



DARE UK

What is a trusted research environment (TRE), why do they matter, and how does DARE UK aim to transform them?

Lunchtime Public Webinar, 7 December 2021

Agenda for today

12:00-12:05: Welcome

Gerry Reilly, DARE UK

12:05-12:15: What is a trusted research environment (TRE)?

Susheel Varma, DARE UK

12:15-12:25: What does the DARE UK programme aim to achieve?

Fergus McDonald, DARE UK

12:25-12:40: Research case study: Using data to better understand outcomes for looked-after children in Northern Ireland

Aideen Maguire, Queen's University Belfast and Trása Canavan, Barnardo's NI

12:40-12:55: Q&A and discussion

12:55-13:00: Polls – share your thoughts

- Please remain **muted** at all times, unless invited to ask a question during the Q&A session
- To ask a question during the Q&A session: please use the **‘raise hand’ function** if you wish to ask a question out loud; or you can ask your question via the **Chat box** before and during the Q&A session
- Please keep your **video** off during presentations – you are encouraged to turn your video on during the Q&A/discussion session
- The webinar is being **recorded**

DARE UK (Data and Analytics Research Environments UK)

What question are we trying to answer?

“How should a national data research infrastructure be designed so that sensitive data can be connected and analysed in a secure, flexible, efficient and sustainable way?”



UK Research
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Health Data Research UK



What is a trusted research environment (TRE)?

Susheel Varma, Technical Lead, DARE UK Phase 1

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What is a TRE?

A TRE is a **Trusted Research Environment**. Also known as 'Data Safe Havens', TREs are highly secure computing environments that provide remote access to health data for approved researchers to use in research that can save and improve lives.

Why are they important?



TREs make research safer. Making data available through a TRE means that people can be **confident** that their personal health data is accessed **securely** and their **privacy protected**.

TREs help make research **efficient, collaborative** and **cost effective**, providing rich data that enables **deep insights** which will go on to improve healthcare and **save lives**.

TREs provide approved researchers with a **single location** to access valuable datasets. The data and analytical tools are all in **one place**, a bit like a **secure reference library**.

How is my data safeguarded?

Health data should always be kept safe and secure, and used responsibly to ensure privacy. Health Data Research UK ensures these high standards are met by promoting the use of the 'Five Safes' model across all TREs.

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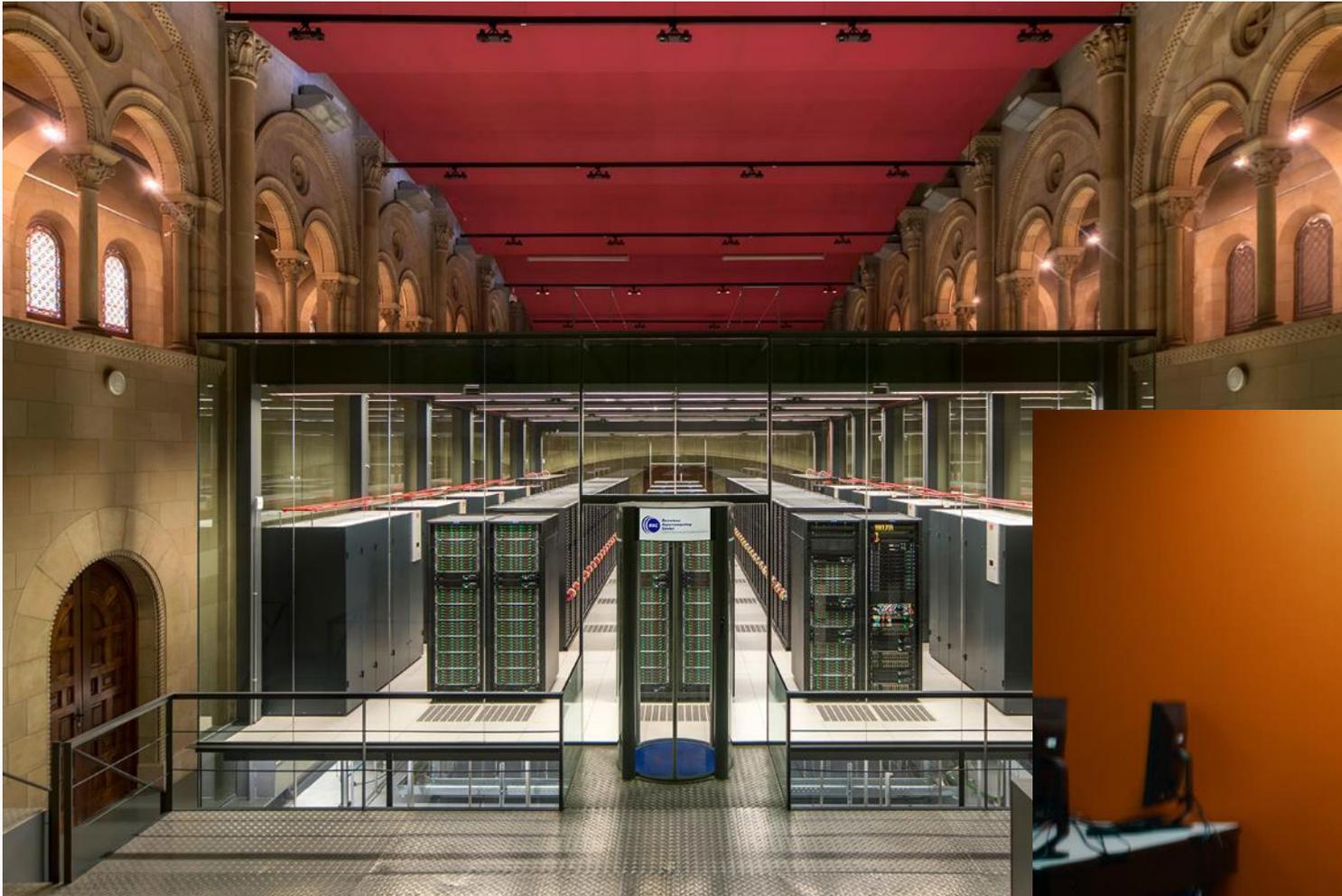
Safe People
Only trained and specifically accredited researchers can access the data
- 

Safe Projects
Data is only used for ethical, approved research with the potential for clear public benefit
- 

Safe Settings
Access to data is only possible using secure technology systems – the data never leaves the TRE
- 

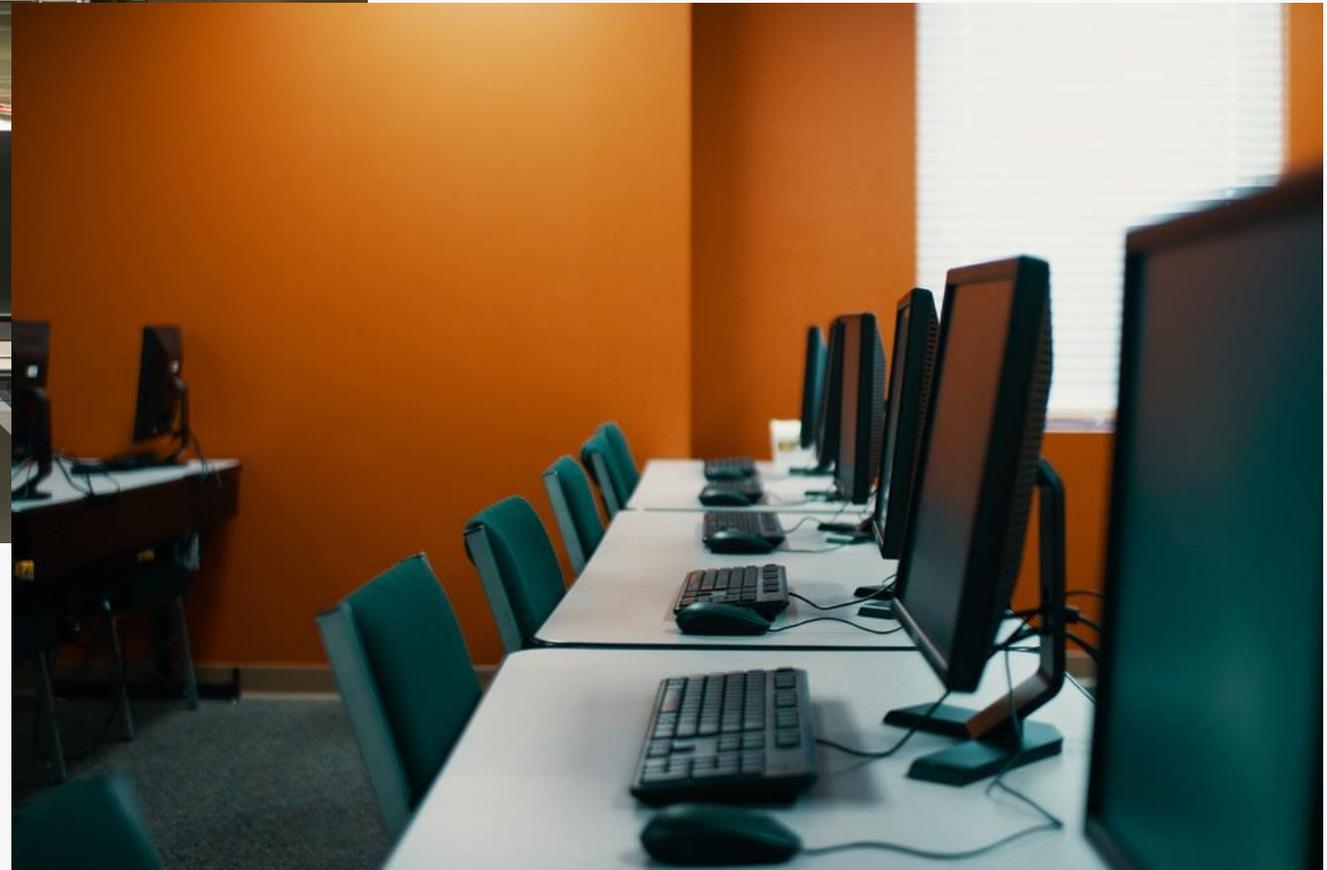
Safe Data
Researchers only use data that have been de-identified to protect privacy
- 

