

Introducing the England and Wales Office for National Statistics Longitudinal Study (ONS LS) and the Scottish Longitudinal Study (SLS) for research use. Additionally, demonstrating the linkage of health data to the SLS including maternity and Child Health Surveillance Programme data.

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What are the longitudinal studies?

 large-scale, anonymised record linkage study designed to capture representative sample of the population

- built using data available from...
 - Census
 - Vital Events (births, deaths)
 - NHSCR (migration into or out of the country)



Comparison of the 3 longitudinal studies:

- ONS Longitudinal Study (<u>ONS LS</u>) covers England & Wales: approximately 1% sample: 1971 onwards <u>www.ucl.ac.uk/celsius</u>
- Scottish LS (<u>SLS</u>) covers Scotland: 5.3% sample: 1991 onwards <u>http://sls.lscs.ac.uk</u>
- Northern Ireland LS (<u>NILS</u>) covers Northern Ireland: 28% sample: 1991 onwards <u>www.qub.ac.uk/research-</u> <u>centres/NILSResearchSupportUnit</u>
- Initial sample drawn from 1971 Census (EW), 1991 Census (Scot.), Health Card registration system (NI)
- Selected by birthday, irrespective of year of birth. No. of birthdays: 4 (EW), 20 (Scot.), 104 (NI)
- Maintained through addition of immigrations and new births with one of the sampling birthdays
- Losses to sample through deaths and out-migrations (though all records are retained in the database)

	Office for National Statistics ONS Longitudinal Study	National Records of Scotland Scottish Longitudinal Study	Northern Ireland Research Northern Ireland
Study sample	1% of the population of England & Wales	5% of the population of Scotland	28% of the population of Northern Ireland
ords from 2011 Census	580,000	~270,000	~500,000
Censuses in the study	1971, 1981, 1991, 2001, 2011	1991, 2001, 2011	1991, 2001, 2011
cademic user support	Cellsus Centre for Longitudinal Study Information	Scottish Longitudinal Study Development	NILS-RSU NORTHERN INELAND LONGTUDINAL STUDY RESEARCH SUPPORT UNIT
	& User Support, University College London	& Support Unit, University of St. Andrews & University of Edinburgh	Research Support Unit, Queens University Belfast
Census data available	Complete census data for study members and for people living in the same household as a study member	Complete census data for study members and for people living in the same household as a study member	Complete census data for study members and for people living in the same household as a study member
Event data available	 Civil registration system Births of sample members Births to sample mothers Stillbirths / Infant deaths Deaths of sample members Widow(er)hoods NHS Central Register Immigration Emigration Minor events Cancer registries Cancer data 	 Civil registration system Births of sample members Births to sample mothers Births to sample fathers Stillbirths / Infant deaths Marriages Deaths of sample members Widow(er)hoods NHS Central Register Immigration Emigration Scottish Govt. Education Directorate School level education data including attendance, exclusions, attainment and qualifications Other data available, subject to approval Hospital episodes Maternity data Cancer data 	 Civil registration system Births of sample members Births to sample mothers Births to sample fathers Infant mortality Deaths of sample members Health card registration system Immigration Emigration Internal migration Land & Property Services Housing data Health & Social Care Health data linked in one-off distinct linkage projects (e.g. breast screening, dental treatments) subject to approval

