September 30th 2018

Re: Your communication.

*On November 15, 2018, the FDA's **Patient Engagement Advisory Committee** **(PEAC)** will hold its second public meeting to discuss how the FDA can use patient-driven platforms, such as those that utilize social media, digital health technology and patient registry data, to inform the regulatory evaluation of medical devices.*

My name is (b) (6), from Canada. I ran support groups online for international patients and for Canadians for about fifteen years. I set up the groups as restricted, interviewed new people and moderated conversations. I, and others, also organised participation in research. Now, another group has taken over for international patients and one for Canadians, and a Chordoma Foundation has been established. I understand that the Foundation has set up groups as well.

I found that personal privacy has been important for group members. We undertook and accepted research using external applications such as SurveyMonkey and the ongoing NIH Familial and Non-Familial Studies.

Until recently, there has been comparatively little research on the various forms of chordoma and group members have been receptive to requests. Any approach to a group should be discussed with the moderators and offered to group members for their consideration. Many of the chordoma group members continue quite sick and the groups deal with deaths, so sensitivity must be respected.

If I were to organise this, for a group, I would set up a consultation micro group within any main group, and if agreed, would suggest this to the group members. The consultation set up would be handled internally. We would expect that information gathering or dissemination would be handled from outside and researchers or informants would work with moderators.

Sincerely

(b) (6), Canada

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