Safe Outputs
All research outputs are checked to ensure they cannot be used to identify subjects



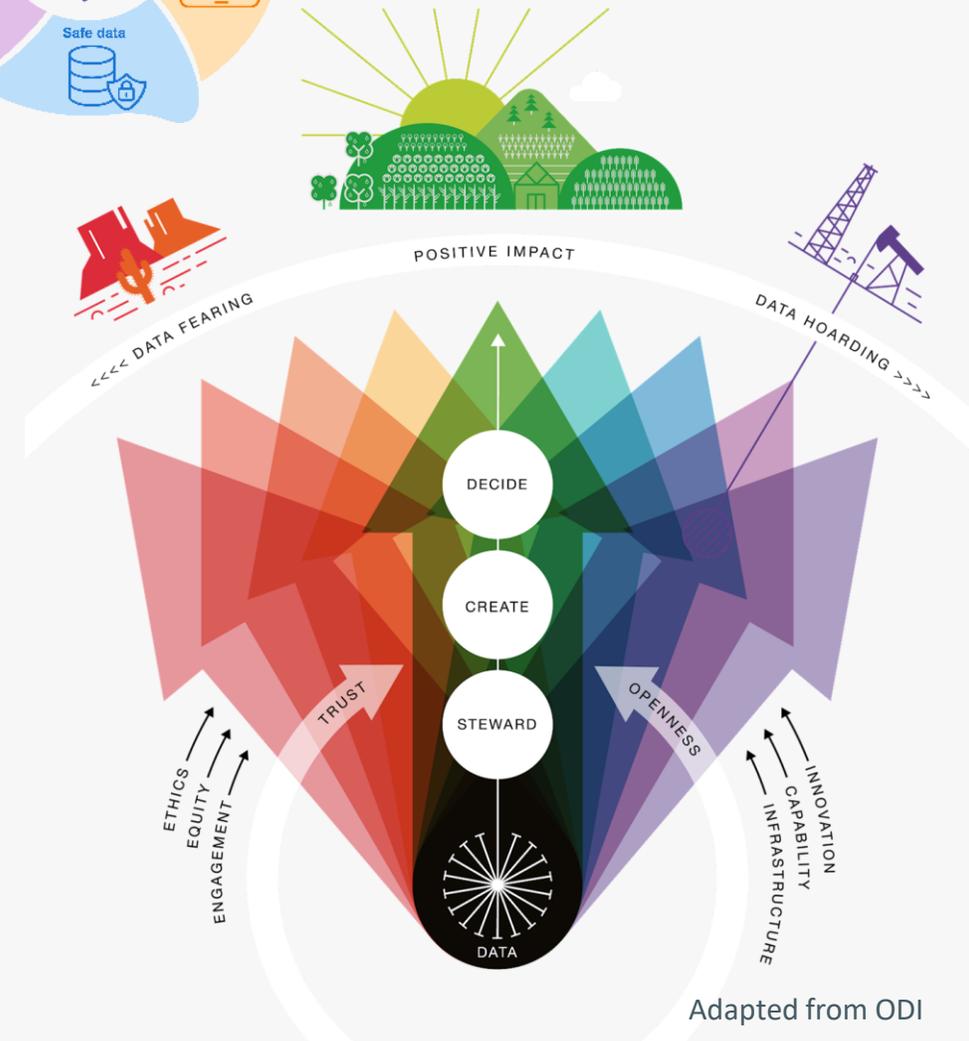
Secure, controlled research environment

Data centre – Compute Servers, Data Storage,
Networking

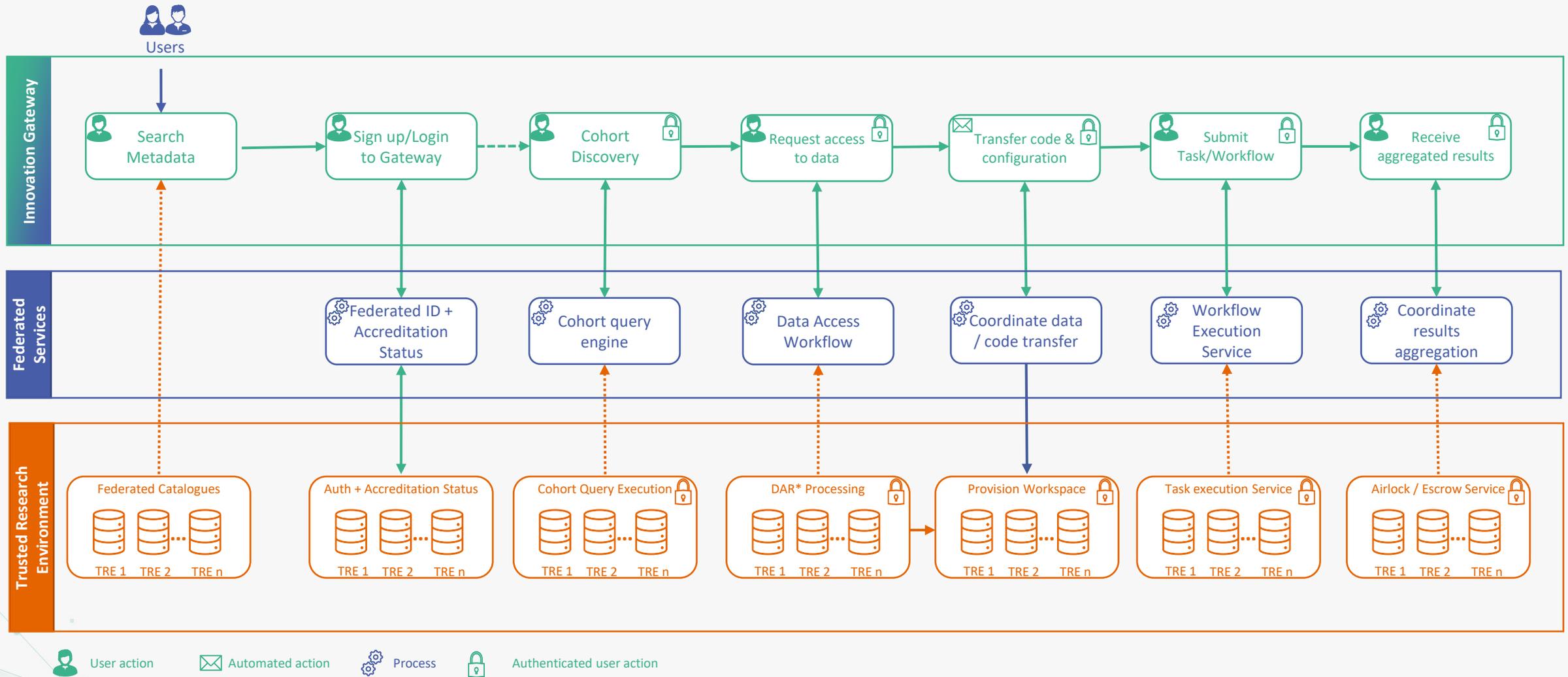


How do TREs work?

- **TREs hold sensitive research data from a range of datasets**, for example relating to the health and education of members of the public, which is originally collected by public services
- The data is **held and accessed in a secure environment** in line with the **‘Five Safes’** – safe people, safe projects, safe settings, safe data and safe outputs
- **Approved researchers**, from trusted organisations, can make a formal application to view the data for research in the **public interest**
- **There isn’t one TRE for all of the UK** – there are multiple TREs across the four nations, holding both UK-wide and nation-specific data



What can Researchers do within a TRE?



Can my data be identified in TREs? Is my data secure?

- There are multiple **security and monitoring processes** in place to prevent your data being identified or misused
- While there can never be 100% guarantee, TREs are geared towards **minimising the risk of identification and misuse**
- TRE providers and their staff have to comply to **strict data processing rules and standards** set by the national legal and regulatory bodies
- Researchers also have to undertake **accreditation** for information governance and safe data handling processes

What are the benefits of TREs?

- Data collected by public services and other organisations gives a **fuller picture of life in the UK** than other methods
- This is valuable for **informing better decision making**
- **TREs make research using this sensitive data safer** – data is accessed by approved researchers in a secure way
- **They enable access to sensitive data** that cannot be shared to personal devices for security reasons



What are the limitations of TREs?

- TREs will not support **every type** of research or researcher
- **Not all** existing datasets are available for research. There may also be **restrictions placed** on the use of data, set by individual data collectors
- There may be limitations on the **capacity of TREs** to keep up with the **demand from researchers** to access their data
- Some TREs allow **remote connections** to approved researchers to conduct their analysis via external, secure technical platforms. However, some hold datasets which researchers can **only access via a physical safe setting**, within the TRE's own buildings and infrastructures



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ADRUK
Data-driven change

How does DARE UK aim to transform the UK's network of trusted research environments (TREs)?

