



TRUE REPLY
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True Reply Case Study - Healthcare Hereditary Neuropathy Foundation

The Patient Knowledge Gap

When dealing with debilitating diseases, patient attrition is a constant challenge. Once the symptoms of debilitating diseases progress to the point where things as simple as walking or using a computer become painful or uncomfortable, we experience the patient knowledge gap. At this point, the foundations efforts to maintain participation levels soon becomes cost prohibitive.



Bridging The Gap

In order to better understand the impact of pain in the lives of those afflicted with CMT, HNF considered the reality of the patient knowledge gap and the potential a platform like True Reply offers in creating a truly accessible experience for patients through the power of voice.

To date, the information available regarding pain and CMT is limited. True Reply using an open-ended, qualitative, voice-based collection methodology, allows the participant an easy way to provide detailed responses regarding their treatment and symptoms, extending their ability to maintain participation in the study.

Through traditional form-based surveys, the data collection methodology is more linear and structured. Face-to-face or IDI-based interviews help address this but, for a non-profit like HNF, are cost prohibitive at scale. True Reply offered HNF the perfect compromise between these two extremes.

Case Study Reference

The Hereditary Neuropathy Foundation (HNF) is a non-profit 501(c)3 organization whose mission is to increase awareness and accurate diagnosis of Charcot-Marie-Tooth (CMT) and related inherited neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

HNF & True Reply

HNF and True Reply set out to better understand pain as an under-researched component of CMT and those living with CMT. After running a preliminary study on behalf of Pharnext, an advanced, clinical-stage biopharmaceutical company, it became evident that those living with CMT were greatly affected by pain and it was affecting their quality of life and living with CMT at a level not previously imagined. To better understand the impact of pain in the lives of patients, HNF used True Reply to deploy a targeted survey with the goal of utilizing an open-ended surveying strategy that would help supply a baseline for future research.

"Deploying True Reply gave us an understanding of pain in the CMT community that was only possible through the beautiful variety offered by voice."

- Allison Moore, HNF Founder/CEO



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Research Benefits

The initial benefits to research were realized within minutes of the first patient survey completion.

Patients recorded answers were open and expansive, significantly more than experienced via form-based surveys at a comparable cost-basis.

Patient participation through their telephone created an environment open to them to share the full breadth of the impact of pain in their lives and how they are dealing with that pain.

Specific was insight into the range of self-medication occurring and the broadness of the types of medications used. Medication spanned everything from off-the-shelf medications like Ibuprofen and vitamins to Marijuana. Even opiates like Oxycontin and Morphine found to be used.

The need to target specific questions was replaced with an open-ended stream of insight that was profound in the understanding of pain in the lives of those afflicted with CMT.

115

participants

621

responses

85%

completion

31 words

avg per answer

10-14 secs

avg time per answer

Practitioner Benefits

The survey administration within True Reply was performed directly by HNF employees.

The dashboard is designed in a very linear fashion and extremely easy to understand. Administrators were able to launch their pain survey within minutes and start collecting call-in feedback immediately.

There is no waiting for your survey telephone number - it's made available instantly at hitting your "Launch Survey" button.

Ease of marketing was a major benefit to HNF. HNF was able to promote participation in the survey via a multichannel methodology - email, website, & online communities (social). Response rates by channel allowed HNF to measure ROI vs. other marketing initiatives deployed in same channels.

Reviewing survey outcome is fast and easy to use. A combination of open-searching, custom keyword ranking, and multi-point filtering allowed the administrator to zero-in on the most valuable participants.

Access to reporting insights is concise and actionable. You can drill into top keywords just by clicking on those trends to have participants and participant responses filtered instantly.



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About the Hereditary Neuropathy Foundation

Allison Moore founded the Hereditary Neuropathy Foundation (HNF) as a non-profit 501(c)3 organization in 2001 upon learning of her sudden onset of CMT. After this frightening and life-changing experience, Allison made a passionate commitment to changing the outlook for people living with CMT.

HNF has since been committed to increasing awareness and accurate diagnosis of CMT and related inherited neuropathies. Major projects include the production of the documentary “Bernadette”, publication of a series of children’s books, *Arlene On the Scene* and *Arlene the Rebel Queen*, and quarterly *CMT Update* Newsletters.

HNF supports patients and families with critical information to improve quality of life and is dedicated to finding treatments for CMT. HNF provides a strong, organizational voice to those living with CMT all over the world.

www.hnf-cure.org

About True Reply - Hear & Be Heard

True Reply was born out of the recognized need for patients with debilitating diseases to have a voice; a continued role in the fight to find a cure.

True Reply has since evolved to become a platform for deploying intelligent, voice-powered surveys for the collection of feedback, opinions, and research via telephone or the Amazon Alexa.

As the first and only platform approved by Amazon for the administration of voice-powered surveys via any Alexa-powered device, True Reply is uniquely positioned to augment and enhance any research project - commercial, academic or in healthcare and healthcare research.

Today we're actively partnering and working with a variety of industries to enhance reach and understanding.



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