We appreciate your input on our study, “Identifying the Value of Patient Group Engagement Activities in Medical Product Development.” This letter shares the main findings from the study interviews.

The objectives of this study were to:

1) Identify benefits of and investments in patient group engagement methods in medical product development.
2) Learn how patient groups and research sponsors define high, moderate, low, and no benefits and high, moderate, low, and no investments.

We conducted 28 semi-structured interviews with representatives from patient groups and research sponsors.

MAIN FINDINGS:

Benefits of Patient Group Engagement
The benefits cited by patient group representatives primarily involved improving the quality and efficiency of clinical trials, improving research participant experiences, and amplifying the patient voice in developing medical products that address patient needs.

Research sponsor representatives noted the same three benefits, but also included deepening relationships and trust between patient groups and industry, and motivating patients and researchers to get more involved in the development of medical products.

High-benefit activities were viewed as those that:
- Have the greatest and most beneficial impact on the patient experience during a clinical trial;
- Could not be accomplished without the direct involvement and/or expertise of patient groups;
- Are essential for advancing medical product development;
- Are easy to implement; and/or
- Are ethically “the right thing to do.”

Moderate- and low-benefit activities were still viewed as important but were described as having less of an impact on patients, requiring less input from patient groups, or having lower priority compared to other activities.

Very few activities were categorized as having “no benefit;” such categorization largely reflected an organization’s lack of direct involvement in those activities.
Investment in Patient Group Engagement

All respondents noted that investing in activities ultimately relied on staff time and organizational effort, and the investment of financial resources.

**High-investment activities** tended to be perceived as longer-term commitments that:
- Require continual financial investment;
- Require a tremendous amount of staff and/or volunteer time and expertise;
- Require organizational commitment; and/or
- Involve outreach and engagement with a larger patient community.

Moderate- and low-investment activities were viewed as requiring less money and staff time to carry out, relying on already-established processes and infrastructure, and they often represented discrete, well-defined actions.

We are now using this information to develop a tool that will help patient groups and research sponsors identify their shared goals.

**Thank you for sharing your thoughts with us!**
If you have any questions about this study, please contact CTTI Project Manager Zachary Hallinan: zachary.hallinan@duke.edu or 919-316-0127.