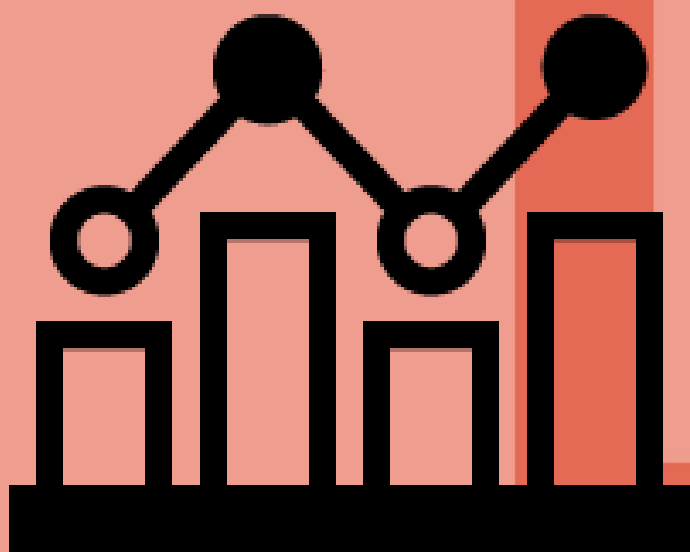


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Summary Profile of the UK LLC Resource: Data Freeze 1

Berman S¹, Evans K¹, Thomas R¹, Crane M¹, McLachlan S², Whitehorn R², Oakley J¹, Flaig R², Turner E¹, Boyd A¹

¹Population Health Sciences, Bristol Medical School, University of Bristol

²Centre for Medical Informatics, Usher Institute, University of Edinburgh

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Document History

Data Freeze Number	Date	Description	Changes from previous freeze
Freeze 1	19/10/2022	Initial freeze	n/a

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1 Introduction

The UK Longitudinal Linkage Collaboration (UK LLC) is a Trusted Research Environment (TRE) that uses an underlying 'Secure eResearch Platform UK (SeRP UK)' infrastructure (<https://serp.ac.uk/>). It is led by the Universities of Bristol and Edinburgh, in collaboration with Swansea University, University of Leicester, University College London and the contributing Longitudinal Population Studies (LPS).

The UK LLC TRE is designed to host de-identified data from many interdisciplinary, UK LPS; to systematically link these to participants' health, administrative and environmental records; and to provide a secure analysis environment. The UK LLC has ethical approval from the Health Research Authority Research Ethics Committee (Haydock Committee; ref: 20/NW/0446).

Each LPS provides information to the UK LLC on a sub-set of their participants (for those where permission has been established and excluding those who have objected to inclusion in the UK LLC TRE or have withdrawn from the LPS). The number of LPS contributing to the UK LLC TRE and the number of participants whose data are provided will change over time (as new LPS join the UK LLC, when LPS recruit new participants or when participants withdraw permission). These changes in participant numbers and status are communicated by LPS through the 'File 1' they submit on a quarterly basis to the UK LLC's linkage trusted third party (Digital Health and Care Wales, which is part of SeRP UK). The File 1 from each LPS contains a participant ID number, participant identifiers (i.e. name, address, date of birth, NHS ID) and a set of permission flags indicating if participants consent to be included in the UK LLC TRE and, if so, whether their identifiers can be shared with external organisations for linkage (NHS Digital) and geomodelling (University of Leicester). Deidentified LPS participant attribute data are submitted by LPS to SeRP UK in 'File 2s'.

The UK LLC's pooled sample is therefore dynamic and the UK LLC denominator will change over time. To manage this, the UK LLC will periodically establish a fixed 'data freeze' of the UK LLC pooled sample and provision data to approved users based on this headline denominator¹. The frequency of these data freezes aligns with refreshes of linked NHS Digital data².

This publication provides a Resource Profile for the 'data freeze' sample denominator:

- **Table 1** – Participants enrolled in LPS and included in the UK LLC resource
- **Table 2** – Participants in the UK LLC resource with permission to link to NHS Digital and their legal basis
- **Table 3** – Key sociodemographic information about participants in the UK LLC resource by source
- **Table 4** – 'Best measure' key sociodemographic information about participants in the UK LLC resource across LPS.

Please note: 'File 2s' can be submitted or updated at any time and if these occur between data freezes, the information presented in Tables 1–4 will not reflect these changes.

