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

Cardiff University
Prifysgol Caerdydd
Centre for Trials Research
Canolfan Ymchwil Treialon

ctru University of Leeds

HDRUK Health Data Research UK

Liverpool Clinical Trials Centre LCTC

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

Trials Methodology TMRP Research Partnership

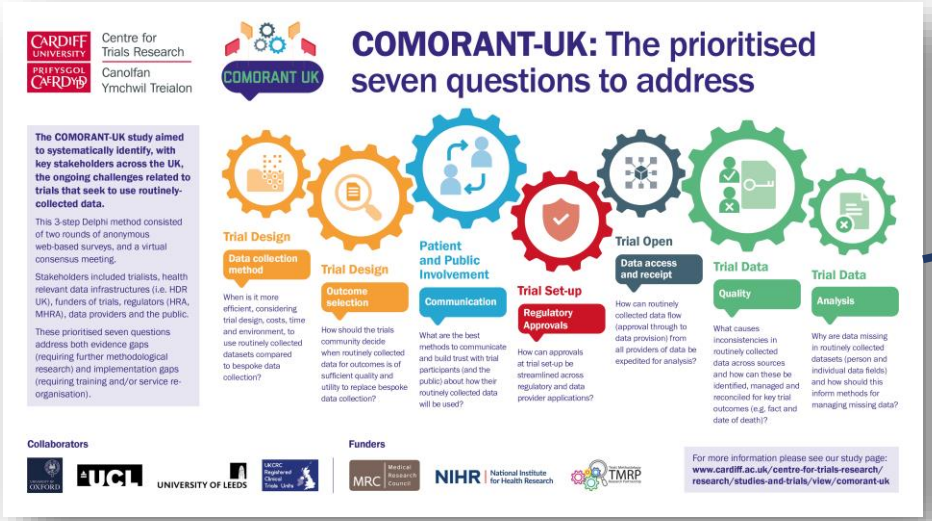
PRIMORANT: Background

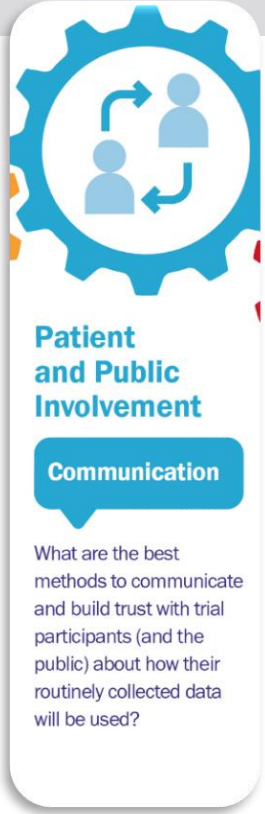
- Many benefits to trialists and the public of using routine data in clinical trials
- But public trust can be fragile
- In our previous work on public involvement for RD, we found that:
  - Members of the public were very keen to be involved in conversations about how their routine data is used for 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 development

- 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

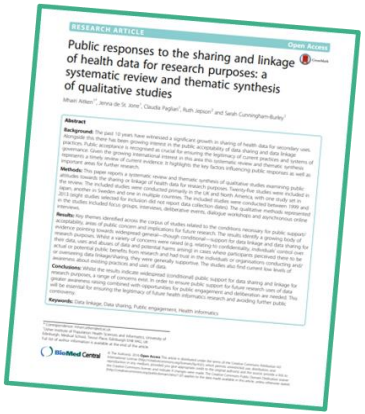
Module 5: Funding and measuring impact

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

M2: Drivers of public trust

- What are they **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?

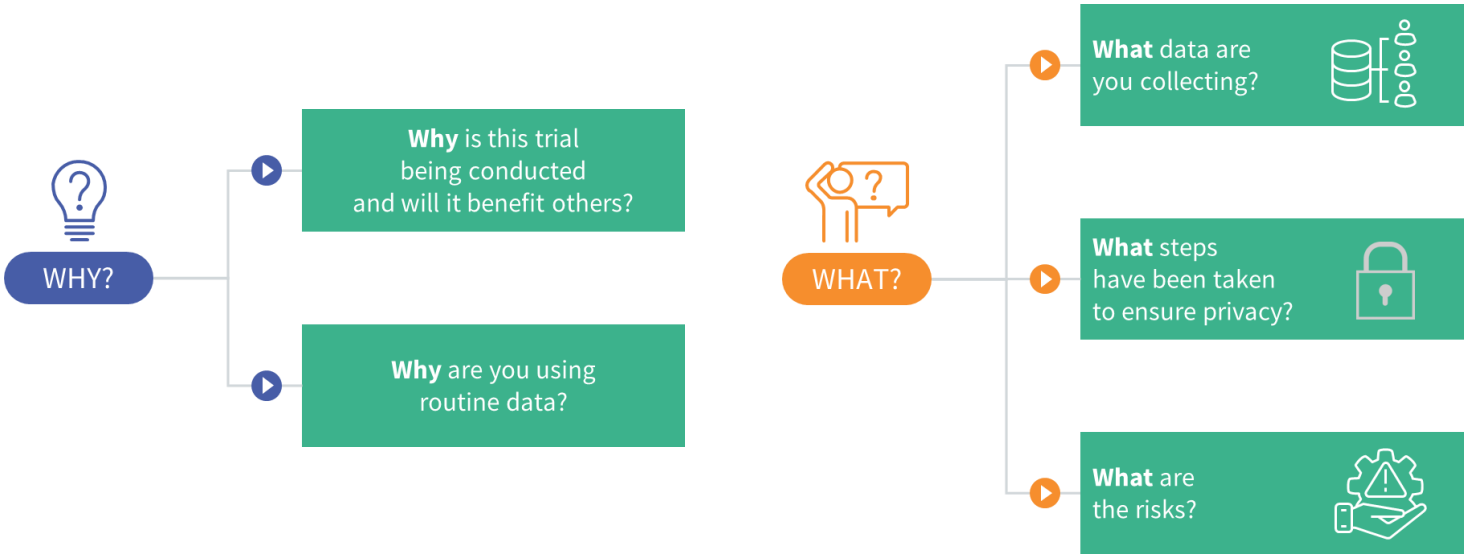
M2: Drivers of public trust



PUBLIC GOOD

DATA SECURITY

M2: Drivers of public trust



M2: Drivers of public trust

