



MRC-NIHR Trials Methodology Research Partnership: Webinar recording

How can trial teams build public trust for the use of routine data in trials?

Presented, on behalf of Health Data Research UK, by:

Rob Trubey and Fiona Lugg-Widger (Cardiff University)

24 October 2023

The slides are available below.

For any queries, please contact uktmn@nottingham.ac.uk

<https://youtu.be/P5mzUv7708M>

PRIMORANT: How can trial teams build public trust for the use of routine data in trials?

Rob Trubey, Fiona Lugg-Widger, Mike Robling, HDR UK



PRIMORANT: Background

- Many benefits to trialists and the public of using routine data in clinical trials
- But public trust can be fragile
- In our previous work on public involvement for RD, we found that:
 - Members of the public were very keen to be involved in conversations about how their routine data is used for research
 - Data providers saw public consultation as essential to successful data applications
 - Researchers were sceptical about value of PPI&E / unsure how to do it well



Working with the Public

Explores with researchers' public perspectives when researchers use administrative data

PRIMORANT: Background



- Training for clinical trialists: **Building public trust in routine data trials**
- Funded by and partnership with **HDR UK and training team**
- Developed through stakeholder consultation work:
 - **CTU survey**
 - **Workshop with public partners**
 - **Recorded conversations with PPIE leads, clinical trialists and topic experts**



Training outline

Official Launch: 13th November
Routine Data in Clinical Trials: Building Public Trust



Module 1: Course introduction



Module 2: Drivers of public trust



Module 3: Involving & engaging – and inclusivity

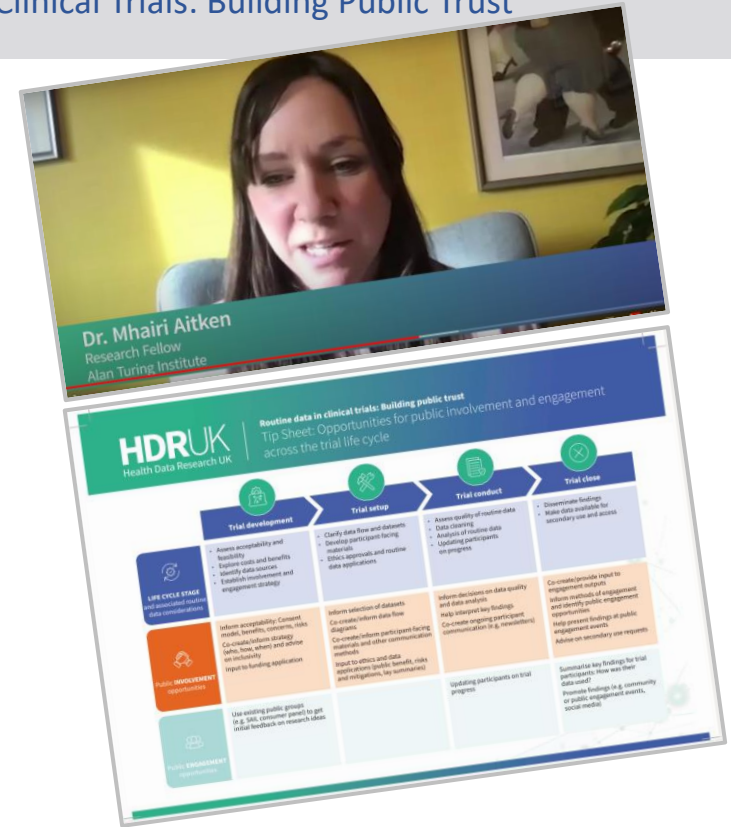


Module 4: Communicating about routine data



Module 5: Funding and measuring impact

<https://www.hdruk.ac.uk/careers-in-health-data-science/futures/>



M2: Drivers of public trust

- What are the **key concerns** that the public have about the use of their routine data in trials?
- What are the **implications for trialists** aiming to build public trust?
- Why does **context** matter?





