

Data sharing experiences from the publicly accessible WHO TB-IPD platform

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INTRODUCTION

“...increase the knowledge base for normative guidance on optimal treatment for drug-resistant tuberculosis...”

- WHO call for new more flexible IPD platform (Mar2021)
- Clear link of IPD with WHO to allow regular public calls for data, and flexibility in systematic review team selection, for GDG
- University College London selected as Data Curator

The **purpose** of the TB-IPD is to facilitate:

- pooling of individual participant data from researchers, local or national databases in the context of TB treatment
- policy update, development and public health research.

- informing future treatment guidelines
- expanding the knowledge and understanding of TB globally

The original project is being expanded to include:

- clinical trials e.g. STREAM
- drug-sensitive (DS) TB
- paediatric and pregnancy data

DATA SHARING AGREEMENTS

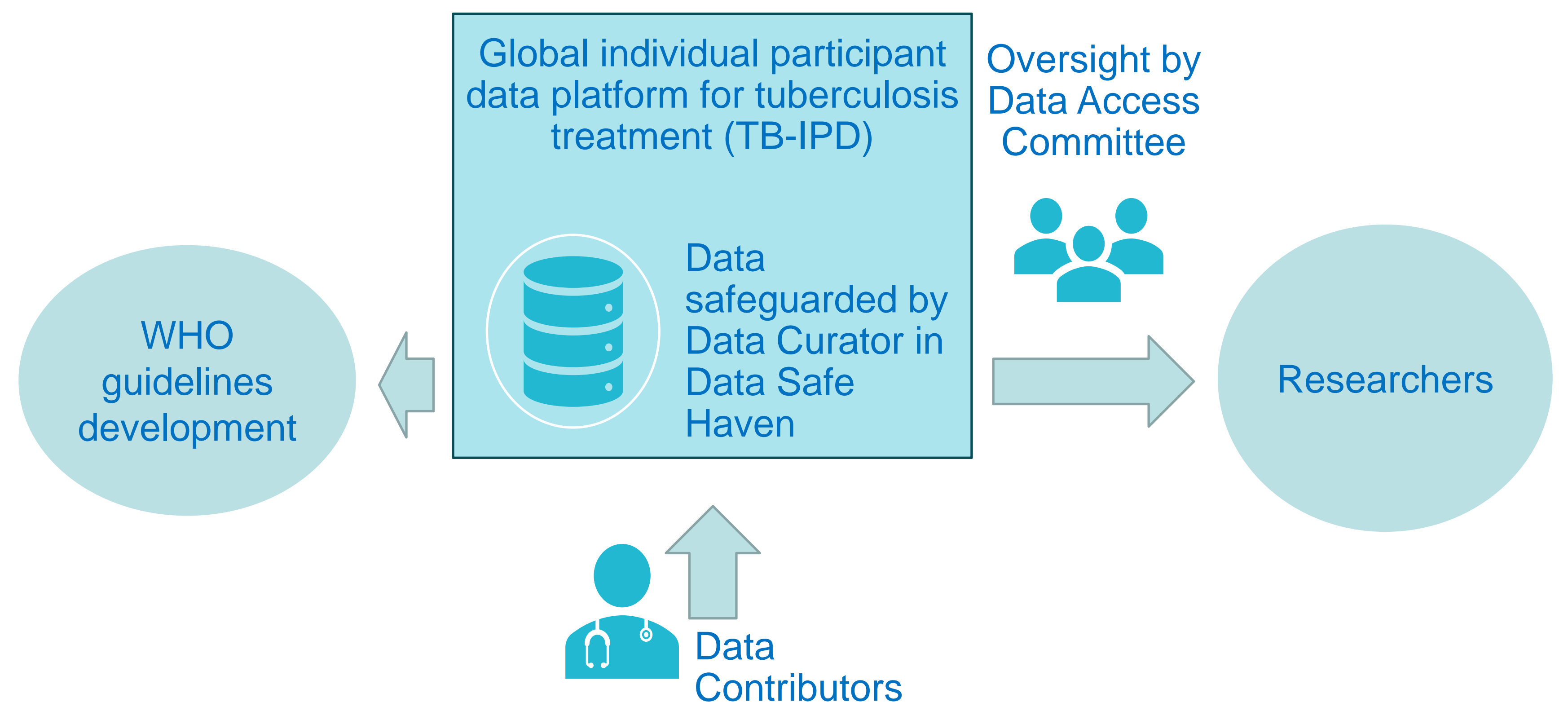
- the most challenging part of this process
- taken over a year to finalise an agreement acceptable to all stakeholders (academia, pharma, national treatment programs)
- need to be generic but satisfy all parties – due to the large number of datasets included, aim to have one DSA used by all
- covers confidentiality; data sharing principles, including use, storage, deletion; liability; ethics; publication and acknowledgement.

