

## Including Patient Voices in Continuing Medical Education: One Provider's Experience

Jennifer McKay<sup>a</sup>, Emma Needham<sup>b</sup> and Wendy Walsh<sup>c</sup>

<sup>a</sup>Editorial Operations, Content Management Analyst – CME/CPD, Wolters Kluwer, Waltham, MA, USA; <sup>b</sup>Editorial Operations, Content Editing Coordinator – Pediatrics, CME, Wolters Kluwer, Waltham, MA, USA; <sup>c</sup>Editorial Operations, Editorial Consultant, Wolters Kluwer, Waltham, MA, USA

### ABSTRACT

In 2021, UpToDate began offering continuing medical education (CME) planned and delivered by patients. The patient-authored medical topic reviews focus on lessons learned from interactions with the healthcare system and emphasise quality of life for those living with specific conditions. Having access to the patient voice at the point of care provides clinicians with a perspective that can improve patient-provider communication and promote shared decision-making. Participants who viewed the patient-authored topics were emailed a survey about the content; several responses indicated that the new topics were useful in clinical practice. While positive responses demonstrate that clinicians value the patient perspective, we also received replies from participants and from the patient authors themselves indicating there is more work to be done in developing patient-led CME. As more patients are invited to join the conversation, their expertise will be increasingly recognised as integral to CME.

### ARTICLE HISTORY

Received 21 August 2023  
Revised 20 October 2023  
Accepted 20 October 2023

### KEYWORDS

Continuing medical education; continuing education; patient voice; patient engagement; patient perspective; patient involvement; point-of-care education

### Introduction

Patients have been involved in clinician education since the 1960s, participating in physical examinations and leading to improvements in mechanical skills. Their involvement in teaching skills unrelated to the physical examination started in the 1990s [1]. Including patients in conferences has resulted in positive changes to research and clinician attitudes [2]. Dr. Graham McMahon, Accreditation Council for Continuing Medical Education (ACCME) president and CEO, states that effective and respectful collaboration between continuing medical education (CME) providers and patients can improve clinician competence and, in turn, patient care [3].

### Accrediting Bodies Support Patient Engagement

Accrediting organisations, such as the ACCME, are encouraging providers to include patients in CME planning and delivery. Patient involvement will lead to CME activities that meet a broader array of physician competencies, including patient care and interpersonal and communication skills.

### Need for Patient Engagement

Partnering patients with medical education teams encourages clinicians to prioritise patient engagement and provides patients an opportunity to highlight care strategies and communication styles that have and have not worked for them. Clinicians are challenged to consider the whole person, humanising care and allowing for more compassionate approaches [4]. A patient-partner education model prompts clinicians to recognise the value of shared decision-making and to consistently integrate patient-centred strategies into their practice.

### Overcoming Clinician Resistance

Clinicians reported hesitance to involve patients in education and research for various reasons, including experiences involving patients with different views than the providers' [1] and perceptions that patients lack scientific knowledge, are unable to look beyond their personal situation, and are not adequately informed to make contributions [2,5]. These concerns demonstrate a lack of recognition of the unique knowledge that only comes from living with a condition, enduring trial and

**CONTACT** Jennifer McKay  [jenny.mckay@wolterskluwer.com](mailto:jenny.mckay@wolterskluwer.com)  Editorial Operations, Content Management Analyst – CME/CPD, Wolters Kluwer, Waltham, MA, USA

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

error related to the disease, and actively observing what works and what does not. If clinicians can reframe patient interactions as opportunities to work with experts who have high personal stakes, then the foundation of a collaborative, productive care team can be more readily established.

## **UpToDate's Answer**

In response to the ACCME's encouragement to offer CME in partnership with patients, UpToDate used its position as a point-of-care resource to connect clinician participants with peer-reviewed patient perspectives on their care experiences. In 2021, after nearly 30 years of offering UpToDate participants only clinician-authored topics focused on answering specific clinical questions, UpToDate began publishing topics written by patients for clinicians.

## **Patients Teaching UpToDate Readers**

UpToDate's "patient perspective" topics are intended to teach UpToDate participants aspects of care that emphasise the healthcare journey and quality of life for those living with specific conditions. These topics, planned and delivered by patients, serve as a helpful starting point for clinicians who want to consider the whole picture when assessing care strategies for their patients. These personal patient experiences may resonate with clinicians and encourage them to participate in open discussions with their patients, prompting patient-clinician collaboration.