Fergus McDonald, Senior Programme Manager, DARE UK Phase 1

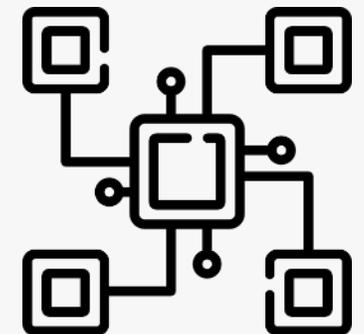
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DARE UK aims to design and deliver a national data research infrastructure that is **joined-up, demonstrates trustworthiness** and supports **research at scale for public good.**



Joined-up

- The UK's network of TREs needs to be able to support **fast and efficient** sharing, linkage and analysis of sensitive data
- TREs need to work in a more joined-up way so that the **benefits of data research can be maximised** across the entire infrastructure, and **knowledge and capabilities shared**
- More **standardised access and governance** would **maximise security, trustworthiness and efficiency**



Demonstrate trustworthiness

- **The public** need to know their data is kept safe and their privacy maintained
- They should be kept informed of **how their data is being used and why**
- **Government departments and public service providers** need to know the data they have collected and are responsible for is kept safe and not misused
- Properly understanding what is considered **trustworthy**, and consistently operating in line with this, is crucial



Research for public good

- The **benefits** of data research must **outweigh the risks**
- Research must be focussed on answering **the most important questions**
- Balancing data misuse with **data ‘missed use’**
- Ensuring data access and use is **fast and efficient** so that the public benefits can be realised in a timely way



DARE UK Phase 1: Design and dialogue

July 2021 – August 2022

- **An extensive listening exercise** with researchers, technologists, the public and others
- **Sprint Exemplar Projects** – use cases, technology demonstrators, best practice
- Stakeholder and public **involvement and engagement**
- **Designing the ‘blueprint’** for a more joined-up, trustworthy national data research infrastructure

DARE UK Phase 1

Public involvement and engagement

Public involvement and engagement are embedded throughout the DARE UK programme to inform our planning and delivery

Public benefit is the driving force of all we do. It is essential we fully understand and address the public's interests and concerns



DARE UK Phase 1

Public involvement and engagement

Public Contributors

- 2 x DARE UK Programme Board
- 2 x DARE UK Scientific and Technical Advisory Group
- 1 x Phase 1 Delivery Team Public Advisor

Public dialogue

- To explore public views regarding what a trusted and connected national data research infrastructure should look like
- A **series of workshops** with members of the public in January 2022
- A **final report** published in Spring 2022

Using data to better understand outcomes for looked-after children in Northern Ireland

Dr Aideen Maguire

Lecturer Social Epidemiology, Queen's University Belfast

 : @Aideen_QUB

Co-I Sarah McKenna (PhD Student)



Context:

- Over 3,000 children “in care” at any one time in Northern Ireland

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Number of children in care at record high in NI

By Eve Rosato
BBC News NI

14 February 2019



A record number of children were recorded in Northern Ireland in 2018, official figures show. According to the Department of Health, records date back to the introduction in 1995.

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Social care This article is more than 9 months old

Councils under huge pressure as number of children in care soars

There are now 78,150 children in care in England, a rise of 28% in a decade

Sarah Marsh
@sloumarsh
Thu 9 Jan 2020 00:01 GMT
535

▲ More young people are being placed in substandard homes, warn charities. Photograph: Elva Etienne/Alamy Stock Photo

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Call to reduce number of children in care in Scotland

By Lucy Adams
BBC Scotland correspondent

19 December 2018



Parents and academics have called for greater support for families to try to reduce the number of children in care.

They also want a less punitive approach to child protection.

Context:

NEWS

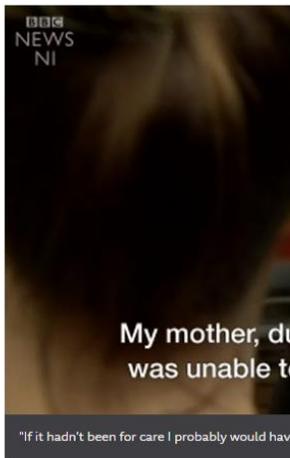
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BBC Account

NEWS

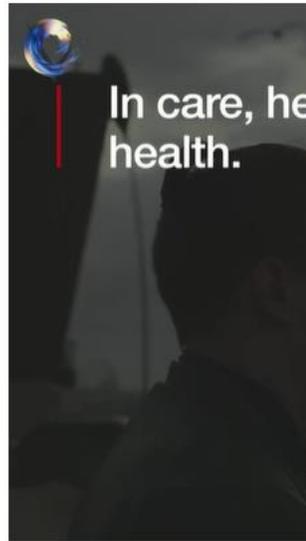
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'Speed up mental health treatment for children in care'

By Louis Lee Ray
BBC Victoria Derbyshire programme

6 November 2017



"I cried myself to sleep every night," says Callum

"It felt like no-one was there for me and no-one cared - I was crying myself to sleep every night."