DATA SECURITY

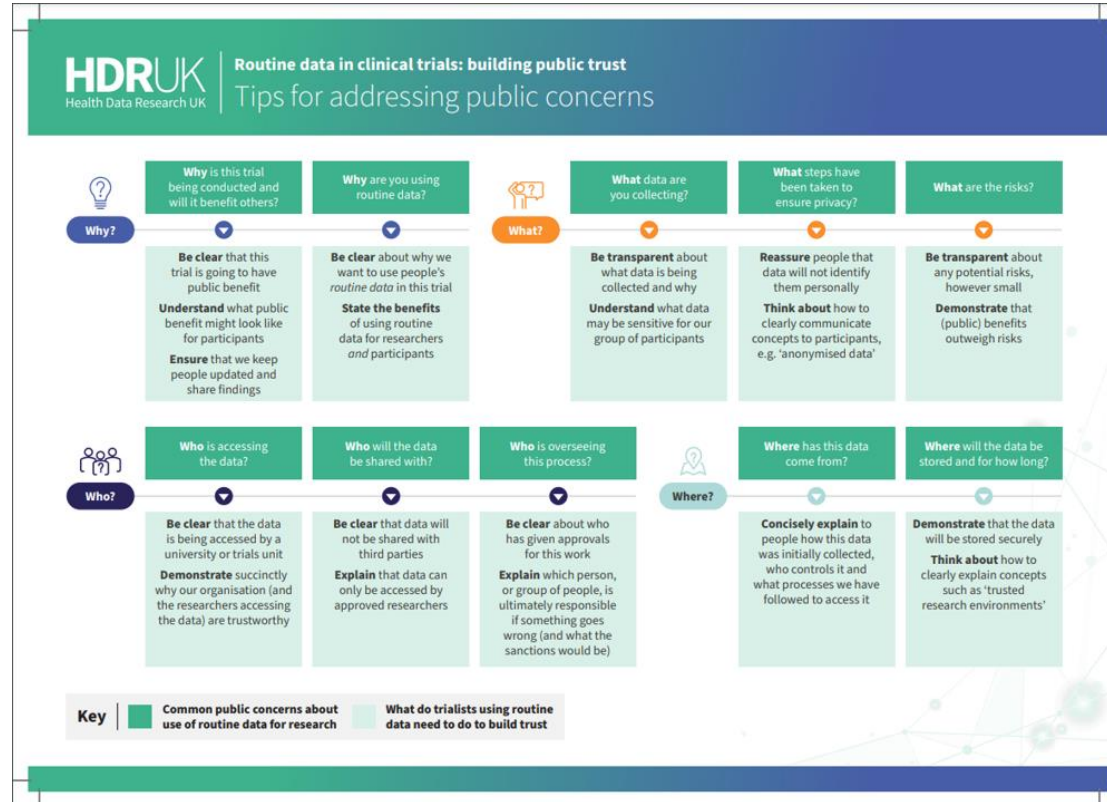
M2: Drivers of public trust



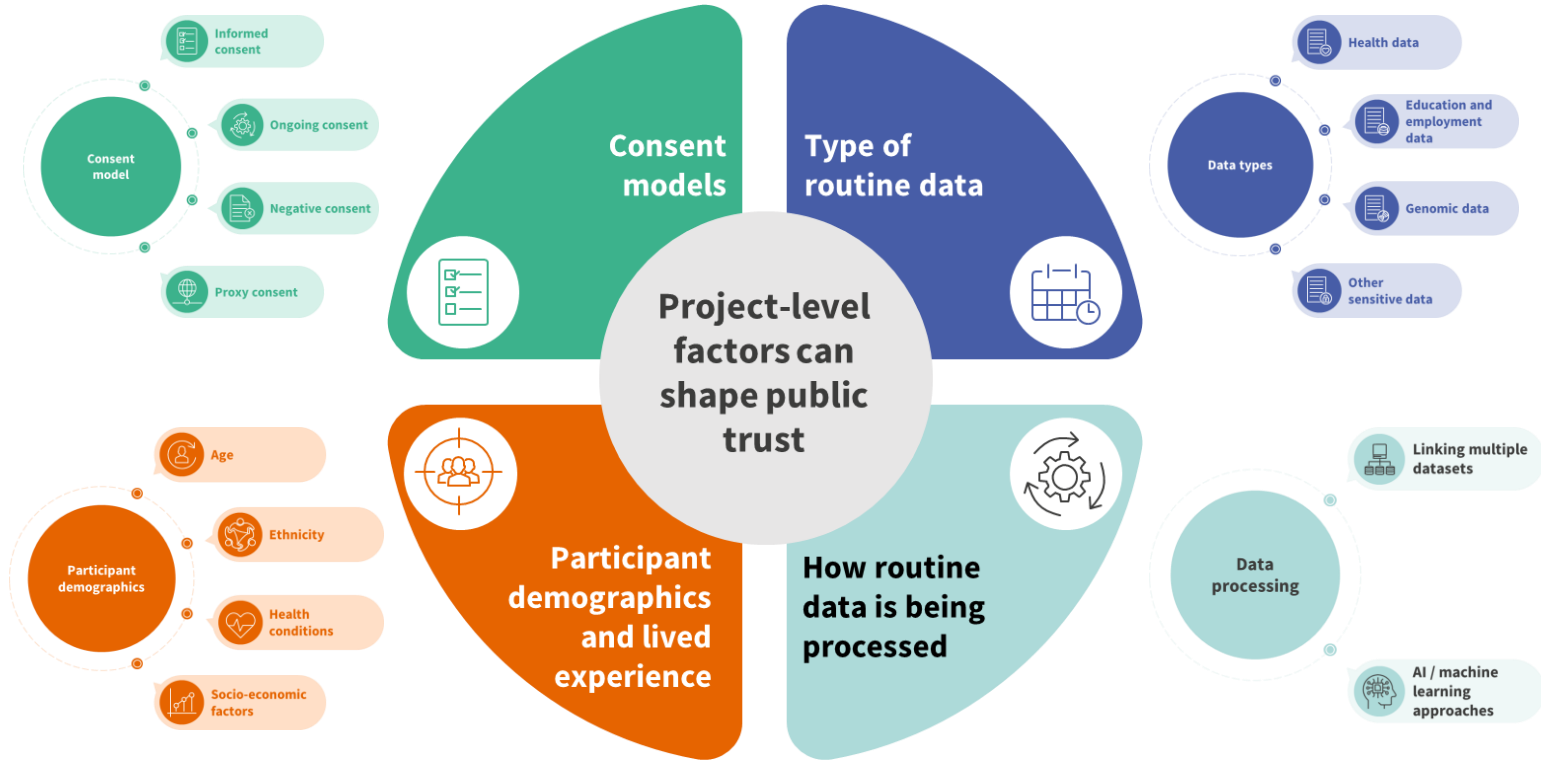
M2: Drivers of public trust



M2: Drivers of public trust



M2: Drivers of public trust - context

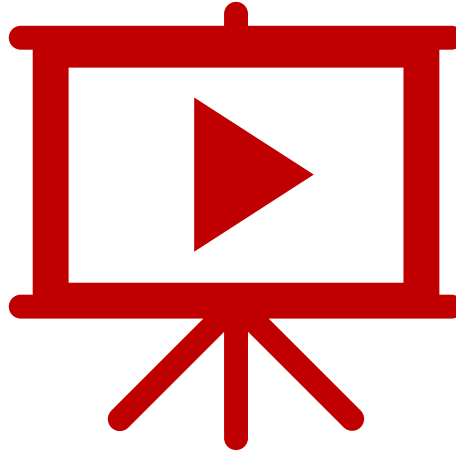


M3: PPI&E for building trust

- **How** should trialists involve and engage with the public in routine data trials?
- **When** should trialists seek to involve and engage the public in routine data trials?
- **Who** should we involve and engage with in routine data trials?



