



UK LLC | UK Longitudinal Linkage Collaboration

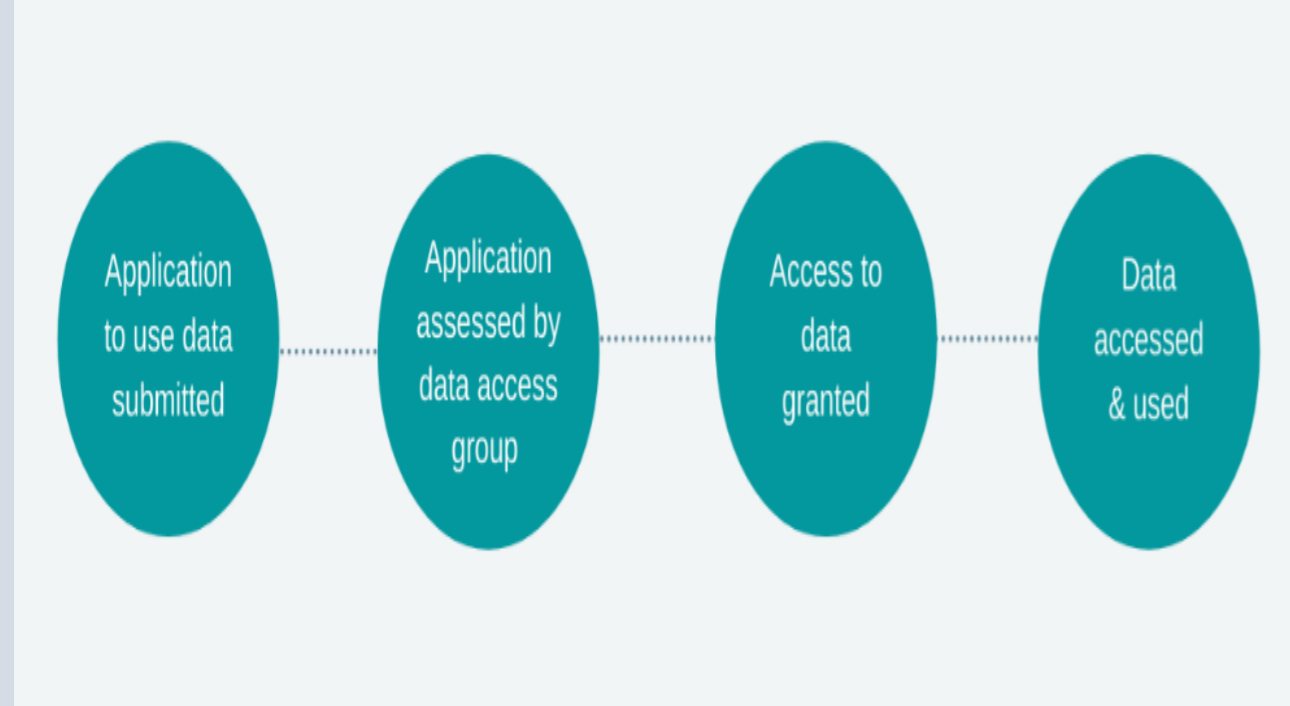
BETTY IDEMUDIA  
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# Enhancing the role of PPIE in Linked Longitudinal Data Access Process