## **Patient Perspective Topic Development**

The editorial process for patient perspective topics mirrors that of UpToDate's clinical topics. In-house Deputy Editors were asked to identify diseases/conditions from which a patient voice would be highly beneficial, such as conditions with a history of misconceptions or patients who have felt misunderstood or unheard. Members of the CME team then worked with external editors and patient advocacy groups to identify potential patient authors. When recruiting prospective authors, we encouraged them to be honest about their experiences and to describe both positive and negative aspects of their healthcare journey.

## **Planning and Delivery**

### **Topic Planning**

We collaborated with members of our editorial team to provide a basic scaffolding as a topic outline. While we included questions for the authors (such as

a background of their diagnosis, testing they had undergone, resources they had found useful, and impacts the medical condition/treatment had on their life), we were clear that it was only a jumping-off point and the decisions regarding what to include were entirely theirs. Patient authors responded with topic drafts that covered their specific experiences; no two topics have the same structure.

### **Editing Drafts**

Once submitted, each draft followed UpToDate's editorial process. The in-house physician Deputy Editor reviewed and edited the content, and the revised draft was then sent to an external Section Editor to evaluate whether major clinical points were addressed appropriately or identify areas that may benefit from further explanation. The author then made further edits to the topic to ensure that it remained in their voice and answered the highest-priority questions for clinicians. When each topic was published, relevant physician-authored topics were updated to include links to the new patient perspective content.

### **Launch**

The first topics, published in 2021, included Parkinson disease, iron deficiency anaemia, lymphangiomyomatosis (LAM), and chronic urticaria. As of October 2023, there are 18 topics in the patient perspective table of contents [6], and additional topics are in various stages of development. Since the first topic was published, the patient perspective topics have been viewed more than 54,000 times in total.

### **Living Documents**

Each author is asked to review their topic once every year. The author updates any outdated content, adds new information, and makes any other revisions as they see fit. Once the authors and UpToDate editors have reviewed the topic, the date on each topic is updated so participants know the material reflects current thinking.

## **Results**

To determine the impact of patient perspective topics, patient authors and participants who viewed the topics were asked to comment on the content. Both groups provided qualitative feedback (described below) that supports UpToDate's goals of expanding the number of topics offered and broadening the experiences represented.

### **Patient Author Feedback**

Patient authors have expressed that they are grateful to have this platform – and they have a lot they want to share with clinicians:

- They wish their doctors had listened more when they reported symptoms prediagnosis.
- They wish they were given crucial information and time to process and ask questions at the time of diagnosis.
- When patients are invited to collaborate with their medical team, everyone benefits.
- Ongoing clinician advocacy and peer support are major parts of dealing with their conditions.

### **Survey Developed for UpToDate Users**

As the patient perspective topics were created for clinician users, we followed up with subscribers who viewed the material to assess their impact. We emailed a short questionnaire to all users who accessed at least one patient perspective topic.

The survey asked the following:

- (1) Did you have a specific question when you clicked on this patient perspective topic, and if so, what was it?
- (2) Please describe insights gained from reading this topic and how these change your practice and impact your care of patients (please be as specific as possible).
- (3) We plan to continue adding patient perspective topics to UpToDate and would like to hear how we can make these topics more useful for our clinician readers. Please let us know how we can improve these topics.

### **Survey Responses**

This survey was sent to 2,081 participants, with responses from physicians, medical students, nurse practitioners, pharmacists, and physician associates. Seventy-nine percent of the responses were positive, including comments such as:

- Respondent 1: My specific question was if I could use the story to communicate and guide towards wellness. My strategy is not changed but encouraged for the patient to be more active and advocate for their health – don't give up. The personal

story is powerful. It moves beyond information and shares the challenge and yet hope of healing. UpToDate can have many different stories for each disease. Consider story choices for different age groups or genders.

- Respondent 2: I'm a medical student and was researching Parkinson's for a practice case. The patient perspective revealed symptoms like loss of smell and loss of arm swing that had not been obvious in the overview information on UpToDate or other sources. The patient perspective also offered clarity on the progress of early symptoms and where the patient might be in the disease process at the time of presentation. I found it very helpful.

I appreciate this resource and hope to see more of them in the future.

- Respondent 3: I'm familiar with UpToDate for more than 12 yrs, just saw the topic, I read it directly. I liked its content and the dilemma we faced as primary care physician to arrange the care among different specialities for the patient.

The remaining 21% of responses were from learners who did not find value in the content or did not appear to understand the intended purpose of the patient perspective topics. Fifteen percent of all respondents commented that they saw the patient perspective topics as helpful for patients but did not mention applying the topics to their practice, including:

- Respondent 1: They can be very helpful to PATIENTS. That's my need. They are generally well written, understandable and serve to answer many questions they may have.
- Respondent 2: I found the initiative of patient information with the patient's view very interesting. It will certainly be very useful for the patients.