See [Datasets](#) | [UK Longitudinal Linkage Collaboration \(ukllc.ac.uk\)](http://ukllc.ac.uk) for further details.

¹ We note that UK LLC projects will often only include data from a sub-set of contributing LPS, and that some LPS may not approve a particular project. Each project-specific dataset is minimised to only include participants from the relevant LPS.

² The UK LLC data pipeline could enable more frequent data updates for the frozen pooled sample, if necessary. For example, during the COVID-19 pandemic, NHS Digital datasets were refreshed monthly, while the sample was refreshed quarterly.

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2 Table 1 – Participants enrolled in LPS and included in the UK LLC resource

The reason for lower contribution rates between LPS often comes down to the fair processing in place and whether COVID-19 data were available for participants. The UK LLC is working with LPS to establish the governance permissions necessary to maximise the number of enrolled participants included in the UK LLC resource.

LPS	N participants enrolled in LPS	N (%) participants sent to UK LLC	N participants not sent to UK LLC
ALSPAC	32 144	6396 (19.9%)	25 748
BCS70	18 888	8530 (45.2%)	10 358
BIB	29 664	28 591 (96.4%)	1073
ELSA	18 807	9080 (48.3%)	9727
EPICN	30 445	15 755 (51.8%)	14 690
EXCEED	11 103	11 045 (99.5%)	58
FENLAND	12 435	12 072 (97.1%)	363
GENSCOT	25 152	22 393 (89.0%)	2759
GLAD	37 940	37 010 (97.5%)	930
MCS	40 207	28 009 (69.7%)	12 198
NCDS58	18 563	8956 (48.2%)	9607
NEXTSTEP	15 629	6165 (39.5%)	9464
NICOLA	8739	5247 (60.0%)	3492
NIHRBIO_COPING	17 193	17 177 (99.9%)	16
NSHD46	5362	4289 (80.0%)	1073
SABRE	5251	4719 (89.9%)	532
TRACKC19	20 630	19 633 (95.2%)	997
TWINSUK	15 736	15 124 (96.1%)	612
UKHLS	42 330	8868 (20.9%)	33 462
Total	396 491	269 059 (67.9%)	137 159^a

^aN participants not sent to UK LLC and reasons for exclusion:

(i) 16 585 excluded because they died <2020.

(ii) 332 excluded because they died >=2020.

(iii) 20 424 excluded because they withdrew from LPS.

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(iv) 1444 excluded because they dissented from UK LLC.
(v) 31 361 excluded because they dissented from record linkage.
(vi) 28 710 excluded because governance not established.
(vii) 38 303 excluded for other reasons.

Footnote**Further details about exclusion criteria**

(i) & (ii) UK LLC does not prohibit LPS from sending data for participants who have died. However, some LPS have policies which preclude these participants from inclusion in the resource. Data for participants who died on or after January 1, 2020 are particularly important for COVID-19 research, and so LPS were requested to send these data where possible.

(v) Participants who have dissented from linkage can still be included in the UK LLC resource, with permission flags set accordingly. However, some LPS policies preclude participants from inclusion.

(vii) The most common 'other' reason for exclusion was that COVID-19 data were not available for participants.

Where a participant was excluded for more than one reason, LPS were asked to count participants once using the exclusion hierarchy (i-vii).

Information presented in Table 1 was provided by the LPS at the latest quarterly File 1 update August 8, 2022 (data processing tasks lead to a lag between submission of File 1s and the publication of the summary profile tables).

The following LPS highlighted that their samples were not representative of their full LPS cohort.

- Due to COVID-19 factors that impacted feasibility, ALSPAC carried out the UK LLC permission exercise via email and so only included participants with an email address. ALSPAC is planning to include a wider sample following a planned postal permission mailing.
- ELSA only provided data for participants who responded to a COVID-19 questionnaire and/or Wave 9 survey.
- NIHR BIOResources (NIHRBIO_COPING) only provided data for participants who responded to the COPING COVID-19 survey.
- UKHLS only provided data for participants who consented to UK LLC during their Wave 8 survey. Participants who did not participate in Wave 8 are currently excluded.

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3 Table 2 – Participants in the UK LLC resource with permission to link to NHS Digital and their legal basis

Permission flags are set at a participant level or at an LPS level by the LPS, giving participants or LPS control over which linkages are established or removed. The NHS in England and Wales operates the National Opt Out (NOO) scheme, where individuals can request that their health record is not shared for research purposes. Where explicit and informed consent is in place, the NOO is overridden. Where opt-out consent approaches are used in conjunction with Section 251 (s251) of the NHS Act 1996, then NOO is fully respected and no records will be accessed. The current NOO rate is 5.4% of the population; information on NOO rates can be found on the NHS Digital website³. For this reason, the UK LLC anticipates lower consent rates where s251 is used.

LPS	N participants sent to UK LLC	Participants with permission to link to NHS Digital	Participants successfully linked to NHS Digital and legal basis		
			s251	Consent	Total
ALSPAC	6396	≥95%	80-84.9%	85-89.9%	85-89.9%
BCS70	8530	80-84.9%		90-94.9%	90-94.9%
BIB	28 591	≥95%		≥95%	≥95%
ELSA	9080	75-79.9%		≥95%	≥95%
EPICN	15 755	≥95%	≥95%		≥95%
EXCEED	11 045	≥95%		80-84.9%	80-84.9%
FENLAND	12 072	≥95%		85-89.9%	85-89.9%
GLAD	37 010	≥95%		85-89.9%	85-89.9%
MCS	28 009	≥95%		80-84.9%	80-84.9%
NCD558	8956	80-84.9%		≥95%	≥95%
NEXTSTEP	6165	75-79.9%		≥95%	≥95%
NIHRBIO_COPING	17 177	≥95%		≥95%	≥95%
NSHD46	4289	≥95%	≥95%	≥95%	≥95%
TRACKC19*	19 635	≥95%		<5%	<5%
TWINSUK	15 124	≥95%	65-69.9%		65-69.9%
UKHLS	8868	90-94.9%		85-89.9%	85-89.9%
Total	236 702	228 531 (96.5%)	27 535 (82.0%)	158 150 (81.1%)	185 685 (81.3%)

³ <https://digital.nhs.uk/data-and-information/publications/statistical/national-data-opt-out/>

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For individual LPS, permission and linkage rates are recorded in 5% bands to minimise disclosure risk.

- Participants in SABRE have not permitted linkage to NHS Digital and therefore do not feature in Table 2.
- Participants in GENSCOT and NICOLA do not have permission to link to NHS Digital due to governance issues and geographical limitations and therefore also do not feature in Table 2.
- *A known linkage error has been identified for TRACKC19, which will be rectified in the next data freeze.

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4 Table 3 – Key sociodemographic information about participants in the UK LLC resource by source

The harmonised key sociodemographic variables currently include sex (assigned at birth), gender, age and ethnicity, from self-reported LPS data and from NHS Digital records. We relied on the expertise of data managers at LPS to identify the most useful variables. Harmonisation work is ongoing and the addition of other key sociodemographic measures are forthcoming.

Sociodemographic variables	N (%) LPS collected self-reported (Total N=269 061)	N (%) NHS Digital routine health records (Total N=185 685)
Sex		
Male	85 710 (31.9%)	69 012 (37.2%)
Female	146 328 (54.4%)	116 648 (62.8%)
NA	<10 (0.0%)	25 (0.0%)
Missing	37 023 (13.8%)	
Total	269 061	185 685
Gender		
Male	19 126 (7.1%)	
Female	45 147 (16.8%)	
Non-binary	577 (0.2%)	
Prefer to self-define	221 (0.1%)	
Prefer not to answer	<10 (0.0%)	
NA	53 (0.0%)	
Missing	203 937 (75.8%)	
Total	269 061	
Age		
<=18 years	13 411 (5.0%)	12 949 (7.0%)
19-30 years	14 969 (5.6%)	19 258 (10.4%)
31-59 years	104 179 (38.7%)	82 765 (44.6%)
60-74 years	51 363 (19.1%)	40 974 (22.1%)
75+ years	36 920 (13.7%)	23 870 (12.9%)
Missing	48 219 (17.9%)	5869 (3.2%)
Total	269 061	185 685

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Sociodemographic variables	N (%) LPS collected self-reported (Total N=269 061)	N (%) NHS Digital routine health records (Total N=185 685)
Ethnicity (7)		
White	103 099 (38.9%)	130 866 (70.5%)
Black	1637 (0.6%)	2020 (1.1%)
South-east Asian	16 955 (6.3%)	15 844 (8.5%)
Other Asian	1213 (0.5%)	1353 (0.7%)
Mixed	1806 (0.7%)	1739 (0.9%)
Other	792 (0.3%)	1475 (0.8%)
NA	486 (0.2%)	17 547 (9.4%)
Missing	143 073 (53.2%)	14 841 (8.0%)
Total	269 061	185 685
Ethnicity (6)		
White	174 615 (64.9%)	130 866 (70.5%)
Black	2018 (0.8%)	2020 (1.1%)
Mixed	3023 (1.1%)	1739 (0.9%)
Other	1284 (0.5%)	1475 (0.8%)
Asian (inc. Chinese)	19 883 (7.4%)	17 197 (9.3%)
NA	655 (0.2%)	17 547 (9.4%)
Missing	67 583 (25.1%)	14 841 (8.0%)
Total	269 061	185 685
Ethnicity (3)		
White	201 709 (75.0%)	130 866 (70.5%)
Non-white	28 109 (10.4%)	22 431 (12.1%)
NA	655 (0.2%)	17 547 (9.4%)
Missing	38 588 (14.3%)	14 841 (8.0%)
Total	269 061	185 685

Footnote

Both LPS and NHS Digital hold multiple entries of key sociodemographic information collected at different time points. To maximise inclusion of participants, self-reported data were harmonised across LPS by selecting all known measures and where multiple entries existed, the most recent was given precedence. NHS Digital data were harmonised using multiple sources.

All LPS collected sex assigned at birth and some LPS also collected gender. For NHS Digital, sex was determined using the most recent record from the Personal Demographics Service. NHS Digital does not provide any gender identification measures.

Ages as of 1 August, 2022 were calculated using month and year of birth, with the 1st of the month used as the default day of birth. For self-reported measures, where year and month of birth were not provided, age was calculated using the date of the collection exercise.

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and self-reported age. Where the day or month of data collection were not available, the 1st or January were used, respectively. For NHS Digital, age was determined using the most recent record from the Personal Demographics Service and filtered against mortality data.

Ethnicity was collected by most LPS, but to varying degrees of granularity. For NHS Digital, a hierarchy of source reliability established by the British Heart Foundation Data Science Centre was used⁴ (from most preferred to least preferred: General Practice Extraction Service Data for Pandemic Planning and Research; Hospital Episode Statistics (HES) Admitted Patient Care; HES Outpatients; HES Accident and Emergency). Where multiple entries existed from the preferred source, the most recent was given precedence. NHS Digital provides greater granularity and therefore ethnicity is reported as a harmonised set of 7, 6 and 3 categories to include all LPS that collected ethnicity data.

⁴ Wood A, Denholm R, Hollings S, Cooper J, Ip S, Walker V et al. Linked electronic health records for research on a nationwide cohort of more than 54 million people in England: data resource. *BMJ* 2021; 373 :n826. <https://doi.org/10.1136/bmj.n826> and BHF Data Science Centre GitHub Repository. <https://github.com/BHFDSC>

5 **Table 4 – ‘Best measure’ key sociodemographic information about participants in the UK LLC resource across LPS**

A hierarchical approach was used to determine the ‘best measure’ of each variable for each participant. If available, the most recent self-reported data were selected and where unavailable, NHS Digital data were used for those participants with linked records. See the Table 3 footnote to understand how self-reported and NHS Digital measures were calculated.

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Socio-demographic variables	ALSPAC	BCS70	BIB	ELSA	EPICN	EXCEED	FENLAND	GENSCOT	GLAD	MCS	NCD58	NEXTSTEP	NICOLA	NIHRBIO_COP	NSHD46	SABRE	TRACKC19	TWINSUK	UKHLS	Total	Total with data
Sex																					
Male	2284	3999	10 159	4011	6449	3852	5562	8591	7166	10 795	4410	2713	2233	7281	2250	3343	8728	2749	3810	100 385 (37.3%)	100 385 (38.2%)
Female	4112	4386	18 431	5069	9306	5151	6510	12 795	29 844	14 188	4508	3435	2801	9814	2039	1355	10 907	12 370	5058	162 079 (60.2%)	162 079 (61.8%)
NA																		<10		0 (0.0%)	0 (0.0%)
Missing		145	<10			2042		1007		3026	38	17	213	82		21		<10		6597 (2.5%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868	269 061	262 464
Gender																					
Male						4528		1443	7236					5919						19 126 (7.1%)	19 126 (29.4%)
Female						5864		2393	29 019					7871						45 147 (16.8%)	45 147 (69.3%)
Non-binary								<10	547					28						575 (0.2%)	575 (0.9%)
Prefer to self-define									208					13						221 (0.1%)	221 (0.3%)
Prefer not to answer								<10												0 (0.0%)	0 (0.0%)
NA						53														53 (0.0%)	53 (0.1%)
Missing	6396	8530	28 591	9080	15 755	600	12 072	18 557		28 009	8956	6165	5247	3346	4289	4719	19 635	15 124	8868	203 939 (75.8%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868	269 061	65 122