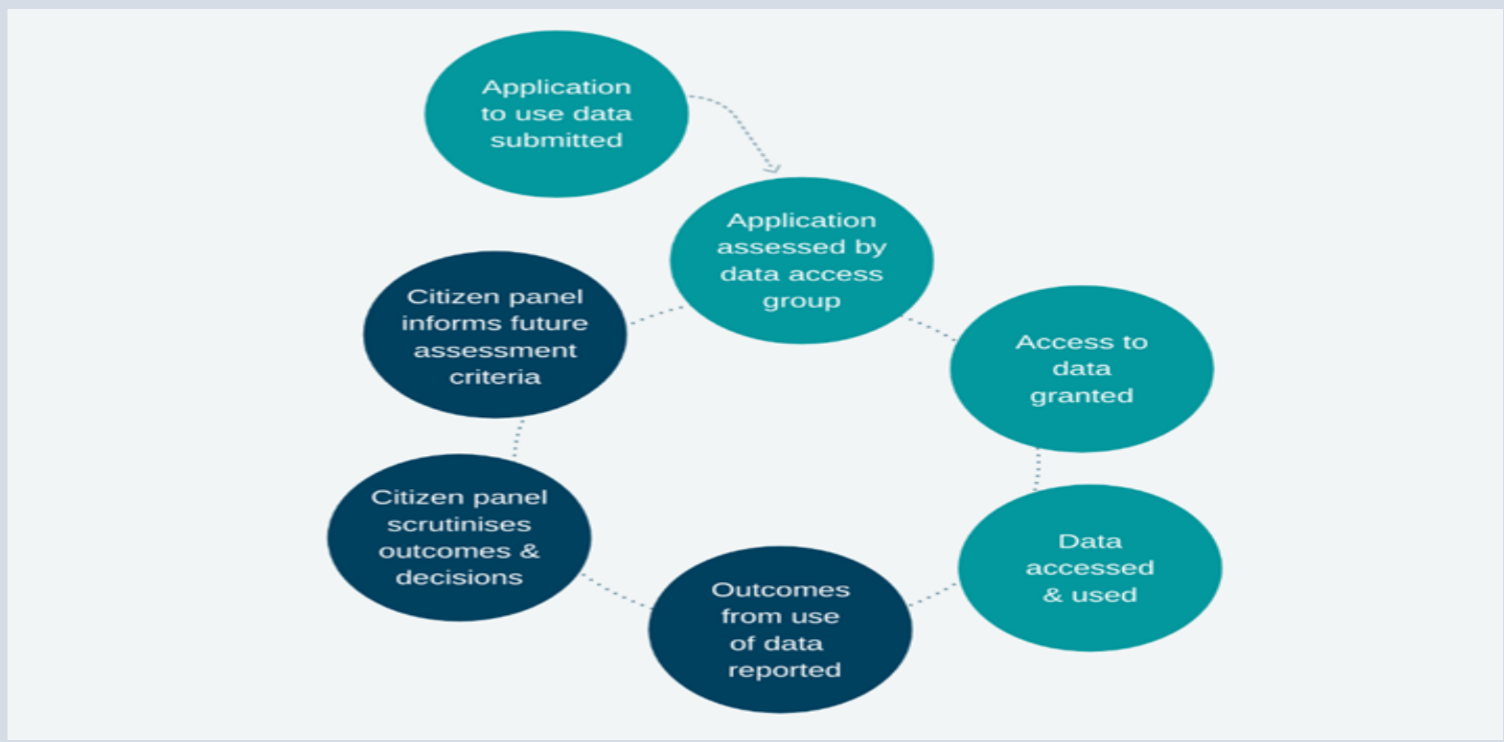
## Background

Engaging the public in linked data access process not only gives them a chance to be involved in the process but also fosters greater trust in the organizations responsible for collecting and storing the data, as well as in the researchers who use the data. The availability of linked longitudinal data facilitates cross-sector research and serves present and future needs for policy-related research (3).

<p><b>What is Linked Data ?</b></p> <p>Linked data is a collection of different information about a specific subject (person/community/household), brought together to understand specific trends.</p>	<p><b>What is the current limitation?</b></p> <p>The public's confidence in the way data is shared for research and innovation, particularly with the private sector, seems to be lacking in recent years (1).</p>	<p><b>What is UK Longitudinal Linkage Collaboration (UK LLC) Citizen Panel's solution?</b></p> <ul style="list-style-type: none"> <li>Engage diverse cross-section of the public in discussions about the acceptance and appropriateness of data usage</li> <li>Inclusion of underrepresented communities</li> <li>Enhance public trust in Trusted Research Environment (TRE)</li> </ul>
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how data access decisions are currently made (2)



Proposed learning data governance model (2)

The UK LLC Citizen Panel aims to create a new framework for public participation in decisions about the extent of research that is conducted for public benefit and whether or not longitudinal data usage and linkage is acceptable and useful.

## Recruitment

- Steering Group
- Longitudinal Population Studies (LPS) participants
- Third Sector Organisations – Seldom-heard group

## Reference

- [Data-driven research and healthcare: public trust, data governance and the NHS | BMC Medical Ethics \(springer.com\)](#)
- [Learning data governance: a new approach to decisions about data | Understanding patient data](#)
- <https://ukllc.ac.uk/>

## Other Project Involvement

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1 | NHS Wales hospital datasets
2 |
3 | Last modified: 18 Jul 2024
4 |
5 | ## Introduction
6 |
7 | The NHS Wales hospital datasets comprise the "Outpatients Database for Wales (OPDW)", "Patient Episode Datasets for Wales (PEDW)",
8 | "Critical Care Datasets (CCDS)", "Emergency Department datasets (EDDS)" and the "Intensive care case mix and activity (ICCA)". The
9 | hospital datasets "do not include" all mental health or maternity-specific hospital activity.
10 |
11 | **OPDW**, **ICCD-10**, **NHS National** and **NHS Wales National codes** are used in the OPDW and PEDW datasets. See the "Coded
12 | variables guide" (/_Coding/coding_intro.md) for further details.
13 |
14 | ## Coverage of hospital datasets
15 |
16 | The hospital datasets cover "inpatient admissions, outpatient appointments", "critical care", "intensive care" and "accident &
17 | emergency attendances" at "hospitals in Wales".
18 |
19 | The hospital datasets "include" private patients treated in NHS hospitals and care delivered by English trusts.
20 | The hospital datasets were linked either by NHS number on a combination of alternative patient identifiable fields; "all five hospital
21 | datasets will be available in the UK LLC TRE".
22 |
23 | **Table 1** Names, temporal coverage and availability of hospital datasets in the UK LLC TRE (the datasets in italics are retired)
24 | | **Name in TRE** | **Full name** | **Domain** | **From** | **Until** | **Data available in TRE (supp1/supp2)** |
25 | |---|---|---|---|---|---|
26 | | OPDW | Outpatients Database for Wales | Outpatients | 01/04/2004 | Ongoing | TBC |
27 | | PEDW | Patient Episode Datasets for Wales | Inpatients | 01/04/1995 | Ongoing | TBC |
28 | | CCDS | Critical Care Datasets | Critical care | 01/02/2003 | Ongoing | TBC |
29 | | EDDS | Emergency Department datasets | A & E patients | 01/04/2009 | Ongoing | TBC |
30 | | ICCA | Intensive care case mix and activity | Intensive care | 01/05/2008 | Ongoing | TBC |

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Building a Guidebook repository on GitHub for NHS Wales datasets

## Acknowledgements

HDR UK: [Home - HDR UK](#)  
UK LLC: <https://ukllc.ac.uk/>  
[Usher Institute](#) | [The University of Edinburgh](#)