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Children in care 'too often miss out on mental health treatment'

By Judith Burns
Education reporter, BBC News

28 April 2016



Children in care are more vulnerable to mental health problems

Children in care are too often missing out on treatment for mental health problems despite being four times more likely to experience them, says a new report.

The Commons Education Committee says children fostered in England sometimes denied treatment simply because they move placement too often.

"It felt like no-one was there for me and no-one cared - I was crying myself to sleep every night."

BBC Account

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Family & Education | Young Reporter | Global Education

Children 'end up in care and custody' over mental health

By Hannah Richardson
BBC News education and social affairs reporter

30 January



Children are ending up in care, custody or hospital because of failings in mental-health services, a report warns.

England's Children's Commissioner says children are still being told they are not ill enough and turned away, only for their conditions to worsen.

Anne Longfield said a "chasm" remained between what children needed and what they received, despite a sustained campaign.

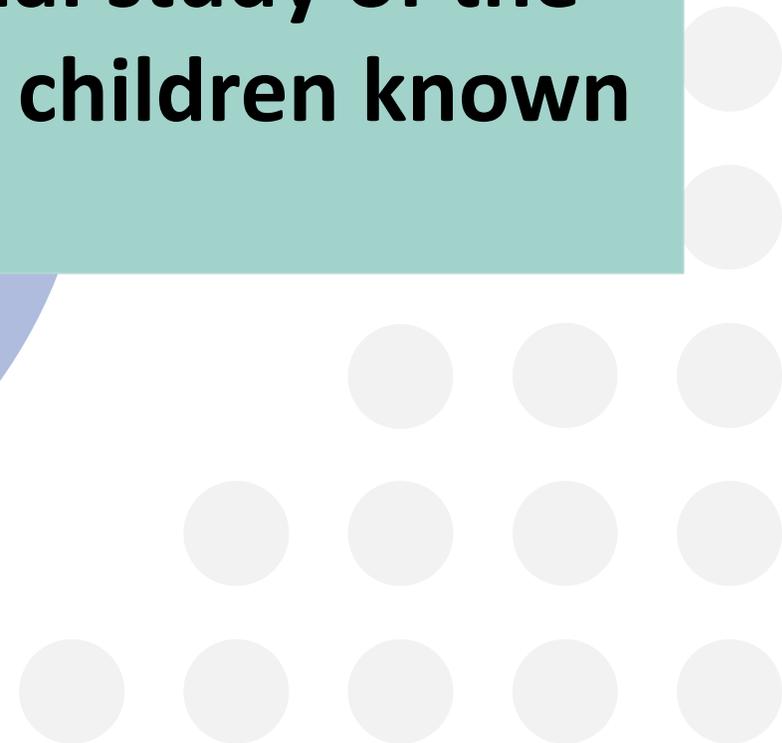
The government said major improvements were already under way.

But Ms Longfield said a comprehensive mental-health service for children remained about "a decade away".

The Northern Ireland Data:



UK's first population wide longitudinal study of the long-term mental health outcomes of children known to social services



The Research:

We needed a Steering Group

- Partnership with DoH
Elaine Lawson (Head of Looked After Children & Adoption Policy)
& Eilis McDaniel (Director of Family and Children's Policy)
- Stakeholders
Trása Canavan (Barnardos)
Koulla Yiasouma (NI Children's Commissioner)