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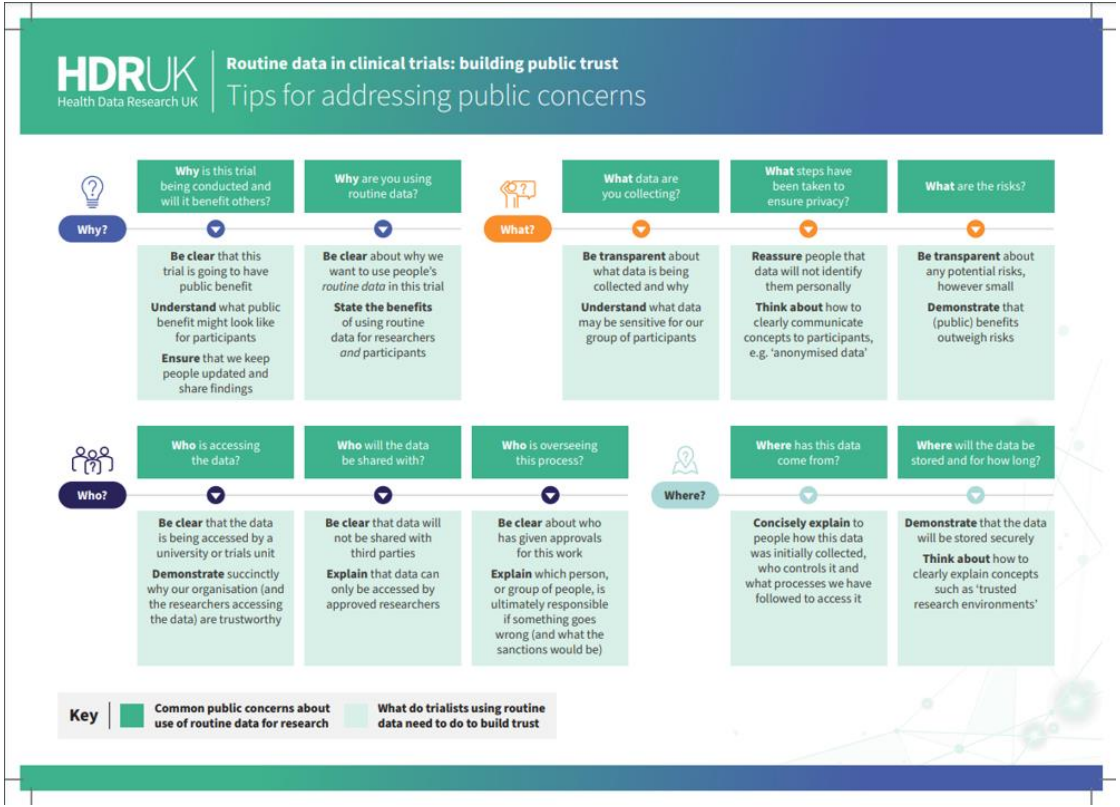
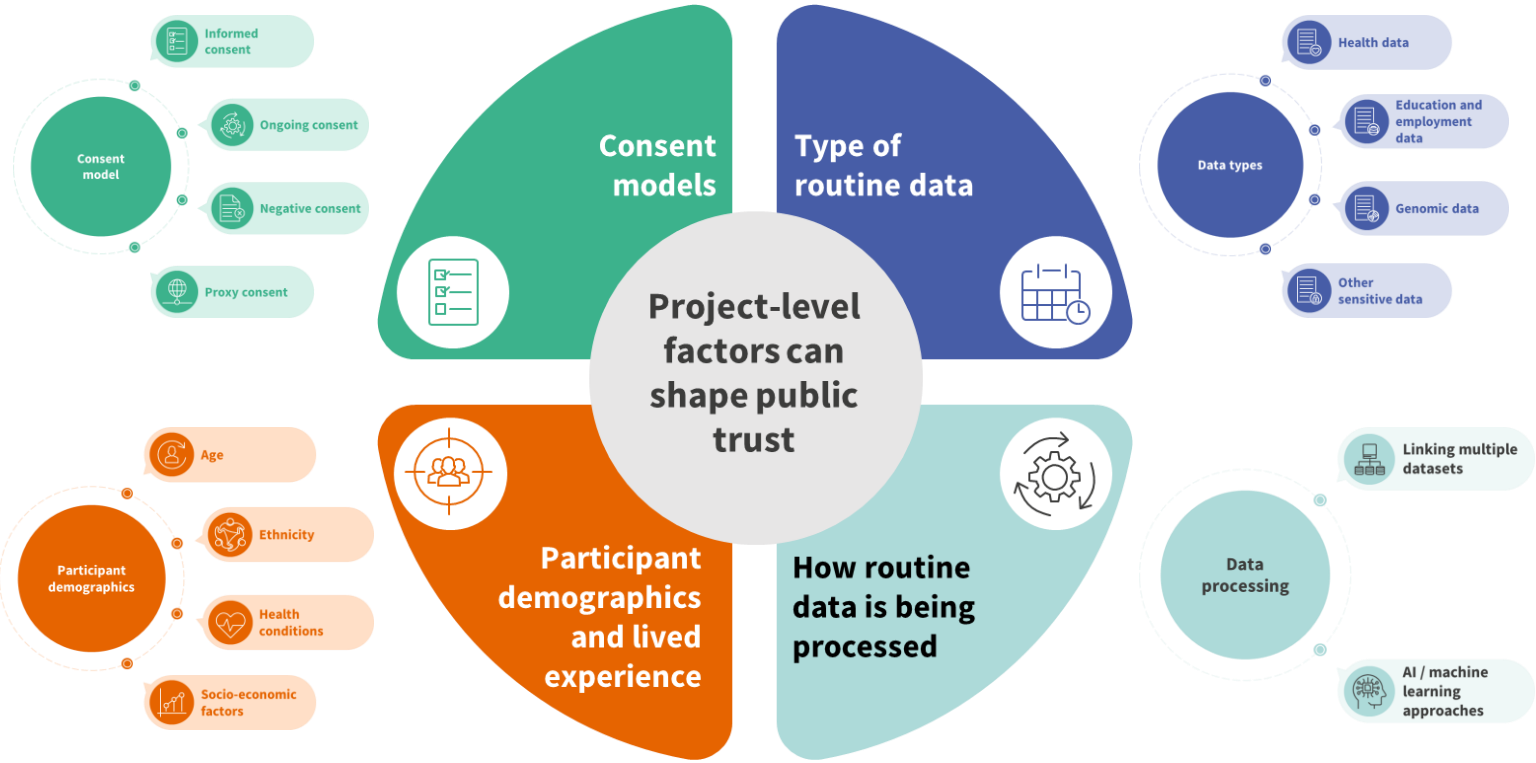