ISSUES

- Country specific interpretation of GDPR within Europe – differing definitions of anonymisation
- Sharing data with profit-making organisations is a sensitive/difficult topic for many data contributors – definition of non-commercial use.
- Contributors may want to change legal jurisdictions from England & Wales.

DATA ACCESS AGREEMENTS

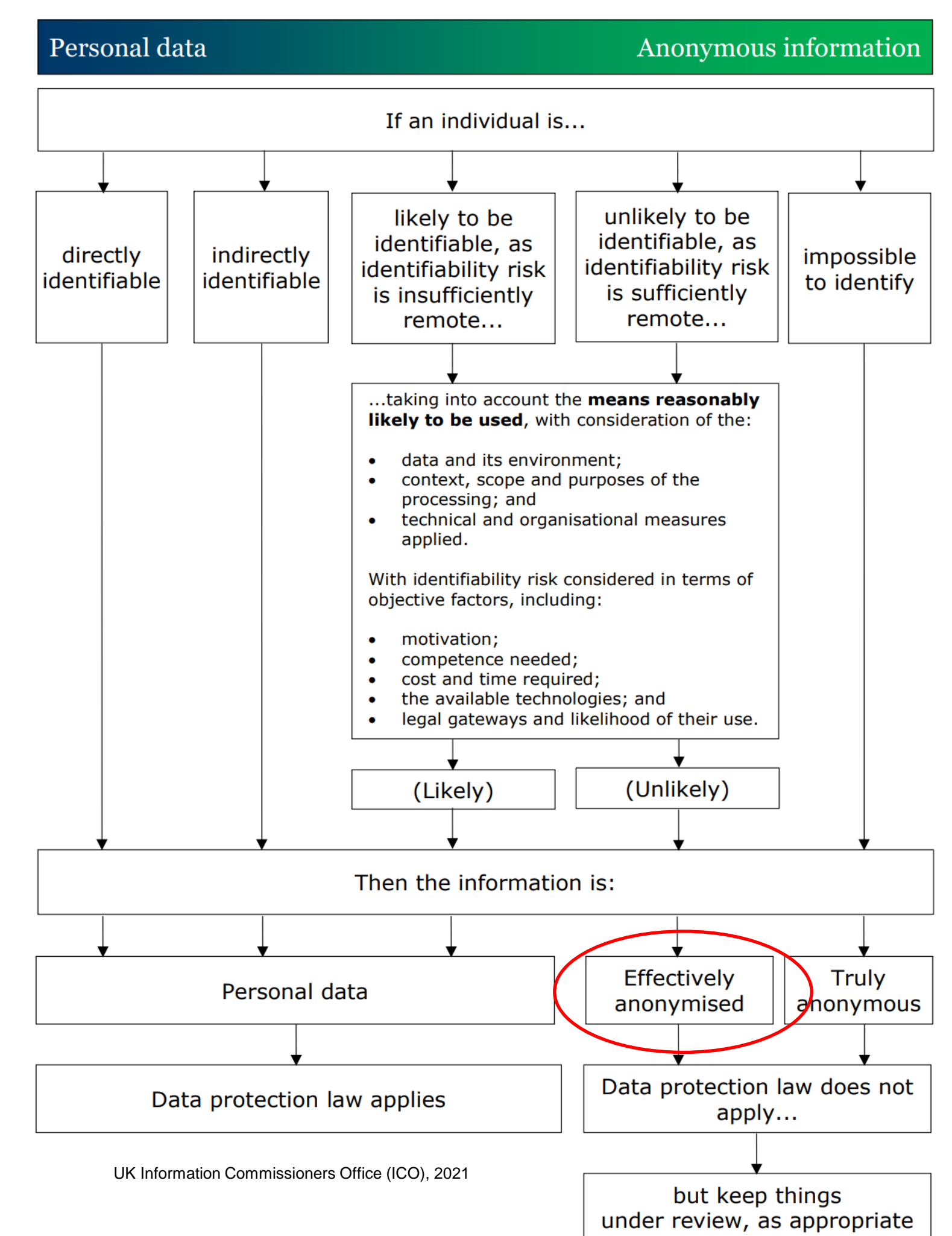
- DAC has complete decision-making control regarding data availability to analysts.
- Data access allowed exclusively for approved projects; no other purposes permitted.
- Only necessary datasets are provided for analyses.
- Only named delegates are allowed to download the data.
- Security of data environment at analyst's side must be suitable.