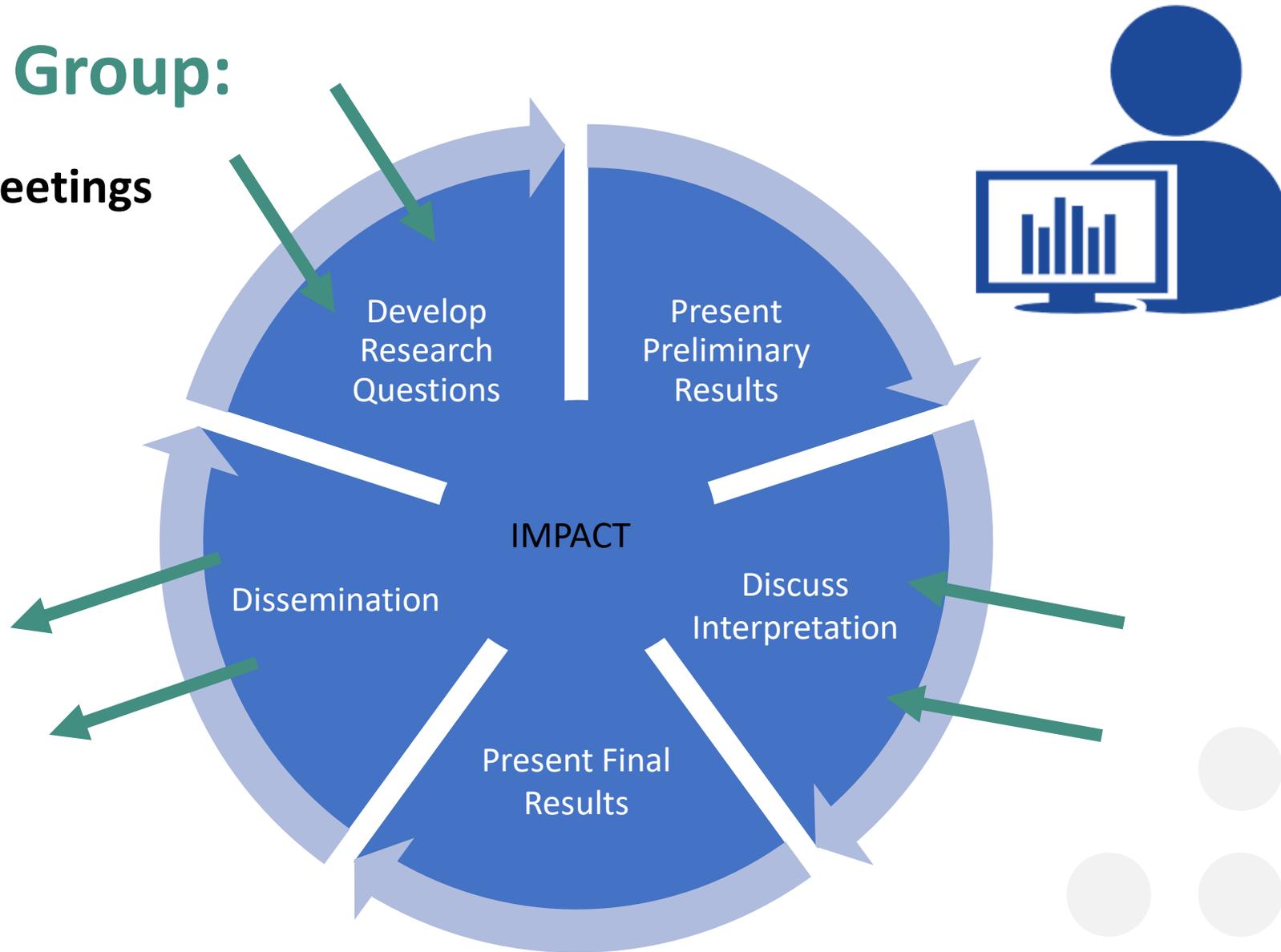
What are our Research Questions?

What information do those
working on the front line & in
policy need?



The Steering Group:

- Tri-annual meetings



The Results:

Mental Health of Children “Currently” Known to Social Services

- **Almost 1 in 10 (9.4%)** individuals aged under 45 years in NI are or have been known to Social Services
- **10 times** the rate of antidepressant prescribing in Looked After Children compared to those not known to social services
- **50 times** the rate of antipsychotic prescribing in Looked After Children compared to those not known to social services
- **25 times** the rate of self-harm in Looked After Children compared to those not known to social services
- **Over 1 in 6 (17%)** of all individuals aged 45 years and under who died by suicide were previously known to social services

Disclaimer: These are preliminary results using administrative data sets that have never before been used for research purposes. Some records from the SOS CARE data sets were unable to be linked to the other administrative data. Researchers are working to improve data capture before presenting final results.

IMPACTING POLICY:

- Cited Twice in the new Strategy for care-experienced children and young people 2021 - **A Life Deserved: “Caring” for Children and young people in Northern Ireland**



Contributing to New Strategies in 2021

- Mental Health Action Plan
- Protect Life
- Child and Adolescent Mental Health (CAMHS)



