

PARTNERSEITZ

THE FUTURE
IS PATIENT

GOOD PATIENT ENGAGEMENT ANYONE?

**Handbook Patient Engagement
Top 10 Successful Patient Co-Creations**

TOP 10

ON COOPERATION BETWEEN PATIENTS AND THEIR RELATIVES WITH INDUSTRY

HOW TO

PATIENT CENTRICITY IS AT LAST AN INTEGRAL COMPONENT OF THE STRATEGIC AGENDA OF MANY COMPANIES IN THE PHARMACEUTICAL AND MEDICAL TECHNOLOGY INDUSTRIES. SO FAR, SO GOOD.

As patient orientation grows, so does the need for suitable formats for long-term and structured cooperation with patients and their relatives in order to understand their challenges and needs in dealing with a disease or jointly develop services that meet their needs such as brochures, websites, podcasts, videos, apps or support programmes through co-creation processes. This involves adherence to important parameters with regard to transparency, compliance, data protection or communication compliant with the Ger-

man Advertising in the Healthcare System Act (HWG). But it is also about taking into account soft factors, such as creating a climate of trust and engaging in respectful and credible dialogue with patients and their relatives. Moreover, there are still prejudices and mistrust regarding the motives of the pharmaceutical industry, which requires additional tact. Our Top 10 therefore show the key factors of collaboration between industry and patients.

01 # PICK THE RIGHT PLACE TO START

OK, we have now spoken with patients and patient organisations and identified challenges, needs and starting points for appropriate support services. But where to start? Somehow we have to decide what to do first. Obviously, the classic parameters for decision-making, such as impact and feasibility of measures, need to be considered. We recommend taking into account the patient value parameter within the decision matrix for all patient-directed activities. Ideally, you have determined in advance in advisory boards, interviews or patient-needs reports which measures have the greatest benefit from the patient's point of view. In addition, the activities must also fit in with the positioning and self-image of the

company. If your focus is on disease awareness, you can think about patient videos, providing relevant disease information in patient-friendly language, digital tools to support diagnosis, or educating physicians on specific symptom pictures. If you have a more complex treatment regimen or adherence issues, developing support programmes for disease and side effect management may make more sense. What you do then should ultimately lie in the sweet spot between patient benefit and business goals.



**DOING WHAT
PATIENTS REALLY
WANT & NEED!**



02 # DO YOUR HOMEWORK

The basis for a partner-like collaboration is that you are able to present yourselves and your intentions to patients, their relatives, and the organisations concerned respectfully and honestly. This involves questions such as: 'Who are you?', 'What is it about working with patients that makes it special for you, what not?', 'Why do you do it?', 'What do you hope to achieve with it?' This is needed to create transparency and clarity for joint projects, but also to find

the right patients to work with. Done well, this can even break down any prejudices and motivate even rather sceptical organisations to cooperate. A well-thought-out patient engagement strategy defines both the parameters for action and the rules of the game in one's own organisation. It can be developed, for example, within a mission statement process in which the above questions are answered.

03 # TOOLBOX

Professional structures are a key success factor when working with patients and their relatives. These are best in the form of a patient engagement plan as part of corporate and brand strategy. In addition to a legally audited concept and defined strategic guidelines, operational tools such as communication plans, success measurement models for the impact of patient activities, templates for patient acquisition, patient formats and patient contracts, including information on data protection, rights of use, data transfer and data stor-

age, as well as a process for the compliant remuneration of patient experts (usually around €50 per hour). A lot of companies set up special, fast payment cycles for this, because 90-day payment terms are not really patient-friendly.

We have created a toolbox with all these documents, which we use as a blueprint for new projects. It is also constantly updated and developed. You can do this too.

04 # GET IN TOUCH

How and where do we find the right patients to work with? For this purpose, we draw on patients from our pool. If we do not find any suitable profiles there, we acquire new patients via self-help groups, patient organisations, KOLs (key opinion leaders) or directly, for example via Facebook groups. Patient organisations can be approached by our client's patient advocacy department or by us directly. Contact with the KOLs is usually arranged through the medical community or via MSLs.

