

BAYER WORLD PATIENT SAFETY DAY SURVEY EXECUTIVE SUMMARY

Summary: Key findings from mixed-methods survey | September 2023

Goal

In cooperation with Bayer, Savvy Cooperative co-created a short survey for 27 participants. This survey was designed to gather patient insights regarding patient safety and overall engagement.

Approach

The approximately 15-30 minute survey involved 27 participants across a range of therapeutic areas and was hosted via the survey platform SurveyMonkey. Findings are based on a mixed-method analysis of the quantitative questions and open-ended qualitative questions.

KEY FINDINGS

INTRODUCTION

The survey was centered around questions of information-finding, definitions of patient safety and what it means for patient safety to be considered across conversations with doctors, patient engagement, and clinical trials. This report will go through the key themes for each question, and will summarize overall themes and considerations at the end of the summary.

SURVEY QUESTIONS & THEMES

We would like to know what you think of when you hear “patient safety.” Out of the following options, please rank them from most fitting definition to least fitting definition.

The overall most fitting definition is considering patient safety in the context of protocols during medical procedures like surgeries, followed by overall communication with one’s healthcare team about one’s condition, side effects, and adverse events and then patient confidentiality.

If you were looking for information on patient safety, what sources would you trust the most to give you good information? Please rank the following options by most trustworthy to least trustworthy.

Participants view their primary care doctors as their most trusted source of information, followed by other specialists and then people affiliated with academic/teaching hospitals. Interestingly, pharmaceutical company websites are viewed as the least trustworthy source of information regarding patient safety out of the options presented.

If you have ever been given by your doctor patient education materials relating to patient safety, what format have these been in? Please select all that apply.

The main format for these materials have been physical pamphlets or leaflets designed by the hospital or a pharmaceutical company, followed by printed pages from websites, emails, and digital pamphlets or leaflets.

Think back to a time when you received patient education materials related to patient safety or read a package leaflet. How easy was it to understand the information?

Generally, participants found these materials easy to understand (but not very easy to understand), followed by materials that were not easy to understand but not difficult to understand.

What are your communication preferences in how you would like to receive information on Patient Safety? Please rank the options from most preferred to least preferred.

Face-to-face is overwhelmingly preferred by participants, followed next by a website/patient portal and email.

If a pharmaceutical company were interested in involving patients in creating materials around patient safety, when and how should they involve patients?

Based on the responses, participants want patients to be involved in every step of the process, beginning with the inception of the project until after release. Patients like the idea of in-person or virtual meetings, focus groups or interviews, and material review. Once the medication is released, patients want to be able to contact the manufacturer with feedback about safety, side effects, and how well the medication was explained to them via patient education materials.

“They should involve patients as soon as they begin developing a drug for the condition. For example, if I see other patients with my condition involved, it would make me more likely to want to be involved and would help me in trusting the pharmaceutical company... how they can involve [patients] is by patient testimony, by having their input on creating materials surrounding patient safety, perhaps have patients speaking out on patient safety at conferences and be in constant contact with a wide variety of patients, meaning all ages, races, genders, etc.”

If you were giving advice to healthcare professionals and/or pharmaceutical companies on how they can engage patients to improve patient safety, what would you recommend?

The two key themes within this response were trust and ease of understanding. Healthcare professionals should stay up to date on best practices and share information with patients using clear, simple language. Educating patients using social media, online trainings, and easily accessible websites can also be a way of helping patients know about what patient safety means.

“I’d recommend that they take their time going over patient safety to patients in a variety of ways such as telling a patient, then providing the patient with materials that emphasize what was discussed. I recommend they give the patient resources to contact if they have questions or concerns. We all take in info. differently therefore, the professionals need to repeat the info., making it easy to understand and leave time for questions the patient may have. I’d recommend also explaining to the patient why patient safety is important.”

When thinking about starting on a new treatment, we would like to know what considerations are most important for you. Please rank the following options by most important to least important.