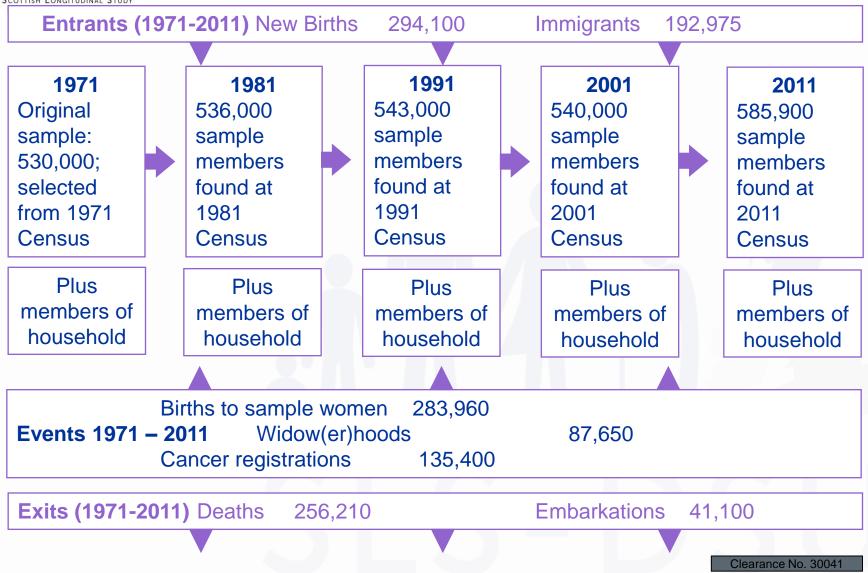


Census & Administrative data Longitudinal Studies Hub – CALLS Hub

- Co-ordinate, harmonise, and promote the work of the 3 Longitudinal Study (LS) support units:
- 1. Centre for LS Information and User Support (CeLSIUS for the ONS LS)
- 2. Scottish LS Development & Support Unit (SLS-DSU)
- 3. Northern Ireland LS (NILS) Research Support Unit (NILS-RSU)
- Provides a single portal for those seeking to use one or more LS in their research
- Data dictionary covering LS's
- Examples of uses of the LS's impact
- Help with running UK level analysis via eDatashield

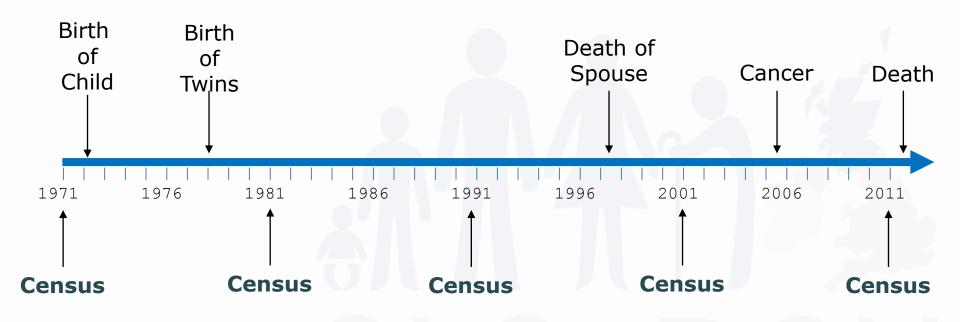


ONS LS Structure 25/09/14 1% - based on 4 birthdays





ONS LS Woman included from 1971 Census





Birthweight recorded in ONS LS

1.2 Information collected at birth registration

Most of the information, for both live births and stillbirths, is typically supplied to registrars by one or both parents.

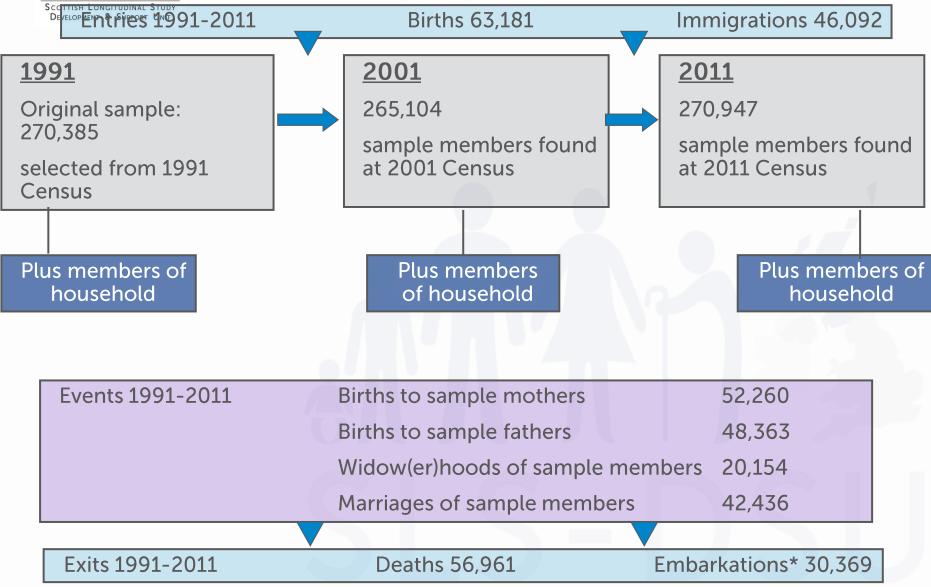
Information not supplied by the parents:

- For live births, details of birthweight are provided by the hospital where the birth took place, or by the midwife or doctor in attendance at the birth. The birthweight is passed to ONS as a consequence of the NHS birth notification being linked to the corresponding birth registration by the registrar.
- For stillbirths, details of cause of death, duration of pregnancy and weight of foetus are supplied on a certificate or notification by a doctor or midwife who was present at the birth, or who examined the body. The certificate or notification is then taken by the informant to a registrar.

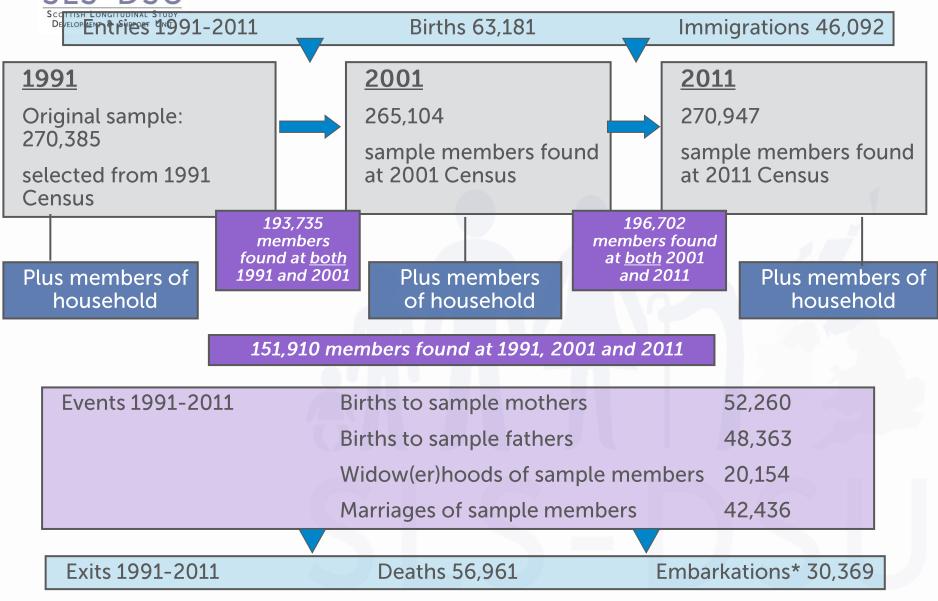
Birth Statistics: Metadata (Office for National Statistics (ONS), Oct 2014)

