.

In all analyses, including the multiple imputation procedure, the MCS sampling design was taken into account using sampling weights adjusted for nonresponse to MCS4 (Plewis, 2007).

To develop country-specific weights, the final logistic regression multivariable models were used to estimate the probability of consent. In both single country and whole UK analysis multiple imputation was performed to take into account missing data on predictors. Country-specific sampling weights adjusted for nonresponse to MCS4 were used in the imputation procedures.

In all UK and country-specific analysis the predicted probability of consent was calculated as 1 minus the probability of non-consent estimated from multivariable logistic model. These calculated probabilities were multiplied by the longitudinal MCS4 weights giving the longitudinal weights for the data linkage MCS4 study. The weights were scaled to have as a sum the number of consenting MCS4 children (e.g. 13,047 for the all UK analysis). These consent weights should be used in the analyses including data from the all UK MCS cohort linked to other databases, e.g. Hospital Episode Statistics.

## Results

### Whole UK analysis

The results in Table 1 concern the distribution of the 14,043 MCS4 children consenting (13,047) and not consenting (996), and show unadjusted and adjusted odds ratios (OR and aOR) and *p*-values obtained from the final fitted multivariable logistic regression models following multiple imputation. The following groups showed a significantly lower probability of consent:

1. Children of Pakistani/Bangladeshi and Black/Black British ethnicity had over a two-fold increase in their odds of consenting.
2. Children living in households defined as flat/maisonette/studio/room/bedsit had 45% increased odds of consenting.
3. Children living in households whose yearly net income is > £31,200 (the fourth quintile of the household income distribution) had around 40% higher odds of consenting.

4. Children living in households where the main respondent was only one of the participant's parents or a person responding by proxy had an almost three-fold increase in their odds of consenting.
5. Children living in households with one child had 33% higher odds of consenting compared to those in households with two or three children.

### Country-specific analysis

Table 2 presents odds ratios and 95% CIs estimated from the final multivariable logistic regression models obtained following the selection strategy outlined in the statistical methods section, and following multiple imputation separately for England, Wales, Scotland and Northern Ireland. Note that only predictors with significant regression coefficients ( $p < 0.05$ ) are shown in the table. In this case the weights were defined on much smaller sets of predictors than those in Table 1; this is as expected, given the degree of between-country heterogeneity. The following groups defined the weights' models by country:

1. In England, the same variables defining the models in the whole UK estimation were included: ethnicity, type of accommodation, household income, living in households where the main respondent was only one of the participant's parents or a person responding by proxy, and number of children in the household played the same role as that in the models for data for the whole of the UK, as detailed above.
2. In Wales the weights were defined only in terms of living in households where the main respondent was only one of the participant's parents or a person responding by proxy increased the odds of consenting by more than three times.
3. In Scotland, comparing with households where both parents responded, the odds of consenting were 75% higher among single-parent households, and over three times higher where the main respondent was only one of the participant's parents or a person responding by proxy. In addition, if the household did not have a stable address, decreased 45% the odds of consenting.
4. In Northern Ireland comparing with households where both parents responded, the odds of consenting were over 4 times higher among households where the main respondent was only one of the participant's parents or a person responding by proxy. Age of the main respondent was also determinant with those under 19 years having odds of consent 90% smaller compared with respondents over 30 years. Type of

accommodation was also in the model, with households defined as flat/maisonette/studio/room/bedsit having a three-fold increase of the odds of consenting, much larger than the increase of 40% observed for England. Households without a stable address had an increase of 3.3 times in the odds of consenting, in the opposite direction of the decrement observed in Scotland.

The minimum, maximum, mean and standard deviation of sampling and non-response adjusted weights according MCS sampling stratum for UK, and for separate countries are shown in Tables 3 and 4. These summary statistics are broken down by the three types of district strata (advantaged, disadvantaged and ethnic) defined in the MCS sampling design.

The weights were stored in the variables **dovwt2\_Linkage** (whole UK analysis) and **dovwt1\_Linkage** (single country analyses)

The minimum, maximum, mean and standard deviation of sampling and non-response adjusted weights according MCS sampling stratum are represented on Table 4.

## Conclusions

The consent weights described in this document should be used in analyses of linked MCS and health data. Whole UK, or country-specific weights are available and should be used accordingly. Both sets of weights are available at the UK data service.



## References

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## Tables

**Table 1.** Distribution of the 14,043 MCS4 children (consenters and non-consenters) according to predictors of consent with unadjusted and adjusted odds ratios estimated with logistic regression after multiple imputation procedure with robust variance estimation of the parameters. The models refer to the whole of the UK sample.