M3: PPI&E for building trust

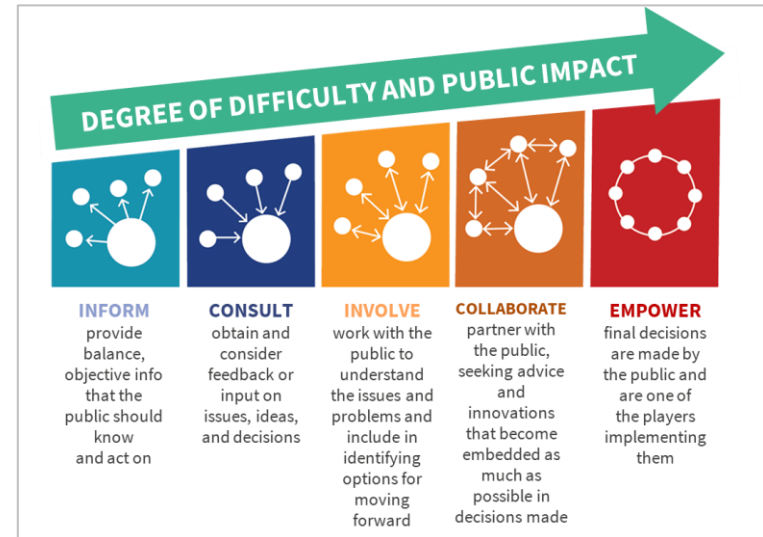


M3: PPI&E for building trust - how?

- Drawing on existing guidance and frameworks
 - **NIHR UK Standards for Public Involvement**
 - **Consensus statement on PI&E in data-intensive research**
 - **PEDRI best practice standards**
- Making sure it's meaningful
- Different ways to involve people in conversations about routine data
- Working to make it engaging

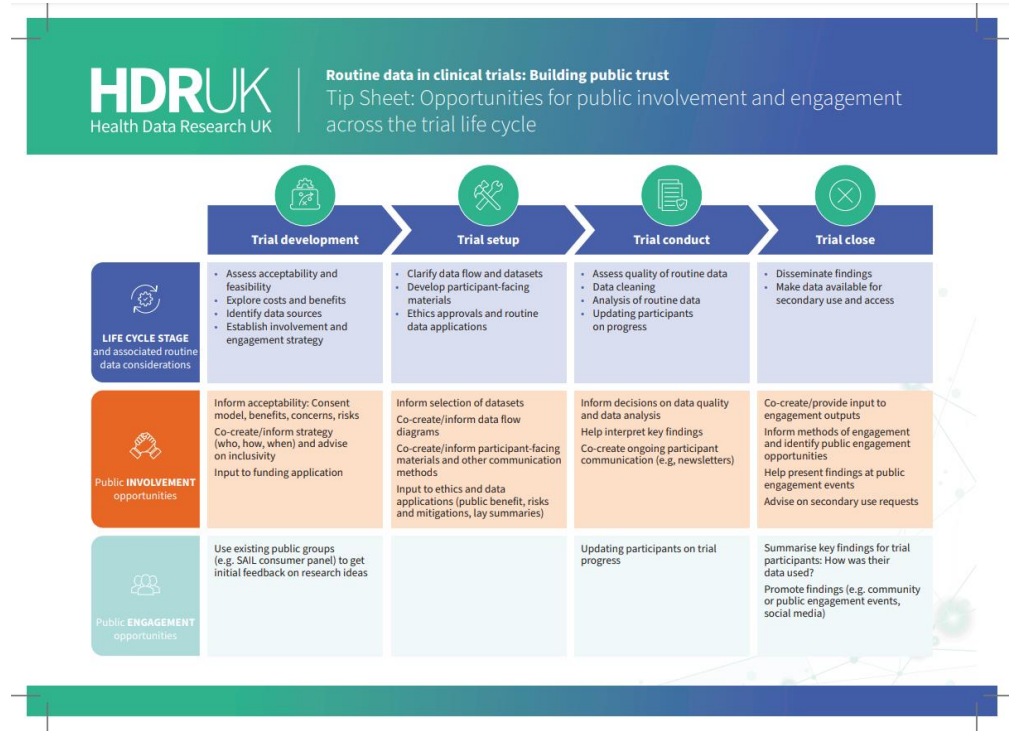
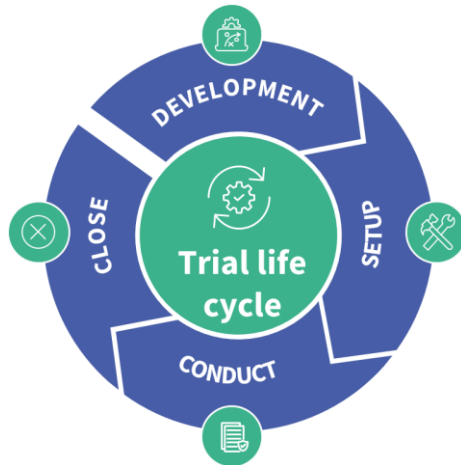


PEDRI: Public Involvement and Engagement Best Practice Draft Standards for the use of data for Research and Statistics



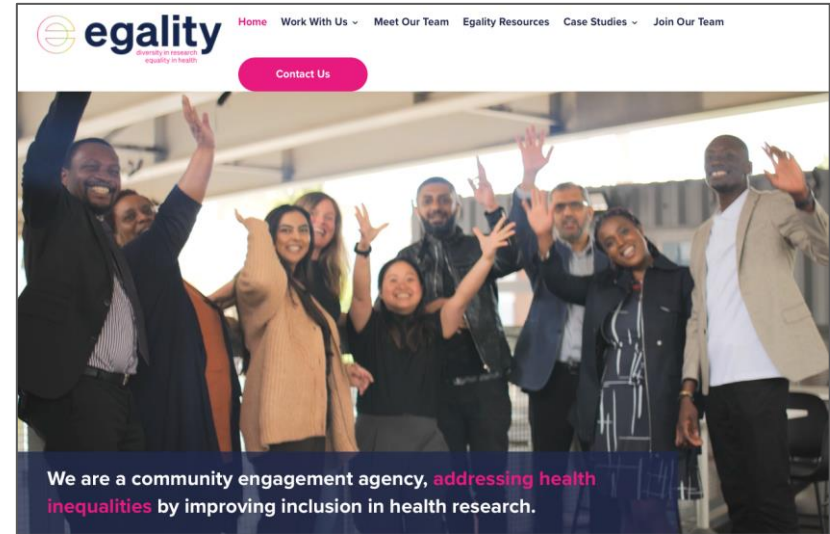
M3: PPI&E for building trust - when?

- As early as possible (including pre-funding)
- Throughout the trial lifecycle



M3: PPI&E for building trust - who?

- Led by your aims
- Focusing on people with lived experience
 - **Carers, family members**
 - **Patient representative groups**
 - **Charities**
- Including 'seldom heard voices'
 - **A diversity of perspectives**
 - **Working with community groups & community engagement specialists**

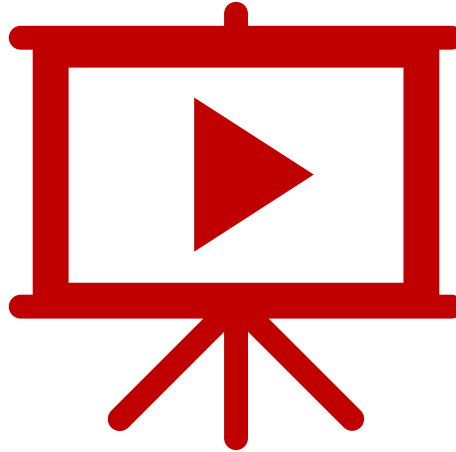


M4: Communication

- How can we communicate clearly about routine data in **participant-facing materials**?
- How can we use videos, infographics and other **creative communication** options to help build trust?
- How do we ensure that our communication is **accessible**?