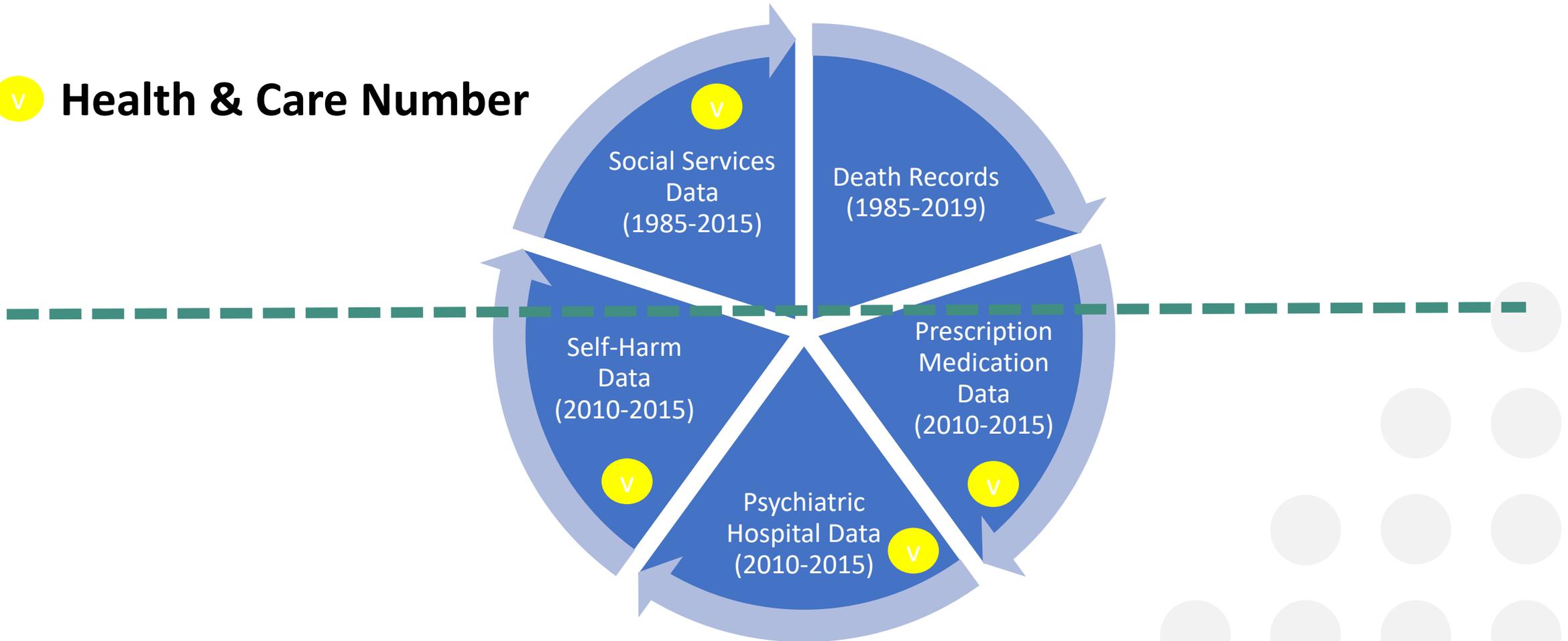
DEPARTMENT OF HEALTH AND DEPARTMENT OF EDUCATION

A LIFE DESERVED: “CARING” FOR CHILDREN & YOUNG PEOPLE IN NORTHERN IRELAND



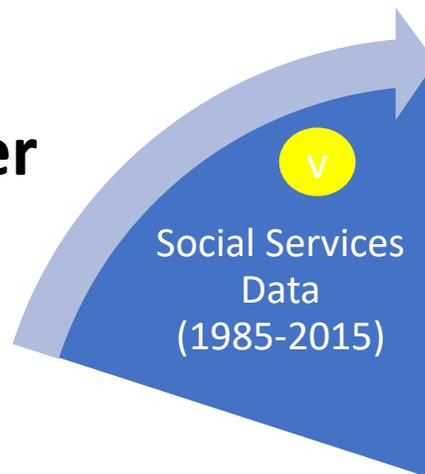
IMPACTING PRACTICE:

v Health & Care Number



IMPACTING PRACTICE:

v Health & Care Number



SOSCARE (Social Services Client Administration and Retrieval Environment)

- ~10% Children in Need Records missing accurate HCN
- Up to 20% Looked After Children records one year missing accurate HCN

Social Services Data	GP Data	Hospital Data
111111111	111111111	111111111
111111112	111111111	111111111
NULL	111111111	111111111



The Collaborators:

“For me, evidence can derive from a number of sources. Evidence from relevant research is important. However, we also need to consider data, practice and stakeholder feedback. All are essential to effective policy making and in the review and evaluation of existing policy.”

Elaine Lawson (Head of Looked After Children & Adoption Policy)

The Collaborators:

“...as a department we regularly receive feedback from children’s rights organisations and other stakeholders **that the right data does not exist** and further development in this area is needed.”

Elaine Lawson (Head of Looked After Children & Adoption Policy)



The Collaborators:

“...I couldn’t believe how much data is collected relating to children in care. However, in the main it is static – it conveys a picture at a point in time; it doesn’t necessarily track a child’s journey into, through and out of care. This is why we need to examine data over longer periods of time. That’s how we learn what works and didn’t work for individual children”

Elaine Lawson (Head of Looked After Children & Adoption Policy)

The Collaborators:

“the preliminary findings were available to further support the need for enhanced mental health services for looked after children and care leavers in the new strategy which it is hoped will be published soon and to inform other work on mental health policy across the Health Department.”

Elaine Lawson (Head of Looked After Children & Adoption Policy)

Embedding public good and community engagement in administrative data research

Trása Canavan
Barnardos



Acknowledgements

Sarah McKenna who completed the analysis for the cross-sectional work

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