

Uncovering the truth

Understanding the patient experience with difficult-to-study conditions



The background

No one was talking about it. Not much anyway. Although it's incredibly common, constipation is a "socially sensitive" condition that people just don't like to discuss. This created a conundrum for two pharmaceutical companies developing a new drug to treat two prevalent constipation-related disorders. These companies needed to know more about patients who suffered from chronic idiopathic constipation (CIC) and irritable bowel syndrome with constipation (IBS-C) in the "real world" and how the conditions impacted their lives. But, while the conditions are common, the data evidence the companies needed was not available.

Calling the data detectives

The two companies knew they needed an innovative approach to gather the data they wanted, so they turned to a unique group of scientists working in the Health Economics and Outcomes Research (HEOR) department of Optum®. Not only did these data detectives possess extensive experience investigating and solving the pharma industry's most difficult data problems, they had the ability to prospectively build a "fit for purpose" real-world data solution that deterministically linked the voice of the patient with medical and pharmacy claims data.

Searching for clues

Once on the case, the Optum data detectives quickly realized they needed more than standard research methods and data sources to generate the data evidence the companies were seeking. The researchers needed to get real patients talking, so they created the first comprehensive, real-world, longitudinal research platform for CIC and IBS-C patients. This platform enriched available claims data with patient-reported outcomes and allowed the researchers to follow the patient's experience over time.



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Compelling testimony

To uncover the patient's voice, study participants were asked to complete:

- A patient-reported outcome (PRO) survey at baseline
- A follow-up PRO survey each quarter over 12 months
- Monthly medication updates that captured new and discontinued treatments
- A 7-day daily condition experience diary at baseline and at month 12

The diary was a particularly novel way to gather evidence about patients' struggles with their conditions since it allowed them to describe their symptoms and experience with treatments in their own words.

True identity

Optum's data detectives were able to reach out to a diverse population of potential study participants. In direct contrast to many Optum competitors, this put Optum in the unique position of being able to link claims data — complete with cost and utilization records — with enlightening insights shared by patients from all over the country. Regional and practice bias was avoided. The patient's perspective was added. A huge gap in knowledge was closed.

Finding a solution

The evidence uncovered in the study was revelation. It not only provided the pharmaceutical companies with answers to the questions asked, but also to many more they hadn't even thought to ask. One particular surprise discovery was how desperately patients were looking for treatments that worked. With just a few relatively new prescription drugs on the market, patients were investigating everything from over-the-counter medications to homemade remedies to concoctions found on the internet — or some combination of the above. Many patients were treating their symptoms for years before seeking treatment from a physician. In other words, people were searching far and wide for relief that the new drug could provide.

Using the evidence

With a robust, new repository of data to examine, the research team went to work. The findings helped the companies to:

- Reveal higher levels of patient satisfaction with the new drug
- Communicate the benefits of the product to payers, clinicians and consumers
- Demonstrate the drug's real world effectiveness matched up well with clinical trial efficacy
- Generate and evaluate new hypotheses to support the value of the product within the existing data platform
- Examine the patient perspective of successful treatment beyond evidence captured in clinical trials

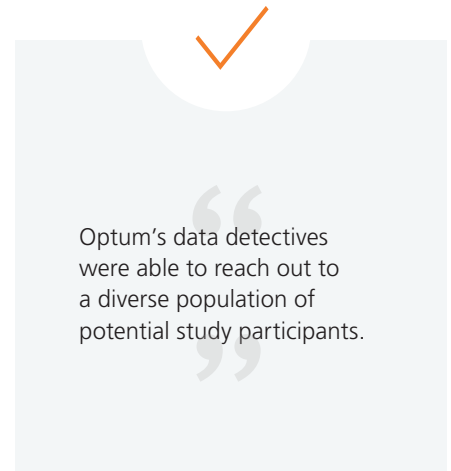
The study demonstrated how important it is to include the patient's voice when assessing the benefits of particular therapies and making decisions about treatment. An understanding of the factors affecting patient treatment preferences is critical for ensuring patient satisfaction. That understanding can also help providers enhance patient satisfaction, care, treatment adherence and health outcomes — and provide our clients with the information they need to propel health care forward.



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