www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/births-metadata.pdf



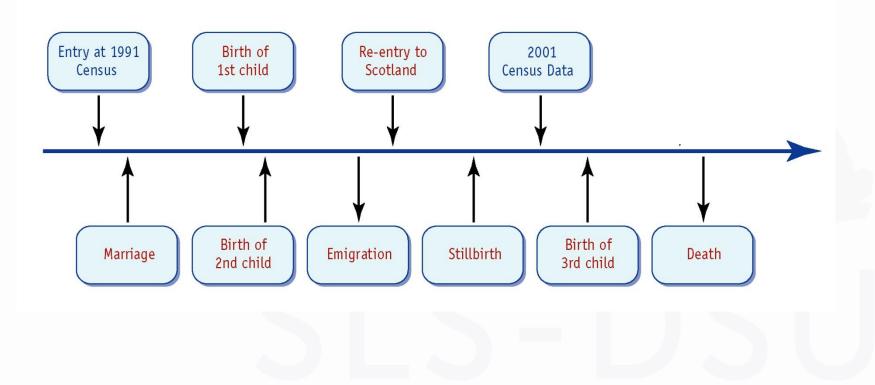


SLS Study structure 5.3% - based on 20 birthdays





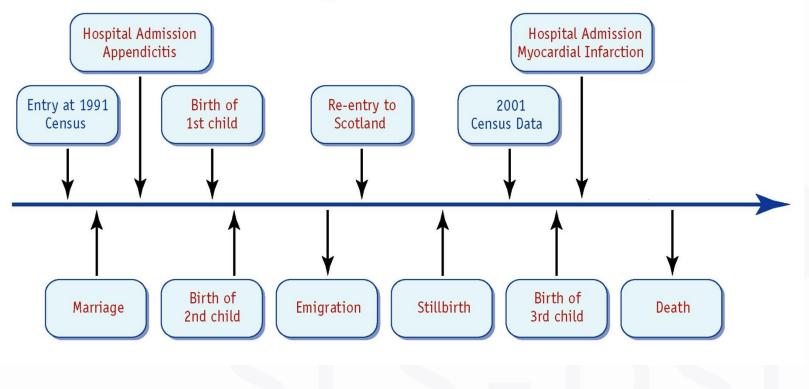
Example Event History of a Female SLS Member aged 21 at 1991 Census





Can add in NHS data...

Example Event History of a Female SLS Member aged 21 at 1991 Census





SLS: Education Data







School Education data 3 datasets:

- 1. School Census data
- 2. SQA attainment data
- 3. Attendance/absence & exclusions data available
- Data from 2007-2010 are now linked to the SLS



	Age at start of school year	Qualifications					
Primary 1	4 - 5						
Primary 2	5 - 6	S3/S4 Standard Grade or Access 3					
Primary 3	6 - 7	Standard Grade or Intermediate 1 then					
Primary 4	7 - 8	intermediate 2 Standard Grade (Credit level) or Intermediate 2					
Primary 5	8 - 9						
Primary 6	9 - 10	S5					
Primary 7	10 - 11	Intermediate 1 Intermediate 2 or higher					
S1	11 - 12	Higher					
S2	12 - 13						
S3	13 - 14	S6					
S4	14 - 15	Intermediate 2					
S5	15 - 16	higher					
		Advanced Higher					
S6	16 - 17						



Data available now 48,233 School census records

STAGE COHORT	-2	-1	0	1	2	3	4	5	6	7	8	9	10	11	12	13
2007 School Census				p1	р2	p3	p4	р5	р6	р7	s1	s2	s3	s4	s5	s6
2007 Exam results																
2008 School Census			p1	p2	р3	p4	р5	р6	р7	s1	s2	s3	s4	s5	s6	
2008 Exam results																
2009 School Census		p1	p2	р3	p4	p5	р6	р7	s1	s2	s3	s4	s5	s6		
2009 Exam results																
2010 School Census	p1	p2	p3	p4	р5	p6	р7	s1	s2	s3	s4	s5	s6			
2010 Exam results					<u> </u>									$\left \right\rangle$		
Number of pupils	3005	2878	2903	3020	2994	3001	2919	3050	3226	3206	3412	3261	3376	3367	2582	1535

Source: SLS



Linking Health Data to the SLS











Health data

Not held within the SLS database but can be linked on a project by project basis after applying to a Privacy Advisory Committee (<u>PAC</u>)