It is important to consider the approach, which, in addition to openness and transparency, should always include the company's motives for making contact. In the conversation, communicative aspects have to be taken into account so that contact persons firstly understand what it is all about and, secondly, are willing to participate or pass on the information to patients that are potential participants. This is done via an information flyer to be handed out to patients and their relatives, combined with their consent for us to contact them. There is then a detailed preliminary discussion with interested patients on their individual medical history, on the contract modalities, but also to check their suitability for formats as well as the different tasks.

**HELLO
PATIENT!**



05 # KEEP AN OPEN MIND

When designing workshops or adboards with patients and their relatives, it is good to ensure an open and friendly atmosphere — with an agenda that offers the freedom to also talk about topics that we were unaware of before. It is about the willingness to embrace the actual needs of patients, to listen and to understand the problems in dealing with their condition. A sophisticated high-performance workshop, running through a fixed catalogue of questions is the wrong setting here. Instead, it is important to give patients space to talk about the aspects that are relevant to them.

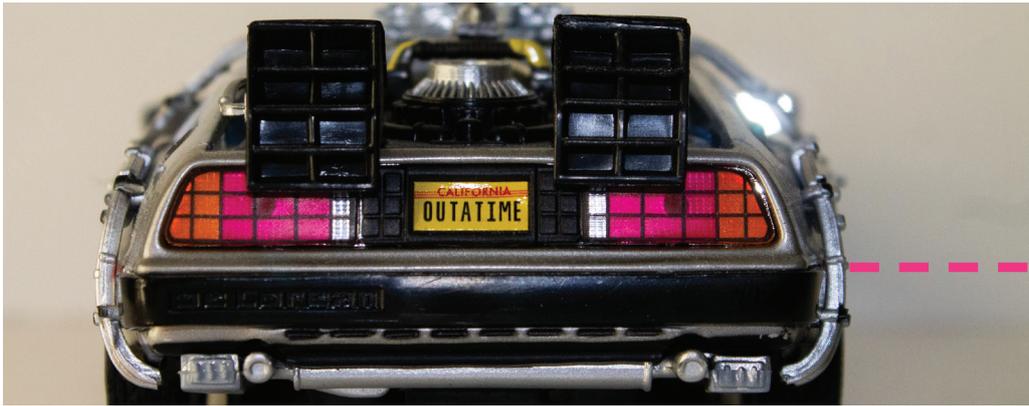
I know this is difficult for us structure-loving people, but it is the only way to find out the really important things. It also requires patient-friendly language and the right amount of empathy and compassion. It is important to remember that patients want no sympathy! Tools for a relationship of mutual trust are, for example, the general use of the first name, that all participants address each other

by their first names or getting to know each other well at the beginning of the collaboration. This is not about listing career stages, but more about private information on family, hobbies, drive and desires — what book is being read at present or what music is currently favourite. In return, patients also tell us the complete story of their disease with all the intimate details.

In general, it is advisable to work with two coordinators in a setting which ensures that all participants have an equal chance to speak, messages are sorted or processed, and all relevant information is documented in a structured manner for later use. When developing solutions in co-creation workshops, techniques from the field of design thinking can also be employed.

PATIENT ENGAGEMENT MEANS TALKING TO PATIENTS





06 # TAKE YOUR TIME

Co-creation takes a while. Co-creation with patients takes even longer. Why is that? In conversations with patients, the complete history of the disease is sometimes told, there are often questions about the contract and the process, and it also takes time to create the technical access requirements. Working with patients and their relatives always includes 'pastoral care', sometimes more, sometimes less. This is not a bad thing, but it must be factored in when planning the project and resources. In addition, patients and their relatives need a designated contact person who is also easily accessible. Call forwarding to reception or to a colleague who does not know who is on the phone or what it is about is a rather bad example. For this purpose, we have installed a patient telephone in addition to permanently assigned contact persons who also have stand-ins and can be reached outside hours. When the phone rings, it is as if mum were calling: everything is dropped.

**IT'S NOT ABOUT
DOING JUST
ANYTHING, BUT
ABOUT DOING
THE RIGHT THING.**

07 # DON'T BE SHY

Yes, yes, 'Dealing with patients is complex', 'We have an ethical responsibility towards patients, their relatives, and society', 'Communication is limited by the German Advertising in the Healthcare System Act', 'Fear of bad press etc.'. In order to be able to offer relevant support, but also to be taken seriously by patients and their relatives, it is necessary to be both open-minded and open to findings with regard to the real challenges and needs, and also not to leave out frightening topics such as handling therapy and side effects.