M2: Drivers of public trust - context



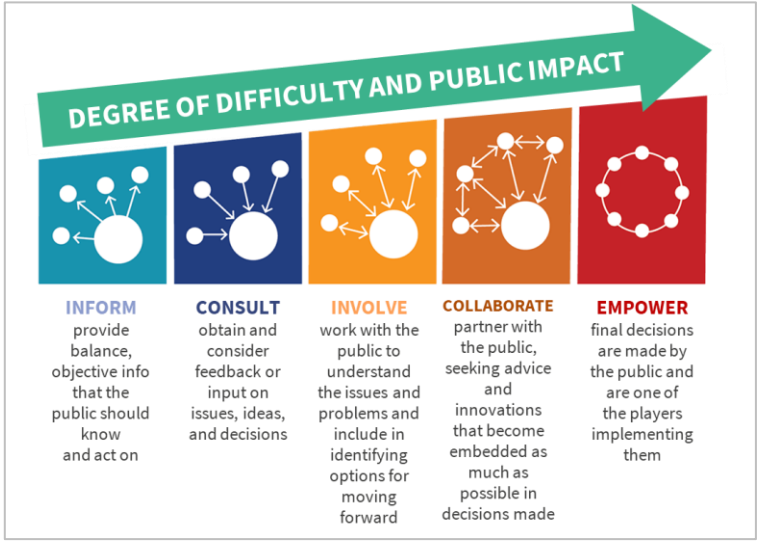
M3: PPI&E for building trust

- **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

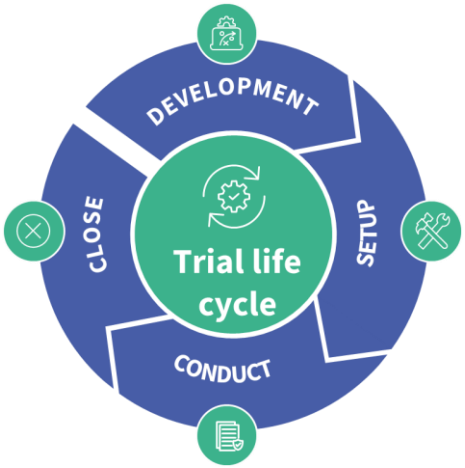
M3: PPI&E for building trust - how?

