

# Updates for Executive Group

Monday 17 June, 2024

# Engagement update summary (1 / 5)

- National Organisations
  - NHSE/DHSC - GP data, Opt-outs, Research Advisory Group
  - Genomics England - education sessions, GEL conference panel, exhibition
  - Health Data Research UK annual conference - exhibition stand
  - Public Engagement in Data Research Initiative (PEDRI) Governing Board
  - CRUK Data Advisory Board - oversees their research data strategy
  - DHSC Data Strategy Advisory Panel
  - Understanding Patient Data Steering Committee
  - Large Scale Public Involvement Steering Group (DHSC/NHS England)
  - OpenSafely
  - Cancer52 - session discussions at annual conference

# Engagement update summary (2/5)

- Regional Secure Data Environments (SDEs) - England
  - North West Health Innovation Network & GP Data Trust (CODU)
    - Two data-trust workshops for Members
    - Proposal to SDE Community of Practice about training
  - East of England Health Innovation Network
    - Approved funding route for NHS England
    - Exploring links with their current PPIE & benefits of uMd membership
  - South West Analytics & Infrastructure in Healthcare (SWAIH)
    - Chris attending and making closing summary at their annual event
    - Local uMd Members invited
- Integrated Care Boards (ICB)
  - David Snelson presentation

# Engagement update summary (3/5)

- Events where use MY data Members or Secretariat have attended or taken part
  - CRUK Data Conference - keynote, chairs, speakers, exhibition
  - LICTR session in Leeds - Chris speaking
  - Galien Forum - Richard speaking and on panel
  - Cross-charity commissioned research: Improving the Data Landscape on Cancer Inequalities - Interview with Chris
  - Cancer52 Parliamentary reception - Alison & Elizabeth attended

# Engagement update summary (4/5)

- Due to take part
  - Foxglove Roundtable, June
  - CRUK PPIE data webinar
  - CRUK UpSMART programme conference (AI/digital tools)
  - Cancer Data Collaborative
  - Veeva community event
  - GEL research summit
  - Synthetic data webinar (diabetes)

# Engagement update summary (5/5)

- Project engagements
  - Plymouth (population health)
  - Vivaldi (use of linked social care data)
  - GRAIL (ongoing)
  - DataSHIELD (software for secure bioscience collaboration)
  - University of Sheffield (smartphone and wearable data)
  - Many more & increasing....
- Focus Group for CRUK Genomics Strategy
- Focus Group for National Disease Registration Service
- Workshop on Infections in Oxfordshire Research Database
- BMJ article drafted

# Consultation responses

- NHS Constitution (June 2024)
- Medical Research Council (MRC) Draft Strategy for Public Partnership (Jan 2024)
- Office for National Statistics (ONS) and Department of Health & Social Care (DHSC) Statistical Outputs (March 2024)
- DHSC Opt-out Deliberation (in confidence response) (March 2024)

# We are increasingly being asked for letters of support for research proposals

- Must all agree to adopt out Principles of Engagement
- We do not endorse, but we can support
- Just in the past month:
  - Crick Institute, Citizen control of data for research
  - North West SDE, Community of Practice & involvement
  - Institute for Cancer Research, Infrastructure proposal
  - University of Bristol, linkage of Genomics data to routine data



# Education Session Schedule (pre summer)

- Physiotherapy data, Friday 28 June
- Statistical Terms, Friday 19 July
- Genomics session 2, Friday 26 July
- Commercial Trials Company (Veeva), date tbc

# Education Session Schedule (post summer)

- Topics which are listed are:
- Linking tissue and clinical data Tissue Access for Patient Benefit, UCL
- UK Longitudinal Linkage Collaboration - Usher Institute/Generation Scotland
- Disease Atlas -UCL
- “Did people opt-out when we asked them about using their data?” - Flatiron
- Reusing existing data-driven research - aspirin and cancer survival
- What is OMOP and what difference will it make?
- What does NHS Digital do with what data?
- The CR-UK PPIE Plan to support their Research Data Strategy
- Cyber security
- Is “anonymised with security controls” the same as “anonymous”? - Scotland

# Education Sessions on hold

- Sudlow Review
  - Not yet published
  - n.b. Cathie Sudlow (the author) now leaving HDR-UK

# Workshop Sessions due

- GP Data Trust (session 1), 10 July 2024
- GP Data Trust (session 2), 29 July 2024
- NHSE plans for access to GP data for research
- DHSC plans for COPI and opt outs (Osman)

# Patient Data Conference

Date: Tuesday 24 June 2025

Location: Leeds

Details:

- Around 250 delegates, free to attend for patients, nominal fee for others (to discourage non-attendance), sponsorship packages, exhibition area,
- To coincide with a new National Patient Data Awareness Day, and the 10<sup>th</sup> anniversary of use MY data