

UK Longitudinal Linkage Collaboration Population Health Sciences Bristol Medical School Canynge Hall 39 Whatley Road Bristol BS8 2PS

UK Longitudinal Linkage Collaboration (UK LLC)

PUBLICATION POLICY

PUBLIC

Version 1.4

15 October 2024

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UK LLC Publication Policy PUBLIC

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Review History

Version	Review Date	Reviewed by	Section(s) amended	Authorised by
V1.1	14/11/2022	Katharine Evans,	2.2 & 5 to emphasise that	Andy Boyd,
		Governance & Policy	outputs/publications must	Director
		Manager	lie within project scope	
V1.2	21/02/2023	Katharine Evans,	Added Ts and Cs check &	Andy Boyd,
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		Manager		
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V1.4	15/10/2024	Katharine Evans, SDM	Added reference to UK LLC	Andy Boyd,
		(Gov & Users)	Explore & updated checklist	Director

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1. INTRODUCTION

1.1 Background

The UK Longitudinal Linkage Collaboration (UK LLC) organisation is led by the University of Bristol (UoB) and University of Edinburgh (UoE) and operated in collaboration with Swansea University, University of Leicester, City St George's, University of London and UCL. UK LLC manages the collation, curation and access to de-identified data about Longitudinal Population Study (LPS) participants held in the UK LLC Trusted Research Environment (TRE).

Safeguarding the anonymity and security of participants' data held in the UK LLC TRE are of paramount importance to UK LLC. All researchers must only include data in papers/presentations that have been approved through UK LLC's output review process. (see the <u>UK LLC Output Review Policy</u> for details)

1.2 Purpose

This policy sets out UK LLC's requirements for researchers to **publish papers and similar outputs** and to **deliver presentations** based on data accessed in the UK LLC TRE.

This policy will be reviewed to respond to any changes in the UK LLC risk assessment or risk treatment plan and at least annually.

2. SCOPE

This policy applies to all researchers who have accessed data in the UK LLC TRE who want to include their analyses in any output for public dissemination. This includes:

- Papers and similar outputs, e.g. reports, books
- Presentations.

3. ABBREVIATIONS

- LPS Longitudinal Population Study
- TRE Trusted Research Environment
- UK LLC UK Longitudinal Linkage Collaboration
- UoB University of Bristol
- UoE University of Edinburgh

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4. ROLES AND RESPONSIBILITIES

Who	What & Why
Researchers	 Only include data that are approved through UK LLC's output review process – see the <u>UK LLC Output Review Policy</u> Share all papers with UK LLC prior to submission Stay within scope of approved project and adhere to data owners' terms and conditions.
UK LLC teams (UoB and UoE)	Review all papers prior to submission.
UK LLC Director (UoB)	UK LLC Director is Senior Information Risk Owner (SIRO) for UK LLC.

5. RULES

- 1. All researchers must ensure that their analyses and outputs fall within the scope of their approved project and adhere to data owners' terms and conditions.
- 2. All papers and similar outputs **must be shared with UK LLC** for review prior to submission for publication.
- 3. UK LLC does not require to see **presentations** before they are delivered, but researchers **must acknowledge** the **use and funding of UK LLC's resource** and the **collaborative contribution of the LPS and other data owners and partners** see details in section 6.
- Contributions to papers and similar outputs should be acknowledged using <u>ICMJE</u> <u>authorship guidelines</u>. UK LLC staff, partners and contributing LPS staff are not expected to be authors unless they have provided material input and where authorship is justified under ICMJE guidelines.
- 5. Researchers should ensure papers and similar outputs are placed into the **public domain as quickly as possible.** UK LLC encourages researchers to use a preprint server such as <u>medRxiv</u> to make their outputs publicly available while formal peer review is underway.
- 6. Papers and similar outputs must be published as **Open Access** in line with <u>UKRI Open Access</u> <u>Policy</u>.
- 7. UK LLC staff do not conduct peer-review or scientific assessment.
- 8. Under all circumstances **UK LLC Executive Group reserves the right to submit letters or papers for publication** in response to any paper or similar output to explain the approaches of the collaborating LPS or to express an alternative scientific argument.
- 9. Datasets from UK LLC's TRE cannot be published in public databanks because the underlying data are sourced from confidential LPS data and linked routine records and can only be accessed in the TRE. Project data can be requested via UK LLC for the purposes of replication and/or scientific challenge. Where this is requested from a journal, we suggest that you provide the following statement:

'Data used in this research are made available via UK Longitudinal Linkage Collaboration (UK LLC), which is a Trusted Research Environment (TRE) developed and operated by the Universities of Bristol and Edinburgh using an underlying 'Secure

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eResearch Platform' provided by Swansea University. These data cannot be used or shared outside this environment. Researchers can apply to access the UK LLC TRE using the procedure outlined in the <u>UK LLC Data Access and Acceptable Use Policy</u>. UK LLC uses a system of managed open access for researchers who demonstrate their project is intended to improve the public good. Researchers can explore the data available in the UK LLC TRE using UK LLC's discoverability and data selection tool (https://explore.ukllc.ac.uk/).'

6. SUPPORTING MATERIALS

It is imperative that all researchers **acknowledge UK LLC and its partners, collaborators, funders and contributing data owners appropriately**. To help researchers, we have prepared the following materials.

Note: the materials contain information about **all the LPS** and **other data owners** that contribute data to UK LLC's TRE – researchers should adapt the materials to **only reference the LPS and other data owners included in their outputs**.

6.1 Papers and similar outputs

See the Publication Checklist in section 7 and detailed information about LPS for the supplementary materials of publications (DOC-ISM-032) on the <u>Resources for Researchers SharePoint</u>.

6.2 **Presentations**

Materials comprise a selection of slides, including acknowledgements and logos, which are available on <u>UK LLC's GitHub</u>.

7. UK LLC PUBLICATION CHECKLIST

UK LLC has worked with all partners, including contributing LPS and other data owners, to establish the **publication checklist** detailed below for papers and similar outputs.

Researchers can access an **editable Publication Checklist** (DOC-ISM-041) in the <u>Resources for</u> <u>Researchers SharePoint</u> to submit with their manuscript to <u>access@ukllc.ac.uk</u>

Data owners have devolved responsibility for review of manuscripts to UK LLC to minimise the time taken to release findings into the public domain. To reduce the length of the methods and acknowledgements sections, data owners have also agreed to be referenced concisely, with more detailed descriptions of their individual LPS samples and acknowledgements provided via supplementary materials (see DOC-DAT-032 on the <u>Resources for Researchers SharePoint</u>).

Please send the **completed checklist**, **your manuscript and lay summary** to <u>access@ukllc.ac.uk</u> for approval **prior** to journal submission with sufficient time for processing. **We expect to process all manuscripts within two weeks of receipt**, but may be able to expedite processing if required. Please note that if there are any substantive changes to the manuscript after UK LLC review, re-review must be sought.

We will review all manuscripts to check that the **publication checklist** is **adhered to**, that all manuscripts fall within the **scope of the approved project**, that all parties are **accurately described** and **acknowledged** and that all **project-specific terms and conditions** are **adhered to**. The UK LLC

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Executive Group may withhold the right to publish any manuscript that threatens to bring UK LLC or any of the contributing data owners into disrepute or which threatens the confidentiality of LPS participants.

UK LLC PUBLICATION CHECKLIST

Со	ndition	Yes	No	If 'No' please explain
1.	I agree to make this paper open access via a compliant journal or some other repository – I have followed the <u>UKRI's Open Access Policy.</u>			
2.	I have included 'UK LLC' as a keyword.			
3.	In the 'Methods' section (or equivalent) I have included the following key text for describing UK LLC: 'The UK Longitudinal Linkage Collaboration (UK LLC) is the national Trusted Research Environment (TRE) for the UK's longitudinal research community. Led by the University of Bristol and University of Edinburgh, UK LLC is designed to support the UK's unparalleled collection of Longitudinal Population Studies (LPS) by providing record linkage and secure analysis and data curation services. This project has been approved by UK LLC and its contributing data owners. Information about this project and its outputs can be accessed via UK LLC's Data Use Register (<u>https://ukllc.ac.uk/data-use-register/</u>). UK LLC has ethical approval from the Health Research Authority Research Ethics Committee (Haydock Committee; ref: 20/NW/0446).'			
4.	In the 'Methods' section (or equivalent) I have cited each of the LPS I have used based on their preferred reference citation (see DOC-DAT-032 on the <u>Resources for Researchers SharePoint</u>). I have also provided a link to my supplementary materials with detailed descriptions of each LPS' sample (see DOC- DAT-032).			
5.	 In the 'Results' section I have included the following wording where I have used Ordnance Survey AddressBase® Plus Sites Layer data relating to: England: '©Local Government Information House Limited copyright and database rights 2021, RDCA-395.' Wales: 'Hawlfraint a hawliau cronfa ddata cyfyngedig Ty Gwybodaeth ar Lywodraeth Leol 2021, RDCA-395.' Scotland: 'This data contains data created and maintained by Scottish Local Government.' 			