- SMR00 Outpatient Attendance dataset
- SMR01 General / Acute Inpatient and Day Case dataset
- SMR02 Maternity Inpatient and Day Case dataset
- SMR04 Mental Health Inpatient and Day Case dataset
- SMR06 Scottish Cancer Registry
- SMR11 Neonatal Inpatient dataset
- Accident and Emergency dataset
- Child Health Surveillance (CHSP-PS/ CHSP-S/SIRS)
- Outpatient dataset
- Maternity and Neonatal Linked Database
- Prescribing Information System (PIS)
- Scottish Birth Record
- Scottish Drug Misuse Database
- Scottish Morbidity Database



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- Scottish Drug Misuse Database
- Scottish Morbidity Database



Child Health data

Child Health Surveillance (CHSP-PS/CHSP-S/SIRS)

- Child Health Systems Programme Pre-School (CHSP-PS)
- Child Health Systems Programme School (CHSP-S)
- Scottish Immunisation Recall System (SIRS)

CHSP Pre-School (PS) Reviews

Orkney	
Grampian	
Shetland	
Highland	
Western Isles	
Dumfries & Galloway	
Forth Valley	
Borders	
Greater Glasgow & Clyde	
Tayside	
Fife	
Lothian	
Ayrshire & Arran	
Lanarks <mark>hire</mark>	
*Argyll & Clyde	
299 ¹ 199 ³ 199 ¹	2^{99} 2^{00} 2^{00} 2^{00} 2^{00} 2^{00} 2^{00} 2^{01} 2^{010} 2^{010} 2^{010}



CHSP-PS Reviews

- Birth Details
- Neonatal hearing screening
- Health Visitor First Visit
- 6-8 Week Review
- 27-30 Month Review (from 1 April 2013)
- Orthoptist vision screening (4-5 years)
- Recall Review
- Unscheduled Review

http://www.isdscotland.org/Health-Topics/Child-Health/Child-Health-Programme/Child-Health-Systems-Programme-Pre-School.asp#Reviews

- Historical CHSP-PS reviews:
 - 8-9 Month Review
 - 2-Year Review (replaced by 27-30 month review from 2013)
 - 39-42 Month Review
 - 48 Month Review



CHSP-PS Reviews

Universal Programme of Reviews and Screening Activities

- Neonatal hearing screening
- Health Visitor First Visit
- 6-8 Week Review
- 27-30 Month Review (from 1 April 2013)
- Orthoptist vision screening (4-5 years)
- Non-Universal Reviews
 - Birth Details
 - Recall Review
 - Unscheduled Review

http://www.isdscotland.org/Health-Topics/Child-Health/Child-Health-Programme/Child-Health-Systems-Programme-Pre-School.asp#Reviews



Universal CHSP-PS Reviews: First Visit (FV)

	N-CONFIDENCE th Nurse First Visit Report		PUBLIC HEALTH NURSE COPY
Fublic Healt	an Nuise First visit neport	DATE OF	VISIT:
NAME ADDRESS POSTCODE	· · · · · · · · · · · · · · · · · · ·	CHI NO GENDER BIRTH WEIGHT PLACE OF BIRTH MOTHERS D.O.B. PHN NO	HB HD TIME
	PLEASE WRITE CLEAR	LY IN BALL POINT PEN	EDD *
Please check the	information above and if appropriate, enter amendments below	Please also advise the GP of any chang	les.
Change of Surnal	me to:	Change of Forename to:	
Change of Addres	ss to:	Postcode:	
CASE LOAD PUI	BLIC HEALTH NURSE		
GP / TC NAME:		CHSP TC No.	SIRS TC No.
Schedule for Imm	unisation (Y/N)		

https://isdscotland.scot.nhs.uk/Health-Topics/Child-Health/Child-Health-Programme/First_Visit.pdf

U.	niversa	al CHS	P-PS Revie	WS:
	F	irst Vi	sit (FV)	
Mother/Carer:	Age	Smoker (Y/N)	Health (include current illness)	
Partner:	Age	Smoker (Y/N)	Health (include current illness)	
Is child exposed to passive smoking? (Y/N)				
Concerns raised by carer, enter (R)				
Feeding Illness Crying	Appearance	Weight S	ileeping Other	
FEEDING:- (Based on previous 24 hr per				
B	east milk Formula milk only only	Both	Date, if stopped	
At birth:			breast milk:	
On hospital discharge:				
On discharge from Comm Midwife:				
PHN 1st visit:				

Enter diagnoses, social issues or other concerns that are likely to be relevant to the continuing health and development of the child including congenital conditions.

