Opportunities and experiences of accessing individual patient data for statistical research

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Opportunities
Open access, individual patient data (IPD) provides statisticians and trialists the opportunity to undertake methodological research and reanalysis of clinical trials including IPD meta-analysis.

What’s available and where can you find it
IPD from completed clinical trials conducted by sponsors such as GSK and Roche and funders such as MRC and Wellcome can be accessed from:
- Vivli https://vivli.org/
- YODA https://yoda.yale.edu/

Our experience
We wanted to investigate model based approaches for the analysis of adverse events using clinical trial data.

Top tips
- Make sure the trial(s) have the data you need to answer your question:
  - Contact the sponsor’s data sharing team – they can and are happy to help
- ‘Analysis data-sets’ are ready to use but are not available for all trials:
  - Request ‘analysis data-sets’ over ‘raw data-sets’ if possible
- Make contact with your institutions legal and ICT teams:
  - They can help with the data sharing agreement
- Identify where you will store the data, which members of your team will need access and how you will restrict access
- Access to data comes with strict conditions e.g. notification of any publications:
  - Make sure you are willing and able to comply

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