

So how do you really engage with patients?

Patients are people and each person is unique, with different experiences of disease, different needs and different expectations. We have all been patients at one time or another, and know the frustrations that being unwell can bring to us and our daily lives. There is no shoe that fits all, which is why patient centricity and insight is so important when working in pharma.

The idea of designing a service or solution around the patient has been around for several years. It is however, only recently that the concept of patient centricity has picked up speed and gained real meaning.

Although many pharma companies now state that they put patients at the heart of their business this change in thinking has been a difficult transition for them. There may have historically been a misconception that listening to patients means ignoring the views of other stakeholders, or that the concepts of patient centricity and profitability are counterintuitive. Another perceived barrier is the fact that short-term benefits are not immediately obvious, especially financial ones. However, the good news is that pharma companies are now fighting these preconceptions and focusing on the difference they can make for both present and future patients.

In March this year the first collaborative definition of patient centricity was published in the *BMJ*.

“Putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience for that person and their family”.¹

Pharma companies are now working with patients on a much more regular basis. From holding patient advisory boards, working with patient advocacy groups, as well as having patients join internal company-wide meetings, pharma is now beginning to embrace the concept of patient centricity and understand its long-term benefits.

“Although still a buzzword, patient-centricity is gathering momentum and we see more and more pharma companies looking for ways to gain patient insights and use them to achieve better patient outcomes.”

Caroline Benson, co-founder and Director at Cuttsy+Cuttsy

But how do you actually engage with patients?

Stating that you are patient centric is all very well, but putting it into practice means looking at things from a different angle. It means taking your business head off for a short while and actually listening to and hearing what your patients are saying.

It means discussing with patients what they are going through, and what they find hardest, even if that appears to take the conversation off at a tangent. It means potentially making changes to how treatment is administered, to reflect patient needs and make their adherence to the treatment easier and more likely. It also means keeping them in the loop, and requesting and acting on their feedback.

Patient engagement wheel



Lots of people acknowledge the importance of patient centricity but not everyone knows where or how to start. Here is a list of the key things we think about when working with patients:

1) Collaborate at the very start of your project

One of the first things we have learned as a patient centric agency is the need to involve patients from the very start. Using a survey to understand more about their experiences, their needs and support mechanisms is a simple way to ensure their insights are used from the very beginning. Crafting an agenda for a patient advisory board or developing a patient diary based on their answers to the survey helps to ensure you build a meaningful and sustainable relationship with patients from the beginning of a project. This in turn means they are more likely to want to be involved and continue to be involved as much as they physically can, leading to a project driven by patients, designed by patients, for future patients.

2) Empathise and respect your audience

When working with patients it is important to realise that you may be asking them to talk about a period in their lives that may have been a source of pain, fear or disruption. Many will not be used to talking about their experiences and often their stories are very personal to them. Sometimes these experiences are difficult to speak about and they would prefer to keep it to themselves. Others are happy to discuss these things in depth and some consider themselves to be expert patients. It is also important to recognise that all patients are different and therefore a one size fits all approach will not work.

You may also find that once given the opportunity to talk about their experiences, they release a lot of built up frustration and emotion too. It is therefore sometimes a good idea to plan additional time in your agenda to allow patients to do this before the formal part of the project starts.

Listening to their stories can be very thought provoking but also quite an intense and emotional experience. Their resilience, compassion for tomorrow's patients, and braveness is both inspiring and humbling and underpins why empathy and respect are crucial traits for all involved in a patient project. You may also find that after this experience, your team may need some additional emotional support as some of the stories can be hard to hear.

3) Use safe and relaxed surroundings

If you are talking to patients face-to-face, it is important to choose an environment where they feel safe and relaxed. With some patients you may need to consider specific elements of their condition. Some conditions, for example, may affect people's speech; so they may need to be somewhere quiet or given a microphone so that they know their voice is being heard and understood. Other patients may feel self-conscious about their appearance, and appreciate greater privacy. Some patients may also have difficulty getting around and therefore it is important to ensure that the location of the meeting is on the ground floor or easily accessible via a lift and wheelchair.

4) Consider their possible limitations

The patients you work with may have had their condition for a long time and can often be seriously ill. Depending on their condition, they may need to bring a carer with them, or need extra time for bathroom breaks or just rest periods. Others may use a voice box or a wheelchair. It is therefore important to build the agenda or programme of events around their needs. For example, many cancer patients experience fatigue. Therefore, it may be helpful for them to keep the sessions short, to help avoid them becoming over-tired. Other patients may not be able to tolerate bright lights so a room with soft lighting may be more suitable. In our experience, these types of considerations are really appreciated by the patients and also highlight how much you value their involvement in your projects.

5) Do not over-promise

It is very important when working with patients that you do not over promise. Sometimes conversations can go off at a tangent, which is sometimes where difficult questions are asked and perceptions of quick fixes can occur. This is where an independent facilitator may help. By managing their expectations throughout the course of the project/meeting they can ensure that the patients do not feel let down by the process.

6) Understand the legal and regulatory environment

Different countries and markets have different rules about patient centricity and patient involvement in pharma projects. This can present a number of challenges, especially with the process of approaching patients. Make sure you understand the regulatory requirements of the markets that you're working in, and that all your staff are fully compliance trained. Remember that everyone involved in the project will also need to be fully briefed on the specific compliance demands and have undergone adverse event training.

7) Use the expertise of Patient Advisory Groups (PAGs)

Ranging from small local groups to large national and international organisations, PAGs are formed to give a voice to people living with a specific health condition. Along with providing support, information and resources for those affected by a condition, they are also involved in things like treatment access, health policies and local government initiatives. Their unique insight is incredibly useful and they may also help you find patients to work with. Pharma and PAGs can ultimately benefit from building partnerships and it's important to treat these relationships with the respect they deserve.

8) Ensure all communication is in a language that patients can understand

Whether it is a pre-event survey, an email or a post-event material, all communication with patients should be written with health literacy in mind. Using plain English, simple design and avoiding jargon are just some of the things you must consider when developing materials for patients. Many people struggle with medical information and this struggle can become more difficult when you are suffering from an illness. Reading age can drop quite considerably and it can be difficult to focus, so materials should be developed with a reading age of 10–14 years in mind, font sizes should be carefully considered and graphics used to illustrate points where possible. By doing all of this you can ensure that your patients understand the information they have been given but can also act upon it.

9) Always follow-up and say thank you

Time is precious and when patients have given their time to help you gain vital insights, you owe it to them to make sure they understand how much you value their support and involvement. They really do deserve your thanks.

If the insights gained from their involvement lead to actions, ensure they are aware of this. You may find they would like to stay involved going forward, but ensure all the correct documentation is in place before agreeing to this. Sometimes, although their insights have been invaluable, it may not be possible to turn these into actions. It is equally important to communicate this, making sure you acknowledge this with care.

The most valuable insights from patient engagement are the most unexpected ones. Simple things, which may seem unimportant to you, may be the key to making patients' lives easier and this is why the patient-centricity movement is so important. By working collaboratively with patients, we can make a real difference to not only today's patient but also tomorrow's.

If you would like to find out more email us at: letstalk@cuttsyandcuttsy.com

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1. Yeoman G, et al. Defining patient centricity with patients for patients and caregivers: a collaborative endeavour. BMJ Innov 2017;3:76-83