

How to make patient advocates friends not foes

INSIGHTS FROM THE DOC

The Diabetes Online Community is a group of vocal patients and caregiver advocates using social media to support their community.

TOP 3 THINGS the DOC wants from industry

- 1 Information about **patient support services**
- 2 Updates on **emerging technologies & treatments**
- 3 Details of **charitable or corporate social responsibility** efforts

TYPES OF PROGRAMS the DOC would like to see industry support more

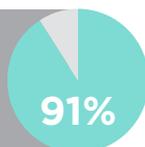


Efforts that are **run by the advocates** vs the company

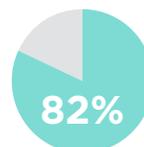


Education to reach **people of color** and **less affluent** demographics

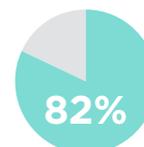
What are the MOST VALUABLE BENEFITS of partnering with industry?



Ability to share opinions to **inform business decisions**



Making connections with others in the community



Access to **leadership/decision makers**

What must industry BETTER UNDERSTAND about working with patient advocates?

- We are **not your sales force**
- Value dissent and other opinions **even if they conflict** with your expectations
- **Get us involved earlier**...we have experiences that should be taken seriously and listened to
- Many of us have **"day jobs"**... consider this when planning events



KEY CONSIDERATIONS

- “ I want industry to be **very realistic with us about things they can and cannot do**. It doesn't feel good when we come up with a bunch of collective ideas but **don't see any progress**. ”
- “ To be truly 'patient-centric,' companies need to **really listen to what the patient needs** and how we feel. ”
- “ We'd like to be **involved much earlier in the process...**to collaborate together, to think of solutions and ideas together and to overcome challenges together. ”
- “ I am concerned about the blurred lines and gray areas that exist when advocates are enticed by free travel without a clear objective and follow-up to show that objectives were met and advocacy driven changes occurred. **I've seen a lot of talk and no action**, when companies have brought advocates together claiming to be interested in their thoughts about pricing and then raised prices anyway.” ”

BEST PRACTICES FOR WORKING TOGETHER

- 1 Involve advocates and influencers early in campaign planning, offer access to decision makers and leaders to create collaborative outputs.
- 2 Help elevate advocates' causes via company/brand social channels, enlist them as partners to share ideas and information...both yours and theirs.
- 3 Don't just engage when a company or brand campaign is underway, continue to keep advocates aware of charitable causes supported, under-served populations your company seeks to reach and services provided to people in need.

ABOUT THE SURVEY

In May 2017, Tonic conducted an independent and anonymous survey of 11 leading members of the Diabetes Online Community (DOC). All participants have worked/partnered with at least one pharmaceutical or medical device company in the diabetes market in the past three years. The objective of this survey was twofold: 1) gain insights from this influential group of bloggers, advocates and influencers and 2) inform industry of best practices and key considerations when planning patient influencer engagement.