SWAR 05: Incentives to trialists for sharing individual participant data

Objective of this SWAR
To examine the impact of providing a financial incentive to authors of randomised trials that are eligible for a systematic review and meta-analysis, versus usual contact strategies to obtain the individual participant data.

Study area: Data Collection
Sample type: Trialists
Estimated funding level needed: Medium

Background
Individual participant data (IPD) meta-analysis is considered the 'gold standard' for exploring the effectiveness of interventions in different subgroups of patients [1] and there has been an increase in the frequency of published IPD meta-analyses [2]. However, obtaining IPD is time consuming and contact with the researchers responsible for the original trials is usually required [3]. Although there is a strong movement to share anonymized IPD from randomised clinical trials (RCTs) [4-7], this has not been well established yet, and the cooperation of the original study authors is crucial for providing the data in a usable format and answering queries about their data. Given that obtaining IPD is important but also time-consuming, efforts need to be undertaken to understand how to optimize this process. Although previous studies have shown that financial incentives may improve response rates in survey requests [8], to the best of our knowledge, there are no studies evaluating whether a financial incentive may facilitate the retrieval of IPD from authors of studies that are eligible for a systematic review; or in fact, any studies evaluating different strategies to optimize the process for retrieval of IPD from such researchers.

Interventions and comparators
Intervention 1: Trialists will be contacted by email, mail, and phone, asked to provide the IPD from their randomised trial and offered a financial incentive for providing their IPD.
Intervention 2: Trialists will be contacted by email, mail, and phone, and asked to provide the IPD from their randomised trial, but will not be offered a financial incentive.

Index Type:

Method for allocating to intervention or comparator
Randomisation

Outcome measures
Primary: Proportion of authors who provide the IPD.
Secondary: (1) Time to return the dataset (defined as the period between the information request and the authors' response with the dataset); and (2) Completeness of data.

Analysis plans
Response rates in the two groups will be compared using the odds ratio and the corresponding 95% confidence interval. Binary logistic regression will be used to examine whether different characteristics of the randomised trials, such as study size and sponsor information, influence the probability of providing the IPD.

Possible problems in implementing this SWAR
A decision will need to be taken on how information about the SWAR is given to the trialists who are randomised to the incentive or control group, and whether the incentive is offered to trialists in the control group who provide their IPD.

References
1) Stewart L, Clarke MJ, on behalf of the Cochrane Working Party Group. Practical methodology of meta-analysis (overviews) using updated individual patient data. Statistics in Medicine 1995;14:2057-79.
2) Riley RD, Lambert PC, Abo-Zaid G. Meta-analysis of individual participant data: rationale, conduct, and reporting. BMJ 2010;340:c221.

3) Cooper H, Patall EA. The relative benefits of meta-analysis conducted with individual participant data versus aggregated data. Psychological Methods 2009;14(2):165-76.
4) Drazen JM. Sharing individual patient data from clinical trials. New England Journal of Medicine 2015;372(3):201-2.
5) El Emam K, Rodgers S, Malin B. Anonymising and sharing individual patient data. BMJ 2015;350:h1139.
6) Hopkins C, Sydes M, Murray G, Woolfall K, Clarke M, Williamson P, Tudur Smith C. UK publicly-funded Clinical Trials Units supported a controlled access approach to share individual participant data but highlighted concerns. Journal of Clinical Epidemiology 2016;70:17-25.
7) Tudur Smith C, Hopkins C, Sydes MR, Woolfall K, Clarke M, Murray G, Williamson P. How should individual participant data (IPD) from publicly funded clinical trials be shared? BMC Medicine 2015;13:298.
8) Dillman DA. Mail and Internet Surveys: The Tailored Design Method. In: Update with New Internet, Visual, and Mixed-Mode Guide. 2nd edition. New York: Wiley; 2007.

Publications or presentations of this SWAR design

Veroniki AA, Straus SE, Ashoor H, Stewart LA, Clarke M, Tricco AC. Contacting authors to retrieve individual patient data: study protocol for a randomized controlled trial. Trials 2016;17:138.

Examples of the implementation of this SWAR

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Date of idea: 30/DEC/2015
Revisions made by:
Date of revisions: