Connecting through screens:
Navigating relationships with patients and advocacy groups in a digital world

Catherine Richards Golini

Karger Publishers, Basel, Switzerland

Correspondence to:

Catherine Richards Golini
c.richards@karger.com

Abstract

As a Healthcare Publications Editor at Karger Publishers, I write, edit, and oversee the development of patient information resources in our *Fast Facts for Patients* series. Soft skills are vital in my role at Karger, where we are committed to collaborating with patients and patient groups for each information project. The challenge in my job lies in building and maintaining these relationships entirely online, as I work remotely.

I joined Karger in the spring of 2022 as a Healthcare Publications Editor. It was the job profile that attracted me, offering a healthy mix of the hard skills necessary for the role (developing, editing, and creating medical educational resources for a broad range of target audiences) and the soft skills of building and maintaining relationships with key opinion leader authors and other contributors. With my background in tertiary education and language teaching and a PhD investigating the lexical characteristics of patient information, the job seemed ideal. Karger is a Swiss company with teams in Basel, Switzerland; Freiburg, Germany; and across the UK. I live in southern Switzerland, at the opposite end of the country from Basel, and work entirely online.

Two years on, I'm still online and the job continues to suit me well. An increase in demand from sponsors has meant that I now dedicate most of my time to patient resources, while relationship building is done principally with stakeholders who were not referred to in the original job description: patients and patient advocacy groups.

Online relationship building

Karger's *Fast Facts* series includes booklets, illustrated leaflets, and videos. Developing a booklet from start to finish takes around eight to ten months. Before writing begins, I will contact patient associations, set up meetings with them to discuss collaborating on the information project, and request their help in finding patients to take part in a focus group. The aim of the focus group is simple: to gain an insight into the experience of living with a disease and to understand what patients need from this information resource. Most patient associations have review boards, made up of people who have expressed their willingness to get involved in these kinds of projects and occasionally some patients in our focus groups know each other, having worked on similar projects previously. More often than not though, they do not know each other. If we are using a freelance medical writer for the booklet, they will also join the focus group. When patients agree to talk to us, they are also agreeing to review the booklet when it's written. Establishing this connection early on and having input into the content may well give the patients a greater sense of ownership and involvement in the booklet. I always have the impression that the patient reviews of the material are done with great care and consideration.

A new project means new relationships

Unlike most patient advocacy groups or associations, we don't focus on one medical area or condition, though a good many of our resources concern rare diseases where information can be scarce. That said, a recent project on urogenital atrophy is an example of a surprisingly common condition that most people have never heard of. And because we write about many different diseases and conditions, we don't use a permanent board of patient reviewers or clinical advisors. Each new information project requires the building of new connections with patient groups and individual patients. This would be hard enough in the non-digital world, but relationship building from scratch can be challenging when done solely via Zoom.

When things don't go smoothly

Early last year, I worked with a patient advocacy group that seemed to view our collaboration as combat and as something that needed to be won at all costs. The project funder had introduced us to the group, but it nonetheless took a good many months and numerous meetings before they were ready to sign the agreement. I joined the project at this point, anticipating smooth sailing, as is usually the case, but I was in for a shock. The first few meetings were entirely unproductive, the atmosphere tense and, at times, hostile. My attempts to present our working practices were shut down or dismissed as "not what we want". I left each meeting feeling demoralised. Two months passed, writing hadn't begun, and I was already behind schedule. What was going on?

A question of trust

For collaborations to work well, communication needs to be clear. Patient associations and patients need to understand what we are asking them to do, we need to understand the extent of their involvement, and both parties need a record of what they have agreed to do. The essentials are put in black and white in the introductory email, with the details fleshed out in subsequent meetings. We finish with the signing of a simple agreement or in the case of patients, a consent document.

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But, equally important for a successful relationship of any kind is trust. After reflecting on my meetings with the patient association described above, it became clear to me that this group didn't trust that we could deliver. Nor, as they let slip later, did they have much faith in the project sponsor. The association wanted the materials, but they had convinced themselves that what we would produce wouldn't be fit for purpose. At the next meeting, I enquired about previous experience with sponsor-funded health-care resources. Sure enough, an unsatisfactory experience in the recent past with a different funder had left them feeling disrespected and misunderstood. This negative past experience was colouring our current interactions. Understanding what lay at the root of their negative attitude was the beginning of a far healthier working relationship.

Digitalisation and interpersonal interactions

Back in the day, if a healthcare information writer consulted with a patient association (and as surprising as it sounds, a good many didn't bother), they were likely to meet face-to-face, maybe over lunch, and small talk would have oiled the social wheels. In 2024, with back-to-back online meetings filling your day and leisurely lunches a dim and distant memory, keeping to schedule is paramount, leaving little time for small talk. My untrusting patient group and I had never engaged in small talk, and while

our meetings began on time, they also began on the defensive. I didn't know where these people were based, what their roles were, or what their relationship was to the health condition (it is quite common for some staff at patient advocacy groups to be patients). And they knew absolutely nothing about me. Needless to say, I began the following meeting by finding out a little more about the people in front of me.