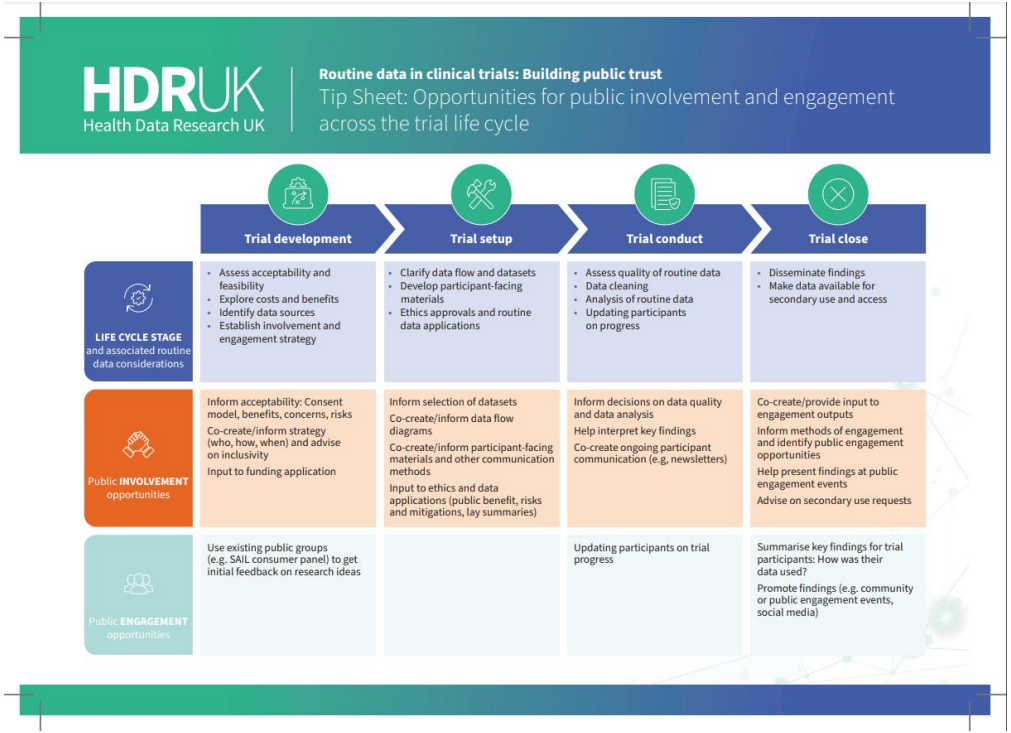
- Drawing on existing guidance and frameworks
  - **NIHR UK Standards for Public Involvement**
  - **Consensus statement on PI&E in data-intensive research**
  - **PEDRI best practice standards**
- Making sure it's meaningful
- Different ways to involve people in conversations about routine data
- Working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



M3: PPI&E for building trust - when?

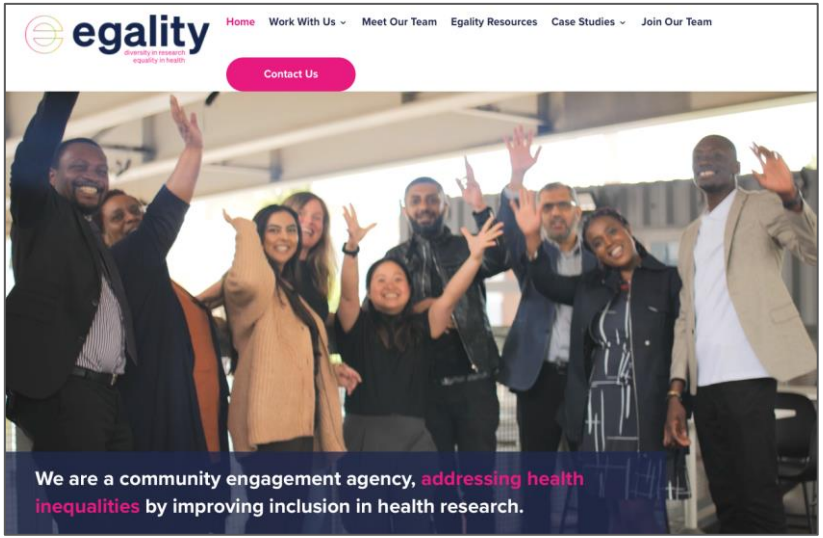
- As early as possible (including pre-funding)
- Throughout the trial lifecycle





