

Patients Involved | Case Report

Patient feedback on a plain language summary of results

Plain language summaries will be required for all interventional studies (Phase I to Phase IV) with a study site in the EU. Patients were asked to review a draft plain language summary from a completed Phase III study approximately one week in advance of a follow-up discussion. Individual telephone interviews with the patients were conducted by GlaxoSmithKline (GSK) staff members. Six patients were interviewed; two were EUPATI trainees. None of the patients had the condition that was evaluated in the study. The patients provided valuable feedback about the wording, structure, and content of the plain language summary.



Who was involved?

GlaxoSmithKline; Patients

Level of patient expertise

- Expert patients/patient advocates with good R&D experience.
- EUPATI trainees and future trainees with experience as patients, but not with COPD, the condition evaluated in the example study.

Benefits

We used the comments from the patients to make some changes to the structure and format of our plain language summaries. For example, we have added headings to the document to make it easier for the reader to find information. We confirmed that the tables were preferable to text explanations of adverse event results. We added clarifying language to help the reader understand more about clinical research.

Challenges

The only challenge was to ensure the activity was accessible to patients who responded to the posting. Initially we were planning to run a focus group in London however it became quickly evident, mainly due to location of patients and their availability, this wasn't going to be the best approach. Flexibility and agility was key; we were able to quickly change our plans and hold individual telephone based interviews with a set interview guide to obtain input. Each interview was audio recorded so feedback could be aggregated with key conclusions drawn plus the wider GSK team could hear the feedback.

Learnings

Every patient brought a different perspective, skill, expertise and level of knowledge. Each raised interesting questions which provoked follow on in-depth discussion both within the interview but also with the GSK team, particularly around the question 'what happens after plain language summaries are released – what happens next for the patient who took part/the medicine/the research?' As a result, in addition to receiving similar points in each interview around reporting the key study finding, we also obtained a wide range of suggestions for overall improvement of the plain language summary document. Beyond this from insights shared, we were able to consider how patients may seek and retain the information provided by GSK.