ENTER PROBLEM STATUS

PLEASE PRINT CLEARLY	Sev	Lat	Professional F	Problem Status	Re	ad Co	de
(1)							
(2)							
(3)							
(4)							
(5)							

https://isdscotland.scot.nhs.uk/Health-Topics/Child-Health/Child-Health-Programme/First_Visit.pdf



Health Visitor First Visit (FV)

- for a SLS sample born 1993 to 2001 (DOBYr)- 29,000 sample members -53% covered in FV
 - ranging from 10% born in 1993 to 79% for those born in 2001
 - for DOBYr 1995-2001 21,00 sample 67% coverage in FV

CHSP-PS Reviews

Orkney	
Grampian	
Shetland	
Highland	
Western Isles	
Dumfries & Galloway	
Forth Valley	
Borders	
Greater Glasgow & Clyde	
Tayside	
Fife	
Lothian	
Ayrshire & Arran	
Lanarkshire	
*Argyll & Clyde	
1997 1993 1995 1991	19^{99} 20^{01} 20^{03} 20^{05} 20^{01} 20^{09} 20^{11} 20^{13} 20^{15}



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of sample linked

Feeding at PHNFirst VisitBreast33.6%Bottle54.1%Both3.3%INVALID9.0%100%100%Total15,000

Source: SLS



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 - for DOBYr 1995-2001 21,000 sample 67% coverage in FV

of sample linked

Feeding at First Visit	PHN	Non-Invalid distribution
Breast	33.6%	36.9%
Bottle	54.1%	59.5%
Both	3.3%	3.6%
INVALID	9.0%	
	100%	
Total	15,000	



Health Visitor First Visit (FV)

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 - ranging from 10% born in 1993 to 79% for those born in 2001
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• of sample *linked*

Feeding at PHN First Visit		Non-Invalid distribution	Distribution from a Report* (1995/6 sample)
Breast	33.6%	36.9%	25.3%
Bottle	54.1%	59.5%	67.9%
Both	3.3%	3.6%	6.8%
INVALID	9.0%		
	100%		Of 74500 sample 52394 (70%) were within the
Total 15,000			CHSP-PS, feeding was recorded for 35260 (67%)

Source: SLS

*Reilly J, & Armstrong J (2001). Assessment of the National Children Health Surveillance System as a toll for obesity surveillance at national and health board level. ISD



DEVELOPMENT & SUPPORT UNIT

Universal CHSP-PS Reviews: 6-8 week

							7				_	1
FEEDING: (Based on pro	evious 24 hr period).	.,	•					C	жт —		+	-
Breast milk only	ormula milk only	Both	Date, if stopped breast milk:			*			CF	+		+
			Child	amile Date ()]		ICD			+
Sleeping: (Y/N) Prone	Supine	Side	Child	smile Ref? (Y				F	IBO			
Concerns raised by carer,	[]							1		wborn H reening		
Feeding Hearing	Eyes N	Crying Novement	Appearance Sleeping	Ben	other		Weight		_ R _	_* L	*	ŗ
	ropriate, in the summa ropriate, in the area be											
											v Sumr	nary
Gross motor skills Pul	ll to sit (head lag decre	easing) \	entral suspension	(head briefly	to horizo	ontal)	Handlin	ng (not flop	py or sti	ff) 🗌]
Hearing and communication	Response to sudden	sound	Respor	nse to unseer	n carer's	voice]
Vision and social awareness	Intent regard of care	r's face	Follow d	angling objec	ct past mi	idline		So	ocial smi	le]
CHI No.												
Physical examination:	Length (cms)	Weight (kg)	OFC (cms)	-		Date meas	ured				
For each of the items I	below, enter N - no	rmal; A - abno	rmal; D - doubtf	ul or uncert	tain; I - r	not done	e/incomple	te.				
Heart Hips R	L Testes P		Genitalia	Fernoral Pt	r	L [ves: (red re	flex) R	L		
Enter diagnoses, soc		concerns that	t are likely to be	relevant t	o the co	ontinuir	ng health a	and deve	elopme	ent of t	he chi	ld
including congenital of	onditions.						ENTER P	ROBLEM	STATUS	5		
						F	Professional			-		
PLEASE PRINT CLEARL	Y				Sev	Lat	Code	Status	F	Read Co	de	
(1)												
(2)												_
(3)												
(4)												