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**



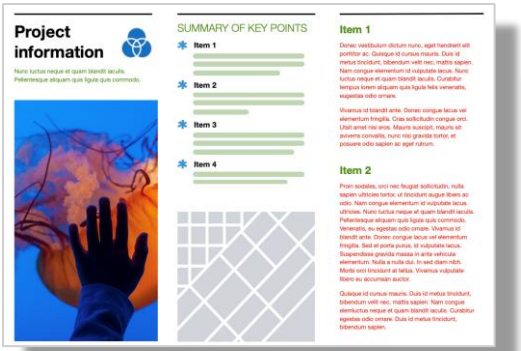
M4: Communication

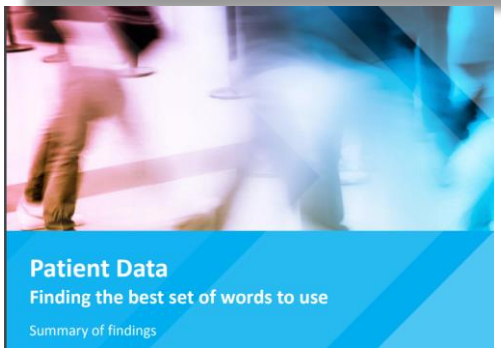
- How can we communicate clearly about routine data in **participant-facing materials**?
- How can we use videos, infographics and other **creative communication** options to help build trust?
- How do we ensure that our communication is **accessible**?

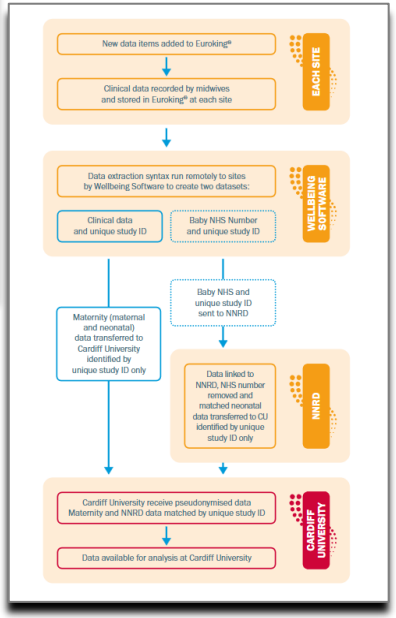
M4: Communication – ppt-facing materials

M4: Communication - ppt-facing materials

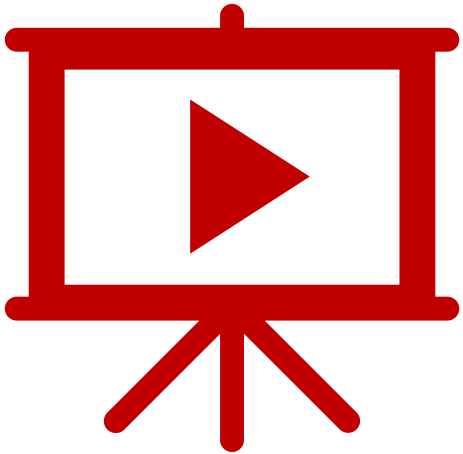
- The challenge of striking the balance – transparency vs information overload
- Layering information
  - **Leaflets**
  - **Online approaches**
  - **Spotlighting key information**
- Avoiding jargon
  - **Understanding Patient Data**
  - **Working with public partners**
- Using graphics, icons and diagrams





