Research Brief

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Retrieval of individual patient data depended on study characteristics: a randomized controlled trial

Summary

The gold standard for generating scientific evidence is the synthesis of randomized controlled trials. The use of individual patient data (IPD) in this synthesis has been noted as being superior to the use of aggregated data. However, obtaining IPD is challenging, as there are several barriers to its retrieval. This study illustrates the retrieval process as well as its barriers and facilitators. Among the findings, the results revealed that providing a financial incentive to study authors does not increase the likelihood of IPD retrieval. Also, IPD retrieval may depend on study characteristics.

Implications

The use of IPD in synthesis is paramount for providing knowledge users with high quality evidence to aid in their decision-making. However, sharing IPD has legal, ethical, and logistical constraints which may discourage researchers in obtaining IPD. There is a need to optimize the retrieval process and to increase its wide-spread availability.

Reference: Veroniki AA, Ashoor HM, Le SPC, Rios P, Stewart LA, Clarke M, Mavridis D,Straus SE, Tricco AC. Retrieval of individual patient data depended on study characteristics: a randomized controlled trial. J Clin Epidemiol. 2019 Sep;113:176-188.

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For more information, please contact Dr. Areti Angeliki Veroniki: averonik@cc.uoi.gr

What is the current situation?

- The synthesis of randomized controlled trials (RCTs) is the gold standard for evidence-informed decision-making.
- There are noteworthy limitations of the use of aggregated data in a meta-analysis and network meta-analysis (NMA). Pooling individual patient data (IPD) from RCTs can result in greater statistical power and confidence in meta -analysis results.
- However, obtaining IPD can prove to be difficult. Reluctance to share anonymized IPD has been suggested as an important barrier.

What is the objective?

- To explore the effect of providing a financial incentive when contacting authors of RCTs to obtain IPD versus usual contact (no financial incentive).

How was the review conducted?

- 137 RCTs that were included in two systematic reviews and NMAs were identified. Of these, 129 authors were identified and contacted.
- A parallel-group RCT design was utilized. Authors of the RCTs were randomly allocated to the intervention group (financial incentive) or the control group (no financial incentive).
- Authors were initially contacted via email. Reminders were sent if a response was not received: (1) 1st reminder via email, (2) 2nd reminder via email and post mail, (3) 3rd reminder via email, and (4) final reminder via email and phone call.
- Seventeen sponsors (i.e., funders) of the 137 RCTs were also contacted.
- The following outcomes were examined: proportion of authors/sponsors who provided IPD, time to obtain IPD, and completeness of IPD retrieved.

What did the review find?

- At the time of this publication, none of the authors provided their study IPD; one sponsor provided two complete IPD datasets (within 318 days of initial contact).
- Receiving a response from authors for IPD retrieval may depend on study characteristics, such as funding type, study size, study risk of bias, and treatment effect.
- Common barriers for IPD retrieval included the inability to identify a study, confusion of data ownership, limitations in data access, and the requirement of IPD licenses.

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