

AWAHRD

A Work and Health Research Data Platform

The AWAHRD (A Work And Health Research Data) project aimed to assess and improve how work and health data can be collected and linked to health and administrative records and to test the feasibility of building a platform for work and health research to improve data accessibility.

Linking Occupational Data to Health and Administrative Records

The opinions of public contributors from the NHS CHECK (nhscheck.org) study, a study on the health and wellbeing of healthcare workers, as well as ex-serving personnel from the UK Armed Forces (kcl.ac.uk/research/kcmhr), were sought through two online workshops and/or written feedback.

The aim of the workshops was to hear the views of members of the public, with specific occupational histories, on the benefits and risks of data linkage and to find out what could be done to ease any concerns.

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All workshop participants acknowledged that linking occupational data to administrative data sets as well as health data would benefit research on the health of the working age population, provided that data are anonymised, consent is obtained and that the research is carried out for public benefit.

Perceived benefits of data linkage

If **safeguards** are in place, it can help researchers analyse big data and help health services **plan for the future**

Could lead to a more **holistic analysis** of a situation

Lends more **power to the analysis** and offers chance to **explore minority groups**

Identify **patterns of disease** and inequalities

Better data architecture **saves time**

Used **constructively for public good** and **inform evidence-based decisions**

Benefits far outweigh the risks – think of all that cannot be achieved if data is not linked



Perceived risks and concerns around data linkage

Older generations may be more risk averse and **vulnerable populations** may need extra support to understand what they are consenting to

Commercial gain and/or political manipulation could lead to immoral handling of data

Data is **never 100% secure**

Decisions and policies may be made based on **low quality evidence**, wrong analysis, or oversimplification

Workers from **specific professions** may need more privacy/anonymity

Workers may feel a **loss of control** not knowing what happens to their data once they've consented, and are not always clear on what they are consenting to



How to mitigate the risks

If public data is used for commercial interests, then **generated profit should support public services**

Increase **legislative** guidance and **organisational commitments to best practices**