https://isdscotland.scot.nhs.uk/Health-Topics/Child-Health/Child-Health-Programme/6-8Week.pdf

	Universal CHSP-PS Reviews:
SLS-DSU	6-8 week
Scottish Longitudinal Study Development & Support Unit	FEEDING: (Based on previous 24 hr period). Enter (Y) in one box only CHT I Breast milk only Formula milk only Date, if stopped breast milk: * Sleeping: (Y/N) Prone Supine Side Childsmile Ref? (Y/N/R) HBO Concerns raised by carer, enter (R) Feeding Iliness Crying Appearance Behaviour Weight Newborn Hearing Screening Results Hearing Eyes Movement Sleeping Other Weight R * *
	Development: If appropriate, in the summary boxes, enter N-normal, A-abnormal, D-doubtful or uncertain or I-not done/incomplete. If appropriate, in the area boxes, enter O-direct successful observation, H-history or carer's report or X-not achieved. Gross motor skills Pull to sit (head lag decreasing) Ventral suspension (head briefly to horizontal) Handling (not floppy or stiff) Image: Construction of the stift of the sti
	Hearing and communication Response to sudden sound Response to unseen carer's voice Image: Communication Vision and social awareness Intent regard of carer's face Follow dangling object past midline Social smile Image: Communication
	CHI No. Physical examination: Length (cms) Weight (kg) OFC (cms) Date measured Image: Complete in the items below, enter N - normal; A - abnormal; D - doubtful or uncertain; I - not done/incomplete. Heart Hips R L Testes R L Genitalia Femoral Pulses R L Eyes: (red reflex) R L
	Enter diagnoses, social issues or other concerns that are likely to be relevant to the continuing health and development of the child including congenital conditions. ENTER PROBLEM STATUS Professional Problem
	PLEASE PRINT CLEARLY Sev Lat Plotostaria Read Code (1)

https://isdscotland.scot.nhs.uk/Health-Topics/Child-Health/Child-Health-Programme/6-8Week.pdf

	Universal CHSP-PS Reviews:				
SLS-DSU	6-8 week				
Scottish Longitudinal Study Development & Support Unit	FEEDING: (Based on previous 24 hr period). Enter (Y) in one box only CHT CHT Breast milk only Formula milk only Both Date, if stopped breast milk: * Sleeping: (Y/N) Prone Supine Side Childsmile Ref? (Y/N/R) * Concerns raised by carer, enter (R) Newborn Hearing Screening Results Screening Results Feeding Illness Crying Appearance Behaviour Weight R * *				
Hearing Eyes Movement Sleeping Other R * Development: If appropriate, in the summary boxes, enter N-normal, A-abnormal, D-doubtful or uncertain or I-not done/incomplete. If appropriate, in the area boxes, enter O-direct successful observation, H-history or carer's report or X-not achieved.					
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	Heart Hips R L Testes R L Genitalia Femoral Pulses R L Eyes: (red reflex) R L Enter diagnoses, social issues or other concerns that are likely to be relevant to the continuing health and development of the child including congenital conditions. ENTER PROBLEM STATUS				
	PLEASE PRINT CLEARLY Sev Lat Code Status Read Code (1)				

. . .



