Correspondence

Sharing Results with Clinical Trial Participants: Insights from an Online Survey of Chinese Consumers

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To the Editor: Clinical trial participants have a right to know the results from the trials that they enable.¹ European and North American research, however, shows that trial results are rarely shared with participants.² Given the increase in industry-sponsored trials in China, we conducted the first investigation into Chinese consumer views about sharing the clinical trial results with participants.

We conducted an online survey in China (November 14–19, 2013). A survey invitation was emailed to a targeted population: adults most likely to participate in clinical trials (urban residents, 18–65 years, high school education, or above). The brief, voluntary, self-administered, anonymous survey questionnaire collected demographic information and opinions. Our self-funded study budget allowed us to analyze data from the first 100 respondents. Consistent with international research,² in China, nearly all respondents (94%) believed that clinical trial participants would like to receive a results summary, and almost all respondents (98%) would like to be given the choice of receiving a results summary if they were trial participants. In terms of quality reporting, nearly all respondents (95%) believed it was important/very important that results summaries were prepared by trained professionals [Figure 1a]. Written summaries were preferred, although other formats were also suitable [Figure 1b]. Most respondents (75%) preferred both Chinese and English versions; no respondents preferred an English-only version. Relevant to recruitment, almost all respondents (98%) believed they should be told before they agreed to participate in a trial if they were unlikely

Figure 1: How should clinical trial results summaries be prepared and distributed? Percent of Chinese consumers (n = 100) who provided the indicated answers for (a) How important do you think it is that clinical trial results summaries are prepared by a professional who has been specifically trained to prepare easy-to-read and trustworthy documents and (b) If you participated in a clinical trial and wanted a summary of the results, how would you like to receive the summary? CT: Clinical Trial; CTR: Clinical Trial Registry.

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to receive a clinical trial results summary. Most respondents (68%) believed that if they did not receive a clinical trial results summary, they would be less likely to participate in a future trial.

Sharing clinical trial results with participants has many benefits, such as demonstrating respect and appreciation for participation; facilitating communication between clinicians and participants; and increasing patient satisfaction with trial participation, which may enhance clinical trial recruitment. Conversely, not sharing results with participants could hinder future clinical trial participation.

In practical terms, sufficient time and resources must be dedicated to ensure results summaries are prepared efficiently and appropriately (e.g., adhering to the principles of plain language and nonpromotional). Investigators and sponsors have struggled to comply with guidelines for reporting results (e.g., on results databases); strong efforts will be required to ensure timely and appropriate preparation of results summaries for trial participants.

Although our study provides new evidence on the views of Chinese consumers, we recognize that additional studies (e.g., larger samples and qualitative methods) are needed. However, we have no reason to believe that future research would overturn our key finding that Chinese consumers support the right of trial participants to be offered a results summary.

In conclusion, this first study of a Chinese consumer cohort indicates that investigators and sponsors should offer written results summaries to trial participants. For many sponsors and investigators, respecting this right in China and in other regions of the world, will require a change in practice. The ethical imperative of respecting participant rights and the benefits from doing so warrant such change.

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Conflicts of interest
There are no conflicts of interest.

References