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Condition	Yes	No	If 'No' please
 Condition In the Acknowledgements section I have included the following statement: This work uses data accessed within UK LLC's Trusted Research Environment (TRE). We thank the Secure eResearch Platform (SERP UK) team at Swansea University and NHS Digital Health and Care Wales for providing the TRE's infrastructure and support. This work uses data provided by participants of the contributing LPS, which have been collected through their LPS or as part of their care and support and/or interactions with UK government services. We wish to recognise and thank the participants and each contributing LPS team. We thank the following LPS for contributing data that made this research possible [KEEP ONLY THE LPS YOU HAVE INCLUDED IN YOUR RESEARCH]: Airwave Health Monitoring Study (AIRWAVE) Avon Longitudinal Study of Parents and Children (ALSPAC) Born in Bradford (BIB) 1970 British Cohort Study (BCS70) 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 (GLAD) Study including the Eating Disorders Genetics Initiative (EDGi) and COVID-19 Psychiatry and Neurological Genetics (COPING) Study (INCS) National Institute of Health Research BioResource (NIHR BioResource) COVID-19 Psychiatry and Neurological Genetics (COPING) Study Next Steps 	Yes		explain

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Condition	Yes	No	If 'No' please explain
 Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) Southall and Brent Revisited (SABRE) TRACK-COVID Study TwinsUK Twins Early Development Study (TEDS) including the Environmental Risk (E- Risk) Longitudinal Twin Study The UK Household Longitudinal Study (Understanding Society). 			
A full list of acknowledgments, including support for each LPS, is provided in the supplementary materials.' [see DOC-DAT-032 on the <u>Resources for Researchers</u> <u>SharePoint</u>].			
[ONLY INCLUDE IF USING NHS ENGLAND DATA] 'We thank the NHS and particularly NHS England for their work in curating participants' health records and for making these available for public good research designed to improve health services.' [ONLY INCLUDE IF USING NHS WALES DATA]			
 'We thank SAIL Databank for their work in curating participants' health records and for making these available for public good research designed to improve health services.' [ONLY INCLUDE IF USING GEO-DATA] 			
'We thank the University of Leicester and City St George's, University of London for providing geospatial data and Ordnance Survey for providing AddressBase® Plus.			
 I have deposited all syntax, code lists, software, derived variables and accompanying documentation in the appropriate UK LLC Git repository to be made available to future users. 			
 I have emailed a lay summary of my paper, highlighting findings and potential impact, to <u>access@ukllc.ac.uk</u> 			
 I will send an electronic copy of the final accepted paper to <u>access@ukllc.ac.uk</u> for inclusion on the UK LLC website. 			
10. I will advise the UK LLC Communications Team (<u>comms@ukllc.ac.uk</u>) in advance of any press release, video or media activity planned and I will tag <u>https://www.linkedin.com/company/ukllc/</u> on LinkedIn.			
 I will provide a short scientific summary of this paper if required by UK LLC's Executive Group. 			

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Condition	Yes	No	If 'No' please explain
UK LLC will use the following information to improve the usability of datasets within the UK LLC TRE.	l included the fol manuscript:	lowing	g LPS in my
For your project, you were permitted access to data belonging to a number of different LPS. We want to know which LPS you included in your manuscript and which you omitted. We are particularly interested to understand the reason for leaving an LPS out.	I excluded the fol explain why):	llowing	g LPS (please

8. RELATED DOCUMENTS

- POL-ISM-012 UK LLC Output Review Policy
- DOC-ISM-041 UK LLC Publication Checklist
- DOC-DAT-032 Information about LPS for researchers to include in the Supplementary Materials of their publications.

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