6-8week review

- for a SLS sample born 1993 to 2001 (DOBYr) 29,000 sample members - 50% covered in 6-8week review
 - ranging from 10% born in 1993 to 77% for those born in 2001
 - for DOBYr 1995-2001 21,000 sample 63% coverage



6-8week review

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 - ranging from 10% born in 1993 to 77% for those born in 2001
 - for DOBYr 1995-2001 21,000 sample 63% coverage

• of sample *returned*:

3% mising on height 2% mising on weight 2% mising on OFC - Occipito frontal circumference (in cm's)

Development Observations:

7% Not done/Incomplete on Gross motor skills7% Not done/Incomplete on Vision & social awareness2% Not done/Incomplete on Hearing & communication



SLS members born 1991-2001 & Children of the SLS (COTS) born 1991-2005



First Visit 39,000

Is mother a smoker?			Is partner a smoker?	
No	72.2%		No	62.4%
Yes	27.8%		Yes	37.6%
	100%			100%
Total	35,000		Total	22,000

Source: SLS



SLS members born 1991-2001 & Children of the SLS (COTS) born 1991-2005

Sample size in total 57,000

6-8 week review 38,000

Development Observations:

5% Not done/Incomplete on Gross motor skills

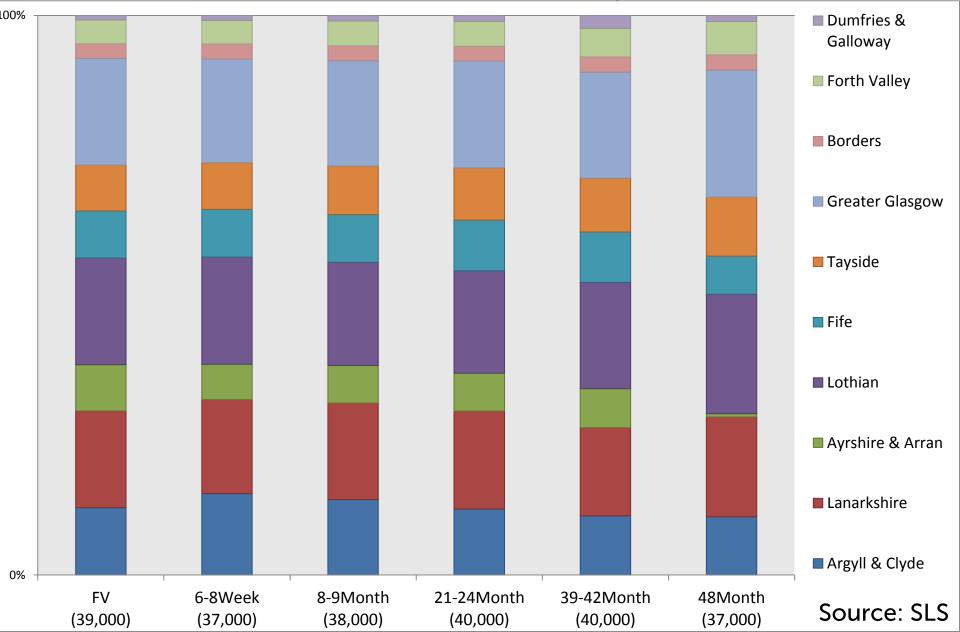
5% Not done/Incomplete on Vision & social awareness

2% Not done/Incomplete on Hearing & communication

Source: SLS

Example Project 2

SLS members & COTS- Sample size in total 57,000





Summary: CHSP for research

- CHSP data useful for research purposes but must think carefully about the sample/cohort given reviews are not all universal & that some were dropped
- Height & weight are more completely recorded than other information
- New universal CHSP-PS 27-30 Month Review (from 1 April 2013) includes LAC
- SLS-RSU Working Paper on using CHSP & maternity data (SMR02) available online May 2015 – will give info on CHSP-PS & CHSP-S



With thanks to

For SLS

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For ONS LS

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