ANONYMISATION

The TB-IPD Platform houses individual participant data which are **effectively anonymised**:

- in TB-IPD:
 - Overtly personal data removed
 - Held in Data Safe Haven (highly secure)
- when released to researchers:
 - No access to keys
 - Higher risk data (e.g. DOB) removed
 - Location information restricted
 - Treatment as intervals, not dates
 - Assurances on security
 - Limited named access
 - Written assurances not to attempt re-identification



GOVERNANCE

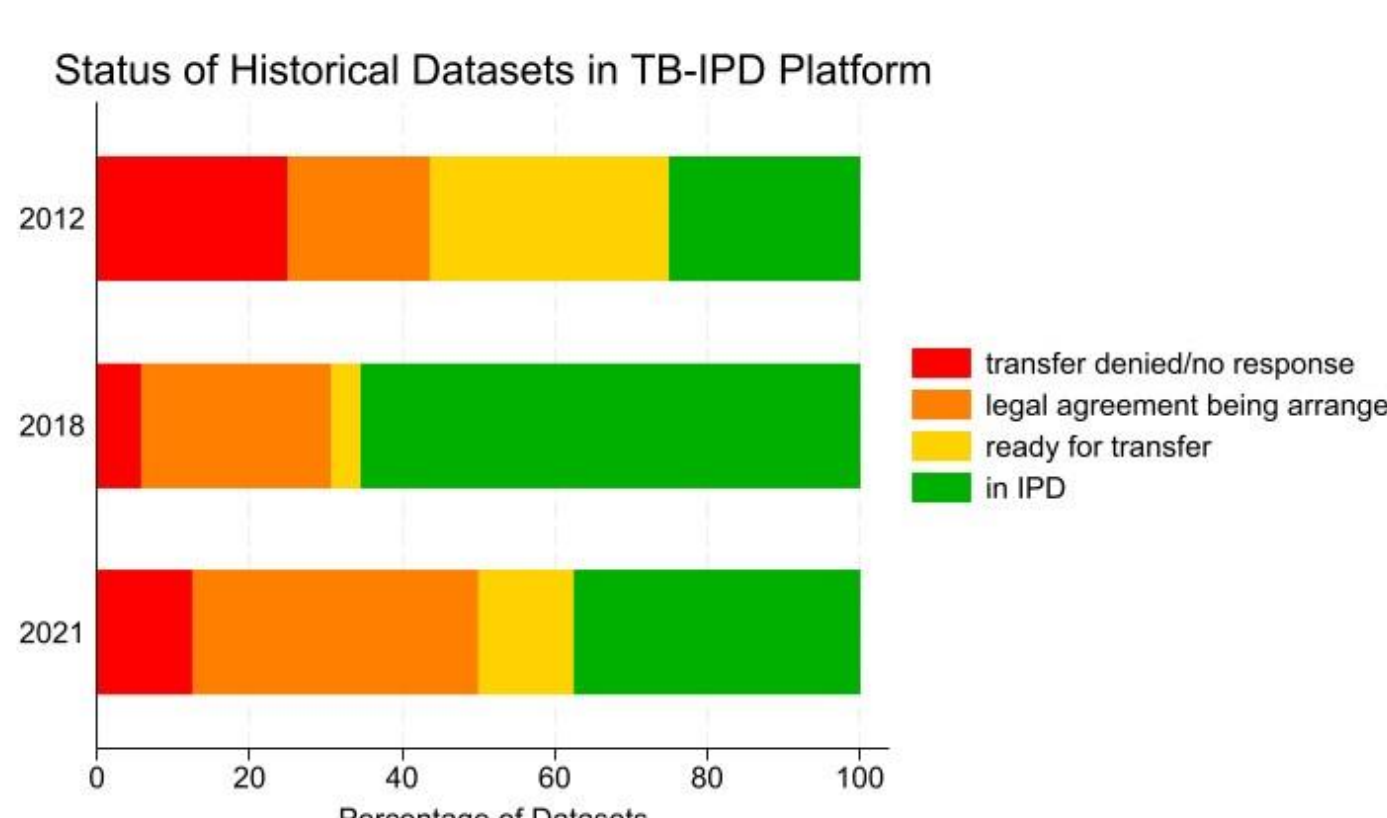
Data Access Committee: responsible for reviewing and accepting/rejecting applications for data access.

Anneke Hesselting (South Africa), Salmaan Keshavjee (USA), Norbert Ndjeka (South Africa), Ezio Távorá dos Santos Filho (Brazil), Bern-Thomas Nyang'wa (The Netherlands), Carla Winston (USA), WHO representative

Steering Committee: responsible for oversight and coordination of the TB-IPD Platform (currently WHO and UCL)

CURRENTLY

N datasets	62
historical	50 (n = 36,248)
paediatric	8 (n = 939)
trials	4 (n = 4041)



- DAC has met 4 times and reviewed 5 requests for data.
- Data has been shared with 4 Data Requestors; leading to 1 publication to date.



Acknowledgements

Neil Stoker (UCL-TB), Alex Potts (UCL Data Protection), UCL Legal Services, Andy Duncan, Trish Greenan, Lydia Walker
Dick Menzies, Jonathon Campbell (McGill)
Greg Fox, Tasnim Hassan (Sydney)
Tony Garcia-Prats, Anneke Hesselting (Stellenbosch)

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