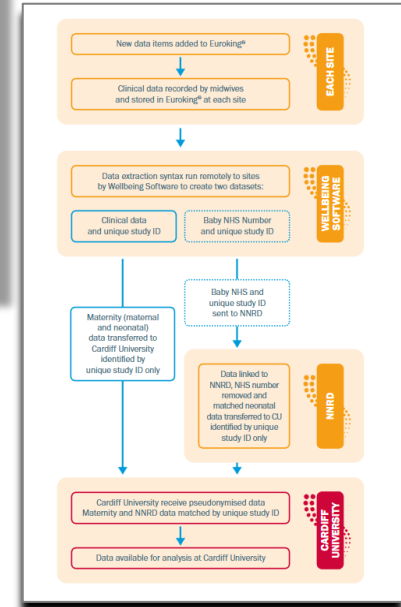


M4: Communication – ppt-facing materials

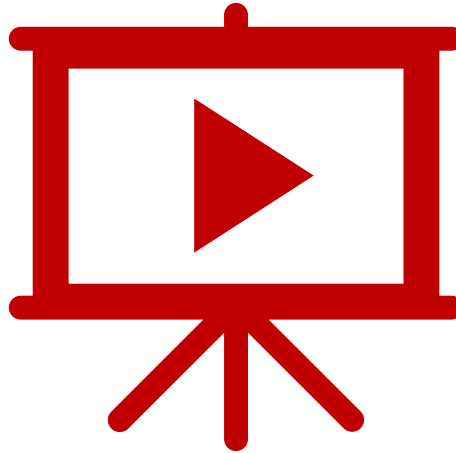


M4: Communication - ppt-facing materials

- The challenge of striking the balance – transparency vs information overload
- Layering information
 - Leaflets
 - Online approaches
 - Spotlighting key information
- Avoiding jargon
 - Understanding Patient Data
 - Working with public partners
- Using graphics, icons and diagrams

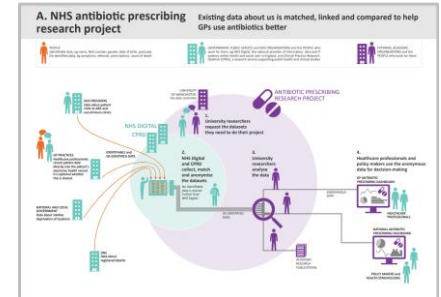
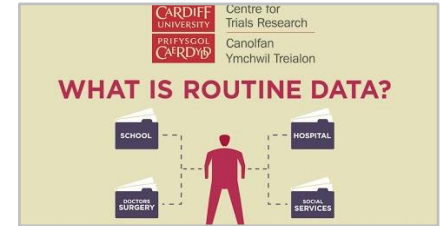
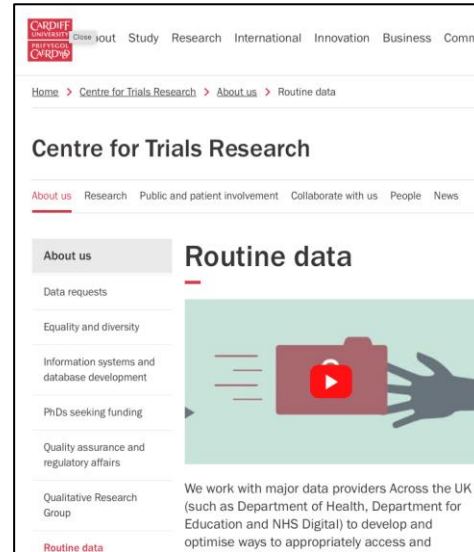