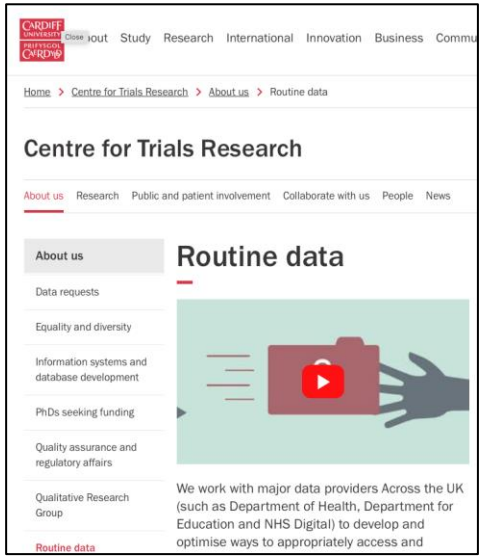


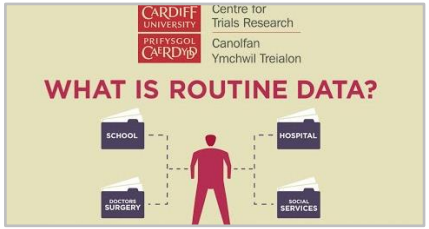
M4: Communication – creative approaches

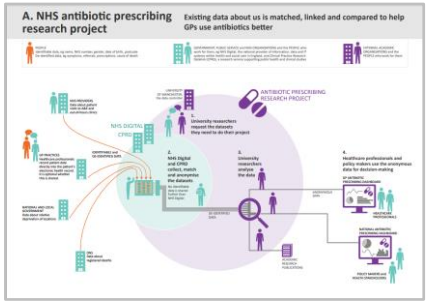


M4: Communication - creative approaches

- 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

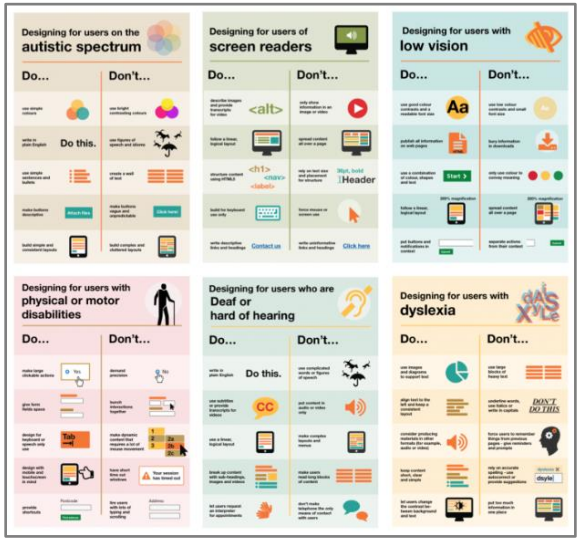






M4: Communication - accessibility

- 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**

Next steps

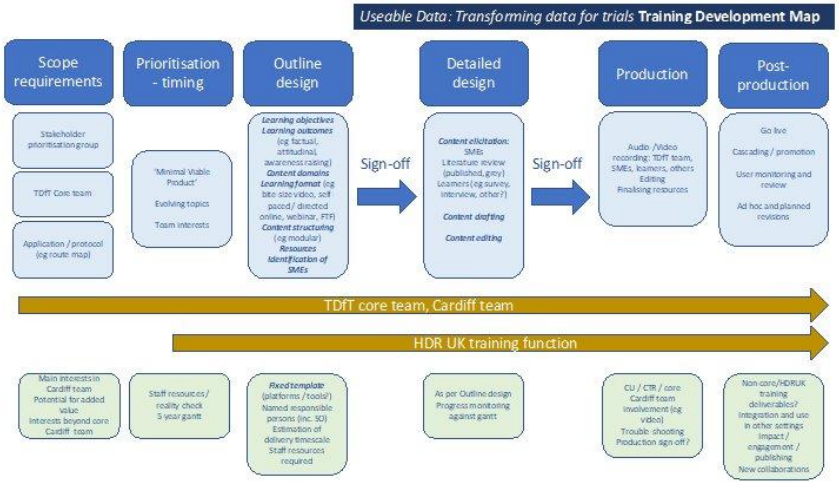
HDRUK Health Data Research UK

TOPCAT
TOWARDS OPTIMISING PRACTICE:
COURSES FOR HEALTH SYSTEMS DATA IN TRIALS

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?