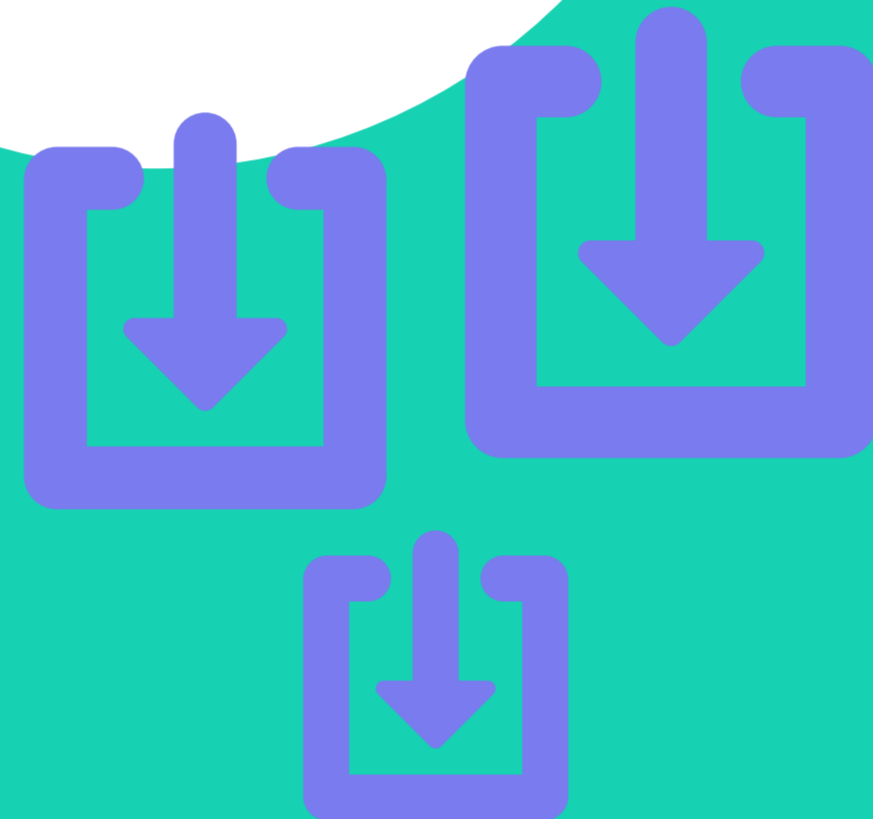
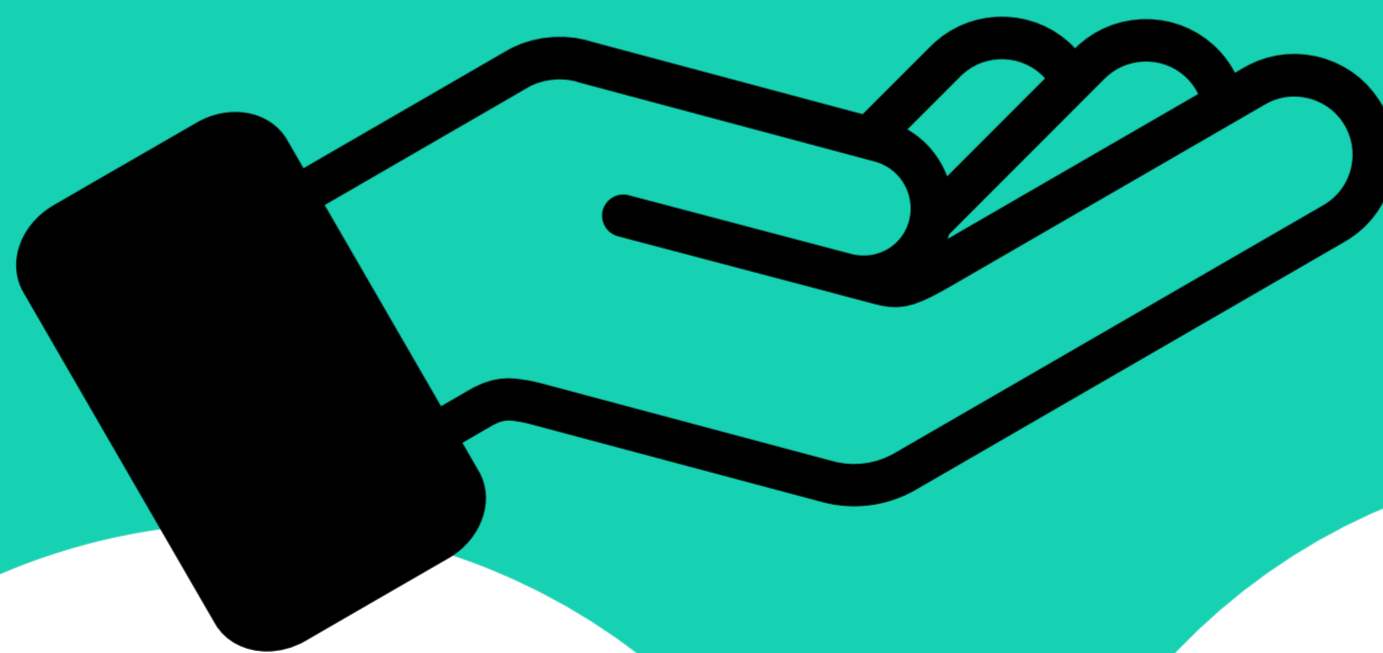
Keep data safe and provide information on **Trusted Research Environments (TREs)** and the **Five Safes**

Provide **periodic updates** to participants

Use **accessible communication**, e.g. video animations

Make **Participant Information Sheets** more **engaging and succinct**; allow for partial consent options

Have well-designed databases that ensure a good trade-off between data security and accessibility



