

TOOL

Feedback of a Patient Organization

HollandBIO and admedicum asked Marleen Katee, President of PSC Patients Europe, and Maryze Sconevelde van der Linde, Patient Advocate Pompe Disease, the following questions:

“What is most important to you when working with the industry?”

- Relationships are built on trust. A “warm” (personal, trustworthy, sustainable) relationship is the best way forward, especially in long-lasting collaborations.
- Work with us. Patient experts are patients themselves, so we have different needs and priorities than healthy individuals. For example: we aren’t deadline junkies. Give us at least 3 weeks to get back with an answer.
- Be clear on what the (mutual) expectations are.
- Do not only talk to us, but above all listen to us. Amazing things can happen...
- Please don’t ask us to translate: we are not a translation agency, we are a patient organization!

“What does the industry need to consider when collaborating with patients / patient organizations?”

- Create lay versions of every paper/document you publish or use, including Travel Policies, Informed Consent and Data Privacy documents
- Work with the patient organisations on those lay versions. With all due respect, as researcher it might be a bit of a challenge to figure out if a text is well-understood or not. This is your ultimate opportunity to give back to the community!
- Train your researchers, event managers, legal counsels etc. on patient-related matters, including how to embed the patient’s voice in your research. Make sure they see the benefits of patient involvement, instead of it being an obligation. Learn them to talk with patients as an equal partner. Above all, learn clinicians & researchers to listen to the patients.
- Don’t expect the patient (or patient organisation) to do all kind of things free of charge. You don’t do that either, do you? A fee is great. However, some patient experts cannot accept a fee, as that will have a huge (negative) influence on their finances (e.g. on welfare or on disability leave) . You can offer to donate to a charity of their choice. Solved!
- Accommodate patients needs: if there is a visit, make sure there is wheelchair access, a meal matching our dietary needs. If we need to come a day earlier because we are tired, so be it. Don’t discuss, just do it and make it happen.
- Expect patients to need more extended deadlines. Being ill is a fulltime job already.

Source: This tool has been developed by admedicum® Business for Patients GmbH.