

Observing Patients Online: the changing face of research

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Abstracts

For years, patients have shouted to be heard. But as online patient communities, chat rooms and forums have gained popularity—and political clout—their voices are resonating.

Now being used to paint real-world pictures of patient drug use, data from online patient communities can no longer be ignored or dismissed. “The history of medicine is that in many respects patients have been left out of the conversation,” says Brian Loew, president of inspire.com. “I think patient communities are a real opportunity to fix that.”

Already, data from online patient communities are being used to deepen understanding of the patient journey through illness, thus improving compliance, informing patient-centred endpoints for clinical trials and influencing reimbursement decisions. Such pools of patients are also being deployed to conduct direct-to-patient clinical research, where patients are recruited and monitored online, thus eliminating the need for clinical sites and investigators. In the face of payer skepticism, however, the question is how fast will it scale up?

Scope

In *Observing Patients Online: the changing face of research*, FirstWord investigates the role online patient communities can play in observational research to enhance knowledge of how drugs are taken in the real world. Based on expert interviews, research and studies, the report examines how the means to recruit patients online and track their experience via patient-reported outcome questionnaires and sensors in real-time has the potential to transform how observational studies are conducted.

Highlights

Who takes the lead in commissioning observational research

Typical studies being commissioned online

How healthcare tracking is going mainstream

Case study of UCB's partnership with PatientsLikeMe

Benefits of crowdsourcing: is it the new serendipity?

The drivers of online observational research

Purchase Reasons

Overview of how online patient communities are transforming observational research

Access to expert opinion from key leaders in the industry

Discussion of conventional versus direct-to-patient trials

Key Questions Asked

What role do online patient forums have to play in observational research?

How is pharma research using patient communities?

What position do payers take?

How can data mined from online sources increase the authenticity of a drug's value?

What role, if any, does self-tracking have in observational research?

Who Should Read This Report

E-business/Emerging Technology Directors

Clinical Research and Trials Directors

Heads of Communications/PR

Market Access Directors/Managers

Marketing Research/Business Intelligence Managers

Key quotes

“We see a shift wherein patients are not just taking part in their care, but defining it. Patients make decisions about managing their disease, defining their quality of life and deciding how their dollars are spent.”

– Brian Loew, President of inspire.com

“The challenge for the pharma industry is to identify the most effective means of communicating patients’ perception of treatment benefits to the different stakeholders in a changing technological climate.”

– Mike Baldwin, Health Outcomes Manager at Novartis, UK

“At present, around 99 percent of all trials are still recruited via clinician sites. The idea of doing research directly with patients is definitely an emerging innovation. It has been piloted and now the question is how fast it will scale.”

– Elisa Cascade, Vice President of Mediguard

Expert Views

Brian Loew, President, Inspire.com

Keiron Sparrowhawk, Partner, PriceSpective

Sue Curron, Vice President and Senior Global Project Leader, Patient Solutions, UCB

Elisa Cascade, MediGuard

Jeremy Shane, President, HealthCentral.com

April Foreman, Psychiatrist

Ben Heywood, Co-founder and President, Patientslikeme.com

Paul Wicks, R&D Director, Patientslikeme.com

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