Collaborators



THE UNIVERSITY
of EDINBURGH



Thomas
Ashton
Institute



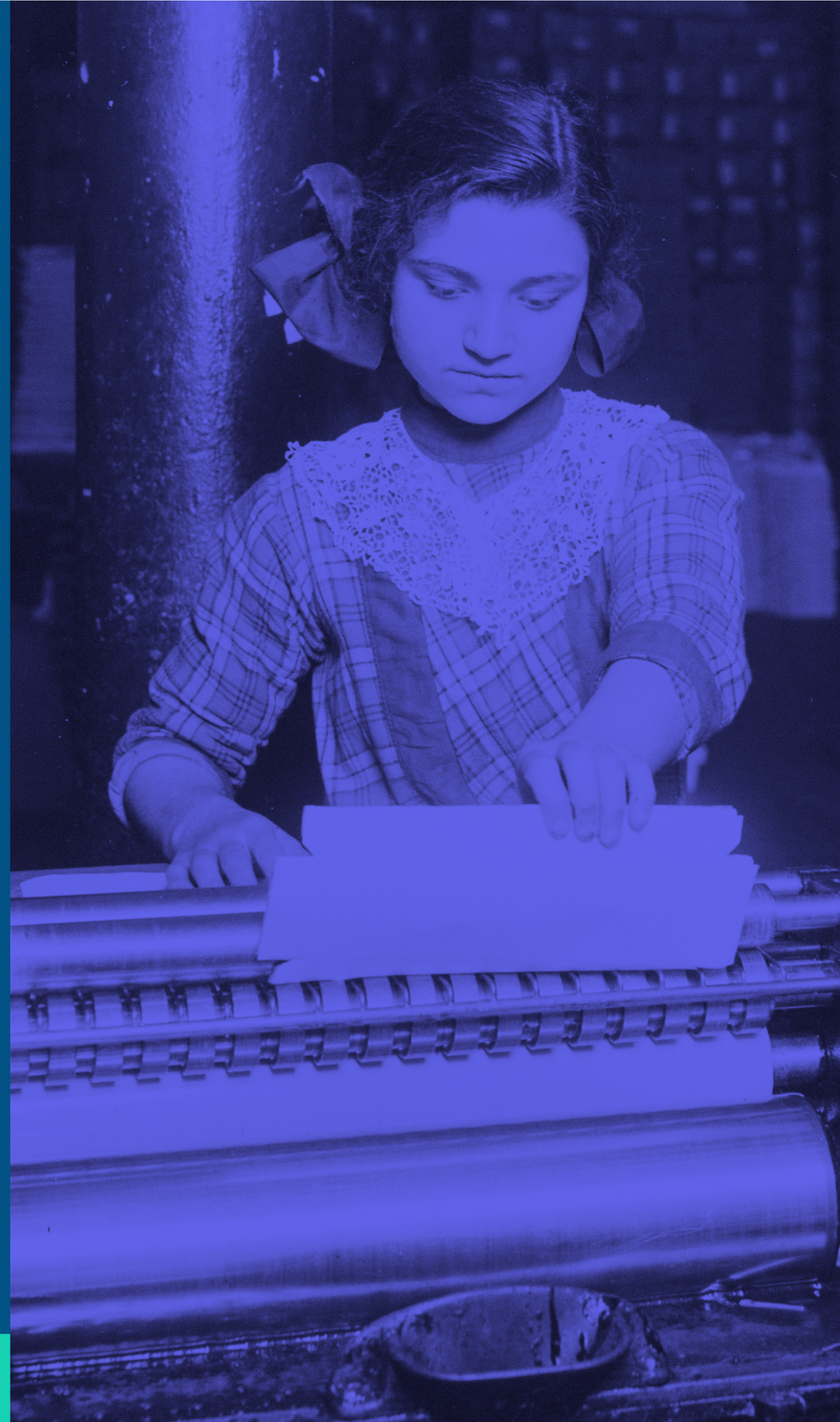
Bespoke research and consultancy from:



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Further documents

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Using occupational data in public health research
A public perception

We asked 10 public contributors who were members of the Public Involvement Programme of UK Longitudinal Linkage Collaboration (ukllc.ac.uk) to participate in an online survey aimed at gathering a public perspective of the understanding, acceptability and use of occupational data in research.



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A Work and Health Research Data Platform and the next steps

A consortium led by University of Manchester and University of Glasgow, in collaboration with the Universities of Bristol, Edinburgh, King's College London and UK Longitudinal Linkage Collaboration was awarded an NIHR Work and Health Development Award. The main aim of this project was to explore whether it would be possible to develop a comprehensive data platform, bringing together information on data sets that could be used and linked to investigate relationships between work and health.



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