The main consideration for participants is how safe the treatment is, the level of side effects/adverse events, and whether that treatment is recommended by their doctor/healthcare team. One person stated the “likelihood of treatment accomplishing its goals” as most important.

If you have ever experienced something you thought might be a side effect of a given treatment, what are your most trusted sources of information to confirm it was indeed a side effect? Please rank the following options from most trusted to least trusted.

Primary care doctors are the most trusted source of information patients will turn to if they are concerned about a side effect. From there, they trust other specialists, followed by healthcare teams affiliated with an academic/teaching hospital.

How trustworthy do you feel the following parts of the healthcare industry are in prioritizing patient safety?

Research/teaching hospitals are viewed as the area of healthcare that most prioritizes patient safety, followed by community hospitals and medical researchers.

If you were participating in a clinical trial, what would you suggest the clinical trial team do to help you feel safe and informed about patient safety-related topics during the course of the trial?

Patients want detailed information that is clear, honest, and easy to understand, as well as the opportunity to ask questions about information presented to them both verbally and in a written format they can take home. Being able to ask the trial team about safety and risks—with the understanding they will be answered honestly—will help participants feel empowered to speak up about how they are feeling throughout the trial. Regular check-ins with the trial team and participant support via hotlines, coordinators, and regular calls and emails are also ways to help participants feel both informed about the trial and comfortable with continued participation.

“I would like all safety consideration to be verbally explained & to also get a copy of the information in a handout (physical & email would be great). I would like them to confirm that I understand all info and also to provide the option to ask further questions or opt out of any part. I'd like everything to be clearly defined in an easy to understand format as well (it's hard to take in information that's dumped in a block of text.)”

If you were considering participating in a clinical trial in the past, how was information about your safety and what to expect during the trial explained to you?

Other than the three participants who have never considered trial participation, participants were given information face-to-face first and foremost, followed by email and phone calls.

Thinking back, did that information make sense and was it easy to understand? Why or why not?

Overall, the information patients received did make sense; some of the ways trial teams helped with understanding was through using pictures, graphs, and language geared toward a non-medical audience. Those who experienced challenges in understanding information mentioned medical jargon, not being able to review information later, and lack of transparency about trial details.

"It did in a medical light make sense. It didn't make sense at first take as the words and descriptions were foreign to me. Only after educating myself did the dots connect sensibly."

In your experience, if participating in a clinical trial, how would you like to receive information about how safe the trial is for participants? Please select all that apply.

Participants would like to receive information face-to-face, followed closely by information packets and brochures, websites, and emails.

OVERALL THEMES

To summarize, patients reiterated throughout their responses that primary care doctors are a trusted source of information who care about patient safety and the holistic well-being of their patients, and who are a first point of contact if a patient is concerned about safety. Specialists are a close second in both trust and credibility across the areas of patient safety discussed.

When it comes to patient safety, there seems to be a lack of clear information as to what defines patient safety as well as how to understand what safety means in the context of trying a new treatment, participating in a clinical trial, or making sense of information received at the doctor's office or hospital. Even though doctors are trusted, there may still be frustration around doctors using technical medical terminology or not providing adequate explanatory materials during conversations. Adapting language to reach a wide variety of patients and care partners will help people comprehend the different facets of patient safety in a way that will empower them.

Patients want to be involved in their care, and they want patients to participate in the creation of materials that will be used to educate people about the safety of any new medications in a way that is simple for non-medical professionals to understand. Keeping patients involved and letting them know what patient safety is, as well as why it is important and how to discuss it, are aspects of engagement that survey participants mentioned as well. Engagement depends on trust, based on responses, so working with patients on drafting materials could foster both trust and further engagement.

Throughout the survey, participants did not seem to have a positive perception of pharmaceutical companies, ranking them as untrustworthy regarding information about patient safety and treatments; and viewing these companies as places they would not seek out information from if they had questions or concerns. This is something to consider in creating public-facing materials related to patient safety and engagement: how can trust be built among patient populations so that safety efforts feel collaborative for patients?