While it isn't appreciated or practised by everyone (cultural differences seem to play a big part here), chit-chat has a significant social function. It can break the ice, relax tension, improve emotion, and is critical in building, maintaining, and deepening relationships. How colleagues choose to work is one thing, but without small talk, I suspect my collaborations, brief and intense as they are and conducted entirely online, would be markedly less successful.

Lessons learned

I now routinely begin my scheduled calls with a patient association at least five minutes ahead of schedule. When I'm meeting patients, I'll arrive 10 minutes early. Without fail, I'll be joined by someone immediately, often a person new to online focus groups and a little anxious. In these situations, small talk is magic, and we can begin

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our meetings punctually – which in itself is another form of reassurance.

Establishing competence

Trust in the digital age is often established by reputation, online presence, and assurances in the form of reviews or accreditation. Being introduced by the sponsor of the project is also a great help as it can serve as a recommendation – though, as I had discovered, it isn't always guaranteed.

For patient healthcare resources, one form of accreditation is via the "PIF Tick" scheme. Run by the Patient Information Forum (PIF)[1] in the UK, the PIF Tick is confirmation that the recipient produces trusted healthcare information. Karger achieved accreditation for our *Fast Facts for Patients* in 2023. Fortunately, many UK-based patient associations have also been accredited by the PIF Tick, so no further explanation from me is needed. However, we often collaborate with patient associations from elsewhere in the world, in which case it falls to me to reassure them that we follow best practices in the production of healthcare resources, that our materials support health literacy, and that we know how to write patient-friendly plain language. And I am always ready to explain what this all means: surprising as it may seem, this knowledge is not universal,

even among patient resource producers and patient associations. My untrusting patient association knew they needed the materials written in patient-friendly language, but they were less confident about how to achieve this and had only a superficial understanding of readability and reading age. They were also unfamiliar with – and initially a little dismissive of – the PIF Tick, but a few links for further reading solved that problem.

Talking about what matters

While getting to know patients in our focus groups is the high point of each project for me, it is also moving and both emotionally and mentally tiring. I can only imagine how much more intense it can be for the participants.

Patient associations act as gatekeepers, and once the agreement has been signed and patients have been introduced to me, the hardest work has been done. Ahead of our focus group, patients will have signed a simple consent form, which makes clear not only what they are agreeing to do but also their rights to withdraw from the agreement ahead of publication. The patient has also indicated how they wish to receive their fee (at Karger, we compensate patients for their time) and have agreed or not for their names to be used in the booklet. I also send the

participants a list of possible questions and invite them to select a couple that they would like to speak on.

I firmly believe that people will talk about what matters to them when given the opportunity, and most meetings need no more than a couple of guiding questions before a natural conversation gets going, especially when small talk has kicked the whole thing off. Conducting focus groups as interviews seems to me to be contrary to the ethos of patient centricity.

Managing and listening

Other than showing support and asking follow-on questions, my role is to listen and manage the session. The hardest task is to make sure everyone gets a chance and that the naturally voluble don't prevent the less confident from speaking up. However, it is also the case that some people want to express themselves, and with this comes emotion. My years as a teacher help tremendously, though rarely did I witness the grief and sadness – and anger – that I sometimes do in patient focus groups. I once made the mistake of scheduling two patient focus groups in the same week – never again.

A humbling experience

It is a great privilege and very humbling to listen to people share their experiences of disease.

Some of the patients I have met have been very sick indeed, and I am in awe of the strength and the support they show each other. I am also struck by how very diverse their experiences of the same disease can be. I have no doubt that what they share with me changes the content of the resource, the way I write, and the tone I use. What motivates these patients to open up to a stranger online is the simple desire to improve the experience of sickness for other people. And as a healthcare content creator, it is my task to create a respectful, warm, and trusted environment so that these stories can be told.

Disclosures and conflicts of interest

The author is employed by Karger Publishers, which publishes the *Fast Facts for Patients* mentioned in this article.

Reference

1. Patient Information Forum. 2023 [cited 2023 Mar 21]. Available from: https://pifonline.org.uk

Author information

Catherine Richards Golini is a Healthcare Publications Editor at Karger Publishers, specialising in writing and editing resources for patients and healthcare professionals. Holding a PhD in Applied Linguistics from Swansea University and having published research on patient communication, she is also a skilled plain language writer and reviewer of plain language summaries. Connect with her at https://www.linkedin.com/in/catherinerichards/