BAYER WORLD PATIENT SAFETY DAY
IN-DEPTH INTERVIEW SUMMARY

Summary: Key findings from in-depth interviews | July 2023

Goal

In cooperation with Bayer, Savvy Cooperative listened to 5 participants about their experiences in learning about side effects, talking with their doctors about reporting side effects, and general observations on what patient safety means to them. This is part of a multi-phase project designed to understand patient perspectives on safety concerns.

Approach

The interviews involved five across a wide variety of therapeutic areas and demographics. A semi-structured discussion guide was used to explore key topics and the interviews were conducted using Savvy's platform (unless otherwise noted). Each conversation was approximately 30 minutes in length.

KEY FINDINGS

INTRODUCTION

These interviews were broadly concerned with how patients come to understand what patient safety is, particularly regarding experiencing and reporting side effects.

DEFINING PATIENT SAFETY

Regarding the definition of patient safety, different things came to mind for each participant. The main areas of focus were patient health information and privacy; physical safety during medical procedures; safety about medications and contraindications; and safety regarding how to actually use certain devices such as auto-injectors. Not everyone immediately connected information about side effects with patient safety, so one consideration might be adjusting materials to encourage thinking about these conversations as a way of keeping patients safe.

"I like to read stuff, so whether that's some data that's out there about safety, I would like to see some of that. And then having that in-person conversation [with my doctor] just to kind of make sure that we've touched everything that we can." -Participant

"[Patient safety is] ensuring that you know everything that you do is safe for you, the person…. Or any obstacles or you know, any dangerous stuff." -Participant

COMMUNICATION & INFORMATION-SEEKING

Patients appreciate doctors who take the time to listen to patient concerns, including answering questions about contraindications, alternative approaches to condition management, and potential side effects. Communicating in a setting where they feel respected builds trust for patients to talk with their doctors if they do notice something is amiss or unusual..

“I can tell they're looking at my chart, making sure there's no interactions with whatever else I'm taking or, giving me the positives and the negatives, which, you know, with most drugs, there's gonna come some kind of symptoms. The good doctor was actually very informative about the symptoms that can happen and then kind of like stated, ‘if for some reason this symptom occurs, then we can go this route.’” -Participant

Several patients did mention searching the internet, like Googling, to see if other people have experienced the same side effects. This was the first step for two of the interviewees, and they mentioned using it as a way to access other patient journeys and figure out next steps to take in talking with their healthcare team.

“I've definitely used Google. I've read about stuff on Reddit, I haven't taken medical advice from Google or Reddit, but there is a side effect I was having with a particular drug that I was on and I searched for it in Google. I found that other people who were taking the same drug had experienced the same thing, which kind of lit a fire under me to go and talk to my doctor.” -Participant

EXPERIENCING & REPORTING SIDE EFFECTS

Not everyone knows what happens when side effects get reported, or that there are multiple channels for reporting. Most participants mentioned talking with their doctors about side effects, but only when those side effects became too severe to manage at home.

When speaking about side effects, participants split them up into small side effects and severe ones, preferring to manage the small ones at home using strategies they learned from the internet. These small side effects may not be mentioned to the doctor right away, but might come up in a future meeting. However, severe side effects were points of discussion with doctors via phone calls, emails, or sending messages via a patient portal.

“I've never really had anything serious enough to report to anybody, other than asking small little things like injection site reactions or maybe like a headache.” -Participant

One participant shared that years after reporting a severe side effect, she applied for life insurance and was denied due to having experienced said side effect. Neither she nor her doctor realized this was something that could happen after reporting, and the patient mentioned it made her feel less comfortable disclosing in the future.

“I was on this medication and what I had, I don't know if [my doctor] reported to the Medical Board or if they reported it to the drug manufacturer, I'm not sure. But I did find out later, like a year later. I was trying to apply for health insurance life insurance. and I was actually prevented from being accepted.” -Participant

CLINICAL TRIALS

Regarding clinical trials and patient safety, participants overwhelmingly want to know about potential risks from the very beginning. Knowing about any potential side effects would be useful in patients figuring out whether or not to enroll.

“I would like to be told up front, not after I started or, after I'm experiencing and it's like, ‘oh yeah, that's a symptom.’ I want to know all [side effects] from bad to worse. What are the possible symptoms with this? So I would just go in fully aware of what could happen.” -Participant

They also would like the information to be presented in an easily understood way, using simple language with options for alternate formats such as video or visual presentations.

“Have it be super concise and not like I'm being talked down to, but explaining.—not using a lot of acronyms, not using a lot of medical jargon—just very straightforward.” -Participant

CONCLUDING THOUGHTS

Overall, there isn’t a cohesive sensibility as to what “patient safety” represents; how communication around medication and side effects happens within medical settings; and how reporting processes function.

Participants used terms like “symptoms” and “side effects” interchangeably and also discussed how some patient education material was difficult to understand, suggesting gaps in what information is communicated.

Patients care about how side effects may impact them whether during their routine treatment plan, adjusting medications, or enrolling in a clinical trial. They like having as much information as possible through a wide variety of different formats so that they can go back and access materials throughout their patient journey. Additionally, they crave information and turn to other sources outside of their healthcare team to find out about potential side effects.

Patient safety, then, should be a topic of priority in helping patients understand how certain information is shared and the importance of open conversations around side effects.