



## **Using ethnography to uncover the authentic patient experience**

*Su Smith, Director of Origins, talks through the benefits of ethnography from a patient and client perspective, how Origins go about doing it and how the data can lead to positive change.*

There are many advantages in gaining a greater understanding of what it's like to live with a medical condition from the patient's perspective. Learning the language they use to describe their symptoms and condition ensures that the most effective communications are created. What's more, a number of the regulatory bodies now require companies to collect patient experience data. We believe ethnography is one of the most powerful processes to uncover the true authentic patient experience.

### **What is ethnography - and how do we do it?**

In research terms it's the study of people in their own environment using methods such as participant observation and face-to-face interviewing. The way we do it at Origins Insights is very subtle, where the patient is in control. There are no film crews, it's often done digitally with video diaries. We believe it's one of the best methodologies to understand the authentic patient experience because, coming from the patients themselves, we get a really good understanding of how they talk about their condition and what is important to them.

Ethnography can sometimes be a 'catch all' term for engaging with patients in our industry. But not everyone does it the way we do. We capture their real, unguarded thoughts and, hearing the actual language they use, this means the feedback is as true as it gets. It's smartphone based, very unobtrusive and, as everyone is used to how they work, this makes it easy for them to take part, when it suits them. One of the most powerful things we get from this type of methodology is the answers to questions we didn't know to ask in the first place. That's perhaps why people who've seen ethnography before are surprised at just how raw, authentic and in depth our outputs are.

### **Why is it good for patients?**

They get to tell you about the truly important things from their perspective without feeling intimidated or led by an interviewer. As a result, they can be really clear on what is important to them and what they think is important for other people to know about their lives. This might be what it's like to live with a condition and be treated by it. Or to look after someone with a condition.

We actually find that some of our younger participants love to involve other people, especially if they've got siblings. So they'll answer the question and then they'll take their

phone and they'll go and ask their brother or sister. For example, "If you could change one thing about my condition, what would it be?" And they're interested to use it as a way of starting the conversation which is fantastic. So, ethnography works really well because we give people the chance to talk about what's important to them up front without leading them and guiding them in any way. And we just say to them, "tell us about your day and tell us what's happening in your life at the moment" and we take it from there.

### **Why is it good for clients?**

It's really powerful in helping our clients differentiate themselves from others. If they can learn about something that no one else necessarily knows they can better engage with their patients. Whether that is learning from them so that they can design clinical trials and attract them to clinical trials in the right way. Or whether that's about engaging with them later once the drug's actually available to understand what it's like to live with it.

If you talk to brand managers within pharmaceutical companies and you say, "If you could do anything to understand their condition, what would you do?" The answer might be that they'd love to go and live with a patient. Of course that's just not possible compliance wise or time wise, so this is as close as you get to that level of insight. It's like helping them to step into their patients' shoes and, due to the way we select the participants, as representative a view of the true patient population as possible.

There's also the regulatory side of things too. A number of the leading regulatory bodies in the world now, including the FDA in the US and the MHRA in the UK are now requiring that companies collect patient experience data - which ethnography enables. Pharma companies are having to be more disciplined about actually engaging with patients and not only collecting this data but doing something about it.

### **What makes a true patient population - and how do we find them?**

It's about finding those patients who aren't easy to find or recruit. Those who aren't necessarily self-selecting advocates who may be more well read about their conditions, and perhaps, more highly educated or not as reflective of minority populations. But it's not just about ethnicity, it's also about socioeconomic levels because that can really affect how a patient interacts with healthcare and how they are able to do the things that often they need to do for themselves beyond just taking the tablet. Some communities have a mistrust for healthcare professionals that may prevent them from accessing appropriate care or treatment.

In practice there are lots of different ways to find patients. The key thing is to not just go down one route that leads to the easiest to find patients. So, as well as using recruitment partners and healthcare networks, we leverage social media and at times we've even spoken to community leaders to ask them to help us to engage. It's about going where people are and people are likely to be. That's how you get the real, authentic responses.

## **How can clients use the findings?**

Traditionally, Pharma companies gained their patient insights through talking to doctors. They would put the lens on that, what they'd consider the clinically relevant things. These tend to be the things that they can control through therapy and through treatment but those aren't necessarily the things that are the most important to the patient. Through ethnography, clients learn a lot about what the truly important things are from a patient perspective, that's very valuable insight. For example, it can reveal where they place the importance of support from different types of healthcare professionals versus support from peer groups. And how they themselves learn more about their condition.

These days, pharmaceutical companies don't just provide the medication, they also provide a service around the medication. It's really important for them to have that patient understanding and for us to help them to get the maximum return from their investment. Just understanding somebody is one thing. How can clients do something as a result to make a patient's situation better or easier? We run interactive workshops helping clients understand what to do with the data and how to make a change and make a difference that will help the client as well as the patients and their healthcare provider. That's why patients and caregivers tell us they love to participate in these projects, to make a positive change.

*Su Smith is Director at Origins. If you'd like to talk through how your patient insights could benefit from ethnography, please contact us....*