Variable		Total	Consent Health Linkage		Univariable		Multivariable	
			Yes (n = 13047)	No (n = 996)				
			%	%	OR	p-value	OR	p-value
Main respondent's age (years) at the birth of the cohort member	14-19	1011	94.1	5.9	0.87	0.345		
	20-29	6219	92.5	7.5	1.12	0.213		
	30+	6813	93.2	6.8				
Main respondent's education	Degree	2834	92.2	7.8	1.32	0.039		
	Diploma in higher education	1557	93.1	6.9	1.15	0.365		
	A/As/S levels	1306	93.3	6.7	1.12	0.344		
	GCSE grades A-G	5718	94.0	6.0				
	Other academic qualifications	386	90.9	9.1	1.56	0.037		
	None of the above	2199	91.4	8.6	1.47	0.002		
When Joined MCS	Sweep 1	13543	92.9	7.1				
	Sweep 2	500	93.4	6.6	0.92	0.706		
Stable address	Yes	12664	92.9	7.1				
	No	1378	93.2	6.8	0.96	0.727		
Cohort member breast-fed	Yes	9511	93.7	6.4				
	No	4470	92.8	7.2	0.87	0.105		
Country	England	8955	93.1	6.9				
	Wales	2039	94.2	5.9	0.84	0.268		

	<b>Scotland</b>	1654	91.2	8.8	1.31	0.064		
	<b>Northern Ireland</b>	1395	92.3	7.7	1.13	0.425		
<b>Cohort child's ethnic group</b>	<b>White</b>	11691	93.8	6.2				
	<b>Mixed</b>	379	91.9	8.1	1.33	0.272	1.23	0.418
	<b>Indian</b>	343	90.9	9.1	1.51	0.111	1.60	0.088
	<b>Pakistani/Bangladeshi</b>	880	86.7	13.3	2.31	0.000	2.27	0.000
	<b>Black/Black British</b>	423	84.8	15.2	2.71	0.000	2.34	0.000
	<b>Other</b>	223	91.4	8.6	1.43	0.286	1.28	0.438
<b>Cohort child's sex</b>	<b>Male</b>	7110	92.6	7.4				
	<b>Female</b>	6933	93.3	6.7	0.90	0.137		
<b>Whether main respondent is in work or not</b>	<b>Is in work</b>	8744	93.4	6.6				
	<b>Not in work or leave</b>	5299	92.3	7.7	1.18	0.077		
<b>Housing tenure</b>	<b>Own/Mortgage</b>	9257	93.3	6.7				
	<b>Rent</b>	4366	93.5	6.5	0.97	0.748		
	<b>Other</b>	277	92.0	8.0	1.21	0.475		
<b>Type of accommodation</b>	<b>House or bungalow</b>	12772	93.4	6.6				
	<b>Flat, maisonette, studio, room, bedsit,</b>	1250	88.8	11.2	1.79	0.000	1.45	0.003
<b>Household annual income</b>	<b>1040-10400</b>	1755	91.8	8.3	1.27	0.062	1.19	0.197
	<b>10400-20800</b>	3897	93.4	6.6				
	<b>20800-31200</b>	3312	93.6	6.4	0.97	0.781	1.14	0.202
	<b>31200-52000</b>	3464	92.9	7.1	1.08	0.575	1.40	0.017
	<b>52000+</b>	1595	92.7	7.3	1.11	0.547	1.46	0.027
<b>Parents response summary</b>	<b>Single Parent</b>	2940	93	7	1.28	0.040	1.22	0.158
	<b>Both parents</b>	9289	94.4	5.6				
	<b>One of the two or no parents</b>	1814	85.1	14.9	2.97	0.000	2.82	<0.001
<b>NS-SEC</b>	<b>Managerial and professional occupations</b>	4058	92.3	7.7	1.15	0.210		
	<b>Intermediate occupations</b>	2429	94.2	5.8	0.86	0.192		

	<b>Small employers and own account workers</b>	911	93.5	6.5	0.96	0.835		
	<b>Lower supervisory and technical occupations</b>	626	94.3	5.7	0.84	0.409		
	<b>Semi-routine and routine occupations</b>	4672	93.3	6.7				
	<b>Not at work or long term unemployed</b>	1206	90.3	9.7	1.49	0.008		
<b>Number of children in the household</b>	<b>1</b>	1771	90.9	9.1	1.36	0.005	1.33	0.016
	<b>2-3</b>	10141	93.2	6.9				
	<b>&gt;=4</b>	2131	93.9	6.1	0.89	0.396	1.30	0.045
<b>Household language</b>	<b>English only</b>	12115	93.6	6.5				
	<b>Mostly English</b>	1350	88.1	11.9	1.96	0.000		
	<b>Mostly other</b>	578	87	13.0	2.17	0.001		
<b>Longstanding illness</b>	<b>No</b>	11348	93.3	6.7				
	<b>Yes</b>	2613	93.1	6.9	1.03	0.764		

\*Due to small sample size it was not possible to estimate the standard error for this category

**Table 2.** UK country specific odds ratios estimated with multivariable logistic regression after multiple imputation procedure with robust variance estimation of the parameter.

		England		Wales		Scotland		Northern Ireland	
		OR	<i>p</i> -value	OR	<i>p</i> -value	OR	<i>p</i> -value	OR	<i>p</i> -value
<b>Main respondent's age at the birth of the cohort member</b>	14-19							0.10	0.003
	20-29							0.86	0.463
	30+								
<b>Stable address</b>	Yes								
	No					0.45	0.026	3.31	0.001
<b>Cohort child's ethnic group</b>	White								
	Mixed	1.33	0.275						
	Indian	1.60	0.094						
	Pakistani/Bangladeshi	2.54	0.000						
	Black/Black British	2.60	0.000						
	Other	1.55	0.207						
<b>Type of accommodation</b>	House or bungalow								
	Flat, maisonette, studio, room, bedsit,	1.39	0.022					2.99	0.034
<b>Household annual income</b>	1040-10400	1.26	0.151						
	10400-20800								
	20800-31200	1.19	0.167						
	31200-52000	1.49	0.023						
	52000+	1.60	0.021						
<b>Parents response summary</b>	Single Parent	1.20	0.294	1.21	0.609	1.75	0.032	1.35	0.319
	Both parents								
	One of the two or no parents	2.63	0.000	3.38	0.000	3.14	0.000	4.39	0.000
<b>No. of children in the household</b>	1	1.42	0.012						
	2-3								
	>=4	0.75	0.071						

**Table 3.** MCS1 and MCS4 minimum, maximum, mean and standard deviation (SD) sampling and non-response adjusted weight estimates for analyses of the whole of UK sample.

	<i>n</i>	Sampling weights weight2	Overall weights wave 4 (dovwt2)				Overall weights wave 4 Record Linkage study (dovwt2_Linkage)			
			min	max	Mean	SD	min	max	Mean	SD
England - advantaged	3593	2.00	1.24	5.45	1.71	0.40	1.24	5.41	1.70	0.41
England - disadvantaged	3247	1.09	0.72	4.99	1.17	0.40	0.70	6.71	1.17	0.43
England - ethnic	1480	0.37	0.26	2.70	0.51	0.20	0.25	2.70	0.53	0.22
Wales - advantaged	595	0.62	0.41	1.78	0.56	0.15	0.40	1.87	0.55	0.15
Wales - disadvantaged	1328	0.23	0.15	0.70	0.24	0.07	0.14	0.69	0.24	0.07
Scotland - advantaged	787	0.93	0.36	3.17	0.89	0.37	0.35	3.05	0.89	0.37
Scotland - disadvantaged	727	0.57	0.22	1.97	0.67	0.31	0.22	2.14	0.67	0.32
Northern Ireland - advantaged	507	0.47	0.19	1.75	0.51	0.20	0.18	1.85	0.51	0.21
Northern Ireland - disadvantaged	783	0.25	0.10	1.13	0.32	0.14	0.10	1.11	0.32	0.14

Notes:

**Weight2:** whole UK sampling weight

**dovwt2:** the longitudinal weight at sweep 4 which is a product of sweep 3 overall weight (**covwt2**) and non-response weight at sweep 4

**dovwt2\_Linkage:** the longitudinal weight for consent study at sweep 4 which is a product of sweep 4 overall weight (**dovwt2**) and consent study non-response weight

**Table 4.** MCS1 and MCS4 minimum, maximum, mean and standard deviation (SD) sampling and non-response adjusted weight estimates for UK country-specific analysis.

	<i>n</i>	Sampling weights (weight1)	Overall weights wave 4 (dovwt1)				Overall weights wave 4 Record Linkage study (dovwt1_Linkage)			
			min	max	mean	SD	min	max	mean	SD
England - advantaged	3593	1.32	0.98	4.29	1.34	0.31	0.98	4.24	1.33	0.32
England - disadvantaged	3247	0.71	0.56	3.88	0.91	0.31	0.55	5.20	0.91	0.33
England - ethnic	1480	0.24	0.20	2.09	0.39	0.16	0.19	2.08	0.41	0.17
Wales - advantaged	595	1.77	1.20	5.23	1.64	0.44	1.19	5.58	1.64	0.46
Wales - disadvantaged	1328	0.65	0.43	2.06	0.71	0.20	0.42	2.06	0.71	0.20
Scotland - advantaged	787	1.23	0.46	4.04	1.14	0.47	0.45	3.91	1.14	0.48
Scotland - disadvantaged	727	0.75	0.28	2.49	0.84	0.39	0.28	2.72	0.85	0.40
Northern Ireland - advantaged	507	1.41	4.39	1.28	0.51	0.46	0.46	4.69	1.28	0.52
Northern Ireland - disadvantaged	783	0.76	0.26	2.85	0.81	0.35	0.26	2.84	0.82	0.36

Notes:

**weight1:** sampling weight

**dovwt1:** the longitudinal weight at sweep 4 which is a product of sweep 3 overall weight (**covwt1**) and non-response weight at sweep 4

**dovwt1\_Linkage:** the longitudinal weight for consent study at sweep 4 which is a product of sweep 4 overall weight (**dovwt1**) and consent study non-response weight.