Members educational session
"The Goldacre Report"

Wednesday 11th May 2022

Good morning

The session is due to start at 11:00

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"The Goldacre Report"

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11:00 – 12:00

Chris Carrigan, Expert Data Adviser

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So what is the Goldacre Report, what does it say, and why is it so interesting?

The Goldacre Review – the brief in brief

- Independent, commissioned by Secretary of State
- 'Better, broader, safer: using health data for research and analysis'
- Some of the problems to address:
  - Data all over the place
  - Data access is probably getting worse
  - Transparency and consistency of data usage is lacking
  - Analytical workforce skills need building
  - Scaling up is always a problem
  - How to engender trust
  - Behaviours need to change

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The process and the author

- The Goldacre Review was commissioned to inform the forthcoming NHS data strategy
  - use MY data [responded to the draft data strategy](#)
  - and we also [input to the Goldacre review](#)
- Ben Goldacre
  - Based at the University of Oxford
  - Developed OpenSafely & OpenPrescribing tools
  - Authored Bad Science, Bad Pharma

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The Goldacre Report – in brief

- Safer platforms: Trust
- Sharing & reproducib
- Consistency & duplica
- Skills: NHS Data Analy
- Governance: approvals

- 3 documents, 136 pages, 185 recommendations.....

Better, Broader, Safer: Using Health Data for Research and Analysis

A review commissioned by the Secretary of State for Health and Social Care

April 2022 / Executive Summary / April 2022 / Summary / April 2022

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@C_Carrigan

Trusted Research Environments (TREs)

TRE's (rather than data releases) will increase security and public confidence and to make it easier for researchers to get at the data

- Data releases decrease control, bring risk and increase cost
- TREs bring the researcher to the data
- Build a small number of NHS analysis platforms
- Accelerate access processes, publish all activity
- Move from pseudonymised to anonymised GP data
- Use TREs to drive collaboration & modern approaches

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Methods, code, technical documentation and tools

Enable sharing of curation and analysis techniques and coding - stand on the shoulders of those who have gone before

- A commitment to Reproducible Analytical Pathways (RAP)
- Create open library for NHS code and methods
- Share state-funded code openly (not the data)
- Recognise the value of, and need for, software development
- Work with academia and industry where helpful and open

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The importance of data curation

Data curation is just as important as the data-driven research

- Standardise NHS data curation (data quality/cleaning, etc)
- Invest in shared novel curation methods, tools and work
- Use TREs to impose standards on data and curation
- Share NHS curation code and documentation

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The NHS Analytical Workforce

NHS analyst community of highly skilled individuals is dispersed, isolated and lacks a supportive professionalised structure

- Create NHS Analyst Service with leadership and career progression
- Create College for NHS analysts
- Train researchers & analysts in computational data science
- Train managers in working with data teams

A simplified approvals process

Simplify, standardise and speed up approval for research access whilst not compromising on rigour

- Map and rationalise approvals, including patient involvement
- Open public dialogue on commercial use of NHS data <u>after privacy issues addressed by TREs</u>
- Make rules on the use of patient records for running the NHS
- Solve the excess of data controllers by one national controller or pooling approvals….

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A radical proposal about data controllership

- "Address the problem of 160 Trusts and 6,500 GPs all acting as separate data controllers: either through one national organisation acting as Data Controller for a copy of all NHS patients' records in a TRE; or an 'approvals pool' where Trusts and GPs can nominate a single entity to review and approve requests on their behalf"

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The role of patients and the public (PPIE)

"Exploration of PPIE as a topic in itself was not a specific request in the terms of reference for this review, nor does the team claim to be experts in this domain"

- Ensuring PPIE is done systematically and robustly at a national level on large recurring questions around data usage

- Move beyond comms & public engagement to transparency and privacy actions

- "Modest" recommendations.....

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So how do the recommendations in the Goldacre review map onto the views of our Members?

- Our health data needs to be used more effectively to drive research and save lives

- There are unreasonable barriers to data for research, slow, confusing, inconsistent and overcomplex approvals routes. TREs must play a critical role to address this

- Overly risk-averse behaviours by Data Controlling bodies must be overcome

- We have concerns that people may use TREs to simply reinforce the existing silo mentality, unless the culture changes from guardianship to usage

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So how do the recommendations in the Goldacre review map onto the views of our Members?

- Our Transparency Principles are clear – transparency includes telling bad news as well as good, and some of the practices which Professor Goldacre has identified fall into that former category

- Urgent work is needed to clarify what "good PPIE is" , alongside "what a good TRE looks like". Without that, the Review seems to be about Trusts not trust.

- This was the most serious omission from the report.

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Take away points

"Continuing with current working practices would mean accepting a huge hidden cost of duplication, outdated working methods, data access monopolies, needless risk and, above all, missed opportunities."

- A welcome report
- Some key recommendations, amongst a great deal of others
- How will these be taken forward in the Data Strategy?
- Focused more on the technical than the "hearts and minds"
- Involvement of patients isn't clear – we need to define our part

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Questions?

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