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Socio-demographic variables	ALSPAC	BCS70	BIB	ELSA	EPICN	EXCEED	FENLAND	GENSCOT	GLAD	MCS	NCDS58	NEXTSTEP	NICOLA	NIHRBIO_COP	NSHD46	SABRE	TRACKC19	TWINSUK	UKHLS	Total	Total with data	
Age																						
<=18 years			12 946						22					<10							12 968 (4.8%)	12 968 (5.0%)
19-30 years	1910		78			58		16	10 584	7574				926			622	781	643		23 192 (8.6%)	23 192 (9.0%)
31-59 years	3844	8530	13 973	1270		2486	5330	9435	21 486	15 742	8956	5749	243	7766		<10	10 153	5698	3794		124 455 (46.3%)	124 455 (48.4%)
60-74 years	422		70	3674	2303	4903	6742	7872	4398	2186			2796	7065		341	7550	4334	3017		57 673 (21.4%)	57 673 (22.4%)
75+ years	<10		<10	3959	13 452	1430		4063	520	45			1992	1329	4289	604	1310	4299	1413		38 705 (14.4%)	38 705 (15.1%)
Missing	220		1524	177		2168		1007		2462		416	216	91		3774		12	<10		12 068 (4.5%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868		269 061	256 993
Ethnicity (7)																						
White	4573	7702	11 863	5802	13 597	7147	11 490	4363	26 963	23 602	8394	3140		13 867	2575		18 757	11 808	8153		183 796 (68.3%)	183 796 (83.6%)
Black	23	42	618	60	<10	86	62	<10	154	850	42	260		53			75	217	115		2657 (1.0%)	2657 (1.2%)
South-east Asian	*	72	13 897	80	*	369	96	45	230	2566	20	481		100			152	*	323		18 513 (6.9%)	18 513 (8.4%)
Other Asian	*	19	894	25	*	47	128	<10	149	53	18	61		56			62	*	79		1602 (0.6%)	1602 (0.7%)
Mixed	69	30	799	23	13	51	94	16	413	440	25	148		82	<10		172	170	100		2645 (1.0%)	2645 (1.2%)

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Socio-demographic variables	ALSPAC	BCS70	BIB	ELSA	EPICN	EXCEED	FENLAND	GENSCOT	GLAD	MCS	NCDS58	NEXTSTEP	NICOLA	NIHRBIO_COP	NSHD46	SABRE	TRACKCT9	TWINSUK	UKHLS	Total	Total with data
Other	13	55	390	38	24	50	27	<10	226	197	49	56		81	10		31	118	11	1376 (0.5%)	1376 (0.6%)
NA	596	131	56	577	883	731	92		2740	47	37	526		1712	322		383	252	81	9166 (3.4%)	9166 (4.2%)
Missing	1098	479	74	2475	1227	2564	83	17 969	6135	254	371	1493	5247	1226	1382	4719	<10	2501	<10	49 306 (18.3%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868	269 061	219 755
Ethnicity (6)																					
White	4573	7702	11 863	5802	13 597	9663	11 490	20 502	34 924	23 602	8394	3140		15 879	2575	432	18 757	11 808	8153	212 856 (79.1%)	212 856 (86.5%)
Black	23	42	618	60	<10	115	62	15	174	850	42	260		62		27	75	217	115	2757 (1.0%)	2757 (1.1%)
Mixed	69	30	799	23	13	89	94	89	928	440	25	148		154	<10	<10	172	170	100	3343 (1.2%)	3343 (1.4%)
Other	13	55	390	38	24	78	27	22	397	197	49	56		22	10		31	118	11	1538 (0.6%)	1538 (0.6%)
Asian (inc. Chinese)	30	91	14 791	105	16	534	224	136	496	2619	38	542		200		464	214	60	402	20 962 (7.8%)	20 962 (8.5%)
NA	596	131	56	577	883	66	92	11	91	47	37	526		492	322	<10	383	252	81	4643 (1.7%)	4643 (1.9%)
Missing	1092	479	74	2475	1222	500	83	1618		254	371	1493	5247	368	1382	3796	<10	2499	<10	22 962 (8.5%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868	269 061	246 099
Ethnicity (3)																					
White	4573	7702	11 863	7989	15 673	9663	11 490	20 502	34 924	23 602	8394	4464		15 879	2575	432	18 757	11 808	8153	218 443 (81.2%)	218 443 (87.2%)