M4: Communication – creative approaches



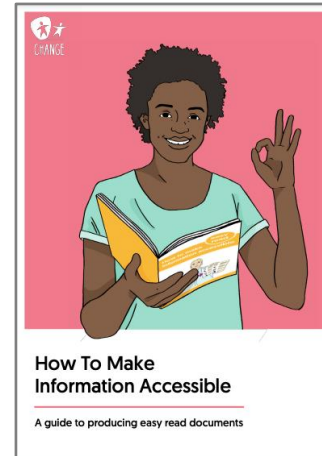
M4: Communication - creative approaches

- Videos and infographics
 - Talking head or animated videos
 - Infographics and data flows
 - Importance of consistency and version control
- Trial / CTU websites
 - Add legitimacy
 - Host a range of useful information
- Involving specialists



M4: Communication - accessibility

- Language considerations
 - **Readability tools**
 - **Translation where needed**
 - **Working with public contributors**
- Accessible formats and design
 - **Summary versions**
 - **Easy Read versions**
 - **Other accessibility considerations for different populations**
- Working with specialists
 - <https://thinklusive.org/>



M5: Costs + evaluation

- Trust-building activities can be resource intensive
 - **Staff time**
 - **Costs involved in working with specialists**
 - **Need to budget and justify costs**
- Evaluation is important
 - **Direct and proxy measures of public trust**
 - **Various tools for evaluating PPI&E**
 - **Not just from research perspective**

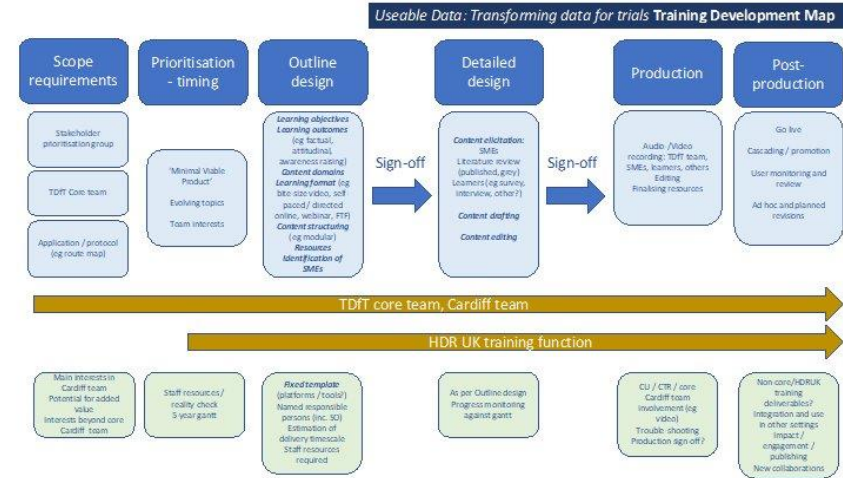


Official Launch: 13th November

Routine Data in Clinical Trials: Building Public Trust

- HDR-UK funded Transforming Data for Trials workstream
- Cardiff leading on training and resources, with HDR UK training team
- Developing training modules across a range of routine data topics
- Subject Matter Experts key – get in touch!

• top-cat@cardiff.ac.uk



THANK YOU | QUESTIONS?

PRIMORANT TEAM *TD4T TEAM

CTR, Cardiff University: Dr Fiona Lugg-Widger*, Prof Mike Robling*, Dr Julia Townson, Dr Rob Trubey*;

HDR UK North: Prof. Amanda Farrin, Prof Paula Williamson, Prof Munir Pirmohamed, Prof Andy Clegg;

MRC CTU at UCL + BHF Data Science Centre: Prof Matthew Sydes*;

MRC CTU at UCL + NHS Digital: Dr Macey Murray*;

University of Oxford CTSU: Dr Marion Mafham*;

HDR UK Training Team: Sarah Cadman; Rosie Wakeham; Sam Wise

on behalf of the Trials Methodology Research Partnership (TMRP) Health Informatics Working Group / Routine Data Topic Group

Questions for the group

- What resources do you use to support your lay members?
- Do you have examples of involvement and engagement you'd like to share?