Patients' needs are not usually in the areas of nutrition and sport, which are often used innocuously — what interests them are roadmaps for the next steps after a diagnosis, information on disease management, lifehacks for dealing with the disease in everyday life and side-effect management. And yes, when we talk about these issues, we will also get one or two reports on side effects. Damn the adverse drug reactions (ADRs), let's deal with them professionally. When working with patients and their relatives, we should do it properly.

08 # TAKE A LOOK AROUND

At various points, it makes sense to think bigger about the co-creation approach and also involve or inform other players involved in healthcare. If medical aspects are to be mentioned in a brochure or if it is a question of producing information materials for a patient briefing, this is logically best done in cooperation with physicians. When developing patient materials, it is always advisable to consider the relatives' perspective as well because they are the first point of contact for patients and are also affected by the consequences of a diagnosis or a disease. It is important for them to know how to engage with patients and how best to help their loved ones.

Since different companies can be involved in patient activities in the same indication, it is advisable to compare them with existing support services or other similar programmes. Then it makes sense either to cooperate or concentrate on solving another problem. A typical example: patients describe pharmaceutical stands at patient days where there are fancy brochures, all in different colours

but containing the same information. In this instance, it would have been better to make arrangements in advance and offer additive services — the same applies to all other support services.

Therapy support programmes or nursing services, where several actors are often involved in patient care, are another example showing it is worthwhile to look beyond the intersectoral horizon. In addition to a joint vision, there should also be agreement on where the mission of one ends and that of the other begins. We call it the 'intersectoral roundtable'.



09 # YOU HAVE ONE JOB

Specific tasks require special experts. It's great that we are all working with patients now. But please, please do it yourself in-house or commission people who have experience in dealing with patients and their relatives and who meet the criteria or requirements mentioned here. We also work with specialists in other areas. They are very easy to find if you ask how many and which patients and organisations they have already worked with or who recommends them. Spoiler, communication agencies tend not to be among them yet. Anyway, specialisation please, after all, you want to do it right. Besides, we do not want to destroy patients' slowly growing trust in the industry.



10 # PATIENT-CENTRIC INNOVATION

It's clear that you are not going to do all this for a one-off project. In addition to time, more of all the other resources is required. So it is smart to use the established structures several times and in the long term. Advisory boards or ambassador programmes, for example, are formats for working permanently with patients

and their relatives. We speak of patient centric innovation when it is standard to continuously involve patients throughout the product life cycle.

PATIENT CENTRICITY IS NOT A SERVICE, IT'S AN ATTITUDE.

Patients are experts at dealing with their disease and no one knows more about it than the patients themselves — go ahead and talk to them. Companies can learn something and broaden their knowledge: 'What is it like to live with a rare disease?', 'How does it impact on everyday life, family, job and hobbies?', 'What are the challenges and needs of patients?', 'Where can we start to solve the problems that patients and their relatives have when dealing with a disease?'

These questions certainly cannot be answered in internal meetings and strategy workshops with agencies and consultants — but they can be answered in dialogue with patients and their relatives. Based on the findings, products and services can be developed and marketed according to needs. Furthermore, the insights offer the possibility to create detailed patient journeys and personas — as a basis for fact-based strategic decisions, effective action, or to produce content for targeted and relevant communication. This isn't any fancy pie-in-the-sky stuff and it's worthwhile for patients, their relatives, and for the company. That's how the future works.

PARTNERSEITZ

ABOUT

We are PARTNERSEITZ. We help companies to work authentically with patients — especially with people who have rare diseases. This involves us talking to those affected by a disease in adboards or interviews, developing needs-based supportive care in co-creation with patients and relatives, creating detailed patient journeys to better understand the challenges and needs in the different phases of the disease, or producing relevant patient content to increase awareness. This ensures that there will be even more good supportive care with and from the pharmaceutical industry in the future. That is what we do.

We founded PARTNERSEITZ to improve the situation of people with rare diseases. Greater awareness, early diagnosis, good counselling, access to information and therapies, no stigmatisation or discrimination. So that at some point, this will be the normal scenario. END OF STORY.



GOOD
PATIENT
ENGAGEMENT
ANYONE?

**Just get in touch
if you want to know more,
discuss ideas, or just say hi!**

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