

The unknown unknowns: why are patient insights so insightful?

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I have been a patient And I imagine a large proportion of you reading this have been too.

During my time as a patient one thing resonated: although I was involved, it was very much around the edges. Some of them were important edges, I admit, but as THE person experiencing the care and the treatment, I felt I had important insights and experiences to contribute. For me, at that time there wasn't a clear way to pass my experiences on, but when the opportunity did come up, I ended up presenting a series of curated highlights that I thought people should hear, rather than anything 'real'.

I felt then and still feel now that patients (and their carers) are an untapped source of interesting.... and do I dare say game changing information. Over the last few years – terminology including 'patient-centricity' and the 'patient voice' have been used more widely by the pharmaceutical industry. There is a recognition that involving patients is not only commercially astute but is the right thing to do. Patient experience is now being sought not just to ratify an approach but to ensure the right one is developed in the first place.

Regulatory and reimbursement agencies are also starting to allow, if not encourage the patient perspective, with the FDA stating in guidance in 2018 that 'patient engagement is critical throughout the medical product development process'

Whilst I would agree with the FDA that this increased focus and desire to ingrain the patient view into all areas of work is critical. I think it's also critical to acknowledge the differences in perspectives and work pragmatically to address them. Patients are commonly viewed in the context of their treatment journey, whilst patients view treatment in the context of their life. We need to consciously challenge our approach to be sure we are unearthing authentic insights based on this broader more holistic position.

Some key areas where patient insights can be used

- To inform clinical trial design, recruitment and retention strategies
- Identify patient relevant outcome measures
- Lobbying and Gov Affairs activity
- Patient journey
- Medical communications activities
- PR and corporate affairs activities
- Patient support services

- Internal education and training
- External education and training
- Patient and PAG education and training
- Brand value propositions
- HTA submissions (where video footage is allowed)

At Origins, we are committed to listening to patients to understand their experiences. It's our passion, it's what we do every day and it's what we believe in wholeheartedly.

We believe that to be the most effective, we must understand patients on their terms, in their environment, at a time that suits them. As not all patients and diseases are the same, we approach each project in a bespoke way and invest in immersive and innovative methodologies that enable us to access authentic insights. Our senior inhouse team of research directors distil these into actionable insights – insights that are tangible, clear and which can be used across functions and programmes, providing intelligence that re-defines success.

We would love to show you how we can help you make a difference to patient's lives. Drop us a line at contact@origins-patients.com and we will arrange a time for us to speak.

"Nothing is more terrible than activity without insight"
Thomas Carlyle