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Socio-demographic variables	ALSPAC	BCS70	BIB	ELSA	EPICN	EXCEED	FENLAND	GENSCOT	GLAD	MCS	NCDS58	NEXTSTEP	NICOLA	NIHRBIO_COP	NSHD46	SABRE	TRACKCT9	TWINSUK	UKHLS	Total	Total with data
Non-white	135	218	16 598	394	71	816	407	262	1995	4106	154	1615		438	11	497	492	565	628	29 402 (10.9%)	29 402 (11.7%)
NA	596	131	56	83	<10	66	92	11	91	47	37	23		492	322	<10	383	252	81	2763 (1.0%)	2763 (1.1%)
Missing	1092	479	74	614	11	500	83	1618		254	371	63	5247	368	1381	3790	<10	2499	<10	18 453 (6.9%)	
Total	6396	8530	28 591	9080	15 755	11 045	12 072	22 393	37 010	28 009	8956	6165	5247	17 177	4289	4719	19 635	15 124	8868	269 061	250 608

Footnote

*Unable to report actual number because of a disclosure control issue.

<10 is reported to minimise disclosure risk. In these cases, small numbers were added to 'missing' to maintain LPS denominators. 'Totals with data' and corresponding percentages are also reported.

6 Acknowledgements

The UK LLC is an initiative of the UKRI-funded Longitudinal Health and Wellbeing (LHW) National Core Study led by University College London (Grant code: MC_PC_20059). We thank the SeRP UK Team at Swansea University and NHS Digital Health and Care Wales for providing the TRE's infrastructure and support. We also thank the wider UK LLC and LHW teams for their contributions.

Data about participants in the UK LLC TRE have been collected through their longitudinal study or as part of their care and support. We wish to recognise and thank the LPS participants and each contributing LPS team, including data managers, administrators and those collecting data. We thank the following LPS for contributing data to the UK LLC TRE:

- Airwave Health Monitoring Study (AIRWAVE)
- Avon Longitudinal Study of Parents and Children (ALSPAC)
- 1970 British Cohort Study (BCS70)
- Born in Bradford (BIB)
- English Longitudinal Study of Ageing (ELSA)
- European Prospective Investigation into Cancer – Norfolk Study (EPIC-Norfolk)
- Extended Cohort for E-health, Environment and DNA (EXCEED)
- Fenland Study
- Generation Scotland
- Genetic Links to Anxiety and Depression Study (GLAD)
- Medical Research Council (MRC) National Survey of Health and Development (NSHD)
- Millennium Cohort Study (MCS)
- National Child Development Study (NCDS)
- National Institute of Health Research BioResource (NIHR BioResource) COVID-19 Psychiatry and Neurological Genetics (COPING) Study
- Next Steps
- Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)
- Southall and Brent Revisited (SABRE)
- TRACK-COVID Study
- TwinsUK
- The UK Household Longitudinal Study (Understanding Society).

We thank the NHS and particularly NHS Digital for their work in curating participants' health records and for making these available for public benefit research designed to improve health services.

An innovative project developing a new approach for linking well-established longitudinal studies to routine records. The data is held in a Trusted Research Environment, established by SeRP UK, where linked data from the studies taking part can be used in COVID-19 research across the UK.

UK Longitudinal Linkage Collaboration

Population Health Sciences

Bristol Medical School

Canynges Hall

39 Whatley Road

Bristol BS8 2PS

info@ukllc.ac.uk

If you require this document in an accessible format,
please email info@ukllc.ac.uk