### **Follow-Up**

One month after respondents replied, we emailed those who reported they used the topics in patient care to ask if they had changed their strategy based on insights they gained. Responses indicated that the topics

impacted patient care, and this supports our efforts to expand our patient perspective table of contents.

- After reading the knee osteoarthritis topic, a respondent recounted a patient who wanted only oral therapy. The clinician explained the need for physical therapy. They worked together and decided that topical treatment, physical therapy, and the option to request oral medication at the next appointment met the patient's current needs.
- Another physician wrote of the Parkinson disease topic: "I found his notes about the trouble getting a diagnosis important (and disturbing). I really appreciated what he said about the date of diagnosis not being reflective of the date the condition began. I will definitely be more aware of this in future patient encounters".

## Discussion

This was UpToDate's first experience working with patients as contributors. We were aware of clinician training [4] and medical conferences [2,7] that involved patients, but we had not seen widespread adoption of patients as authors of CME materials. In introducing this new style of CME activity, the most notable challenge was the question of target audience raised by both participants and authors.

### Clinicians

Survey responses suggest that UpToDate participants are finding value in the patient perspective content. Several respondents recommended we add more topics, which we plan to do. In addition to covering more diseases, we have begun to increase the number of topics available for each condition so clinicians can refer to a variety of patient experiences. With the additional material, we hope to reflect a larger breadth of patient concerns.

We believe incorporating the patient voice into a program widely used by clinicians will help participants make strides towards proactively engaging patients and considering the patient perspective in the care planning process. Live meetings that have involved patients, such as Outcome Measures in Rheumatology (OMERACT) conferences, reported that over time, patient involvement led to changes in how clinicians in the group consider patients and their recommendations [2]; we believe incorporating patient perspectives

into a point-of-care resource will lead to similar improvements.

It will take time for some participants to recognise the value of patient perspectives. In survey responses and other comments, clinicians shared that these topics would help patients better understand their illnesses. While we understand that patients benefit from reading about other patients' experiences, that is not the primary purpose of this content.

Some of the confusion about intended audience is likely due to the format of UpToDate. In a live discussion, when patients are speaking to clinicians, the target audience is clearer. As UpToDate also offers patient education materials, it is understandable that a clinician may see a patient perspective topic and assume it is another variety of patient education content. To combat this misinterpretation, each patient perspective topic starts with an introduction that explains the intent of the material. These topics are also linked from related physician-authored content alongside a description that their purpose is to help clinicians better understand the patient experience and patient concerns.

We will continue to advertise patient perspectives as written for clinician education. Those clinicians who read the topics as they are intended provided positive feedback and embraced the patient voice as a valuable factor in care.

### Patient Authors

Similar to some UpToDate participants, many patient authors faced the barrier of recognising that their target audience was healthcare providers. Despite telling the patient authors that the intended audience was clinicians, providing a list of goals of the topic, and describing that the topic would serve as CME for clinicians, a few authors wrote first drafts directed at fellow patients. Our editorial staff worked with those who wrote for patient audiences to revise their topics with a clinician audience in mind.

The patient authors shared that writing the topics was a cathartic experience. Writing allowed them to continually reflect on their experiences as a participant in their own care. As a patient's topic can be changed at any time, it will evolve alongside the patient's healthcare journey. Many of the patient authors were not familiar with UpToDate and its sizeable international readership. The written content not only appealed to patient authors as a means to share their expertise, but also as a way to impact the practice of a large, global audience of clinicians.

## Conclusion

While we understand it will take time for readers to discover UpToDate's patient perspective topics and embrace what they offer, we believe that by translating patient insights into changes in practice, participants will be reminded of the human behind the medical condition.

Although we do not know the reasons for participants' and patient authors' confusion about the intended audience of these topics, the fact that members of both groups have mistaken them as patient education materials demonstrates a lack of recognition of the value of the patient voice for the clinical community. Making more space for patients as educators can lead to improved patient care and present both clinicians and patients with evidence that there is a need for patient expertise in patient care.

Working with patient authors has been a positive experience for UpToDate's editorial team. The patients we partnered with were ready to engage with our physician editors, and the collaboration between authors and physician editors led to topics that offer widely applicable insights into patients' experiences of the medical system. When edits were necessary, the authors welcomed suggestions.

The firsthand accounts of these authors, who are willing to offer both positive and constructive feedback regarding their care experiences, will help direct clinicians to adjust their habits and consider the perspective that matters most when delivering effective care. Our experience of leveraging our existing editorial and publishing platform to share the patient voice demonstrates that it is not necessary to introduce a new CME activity type to bring patients on as faculty and planners in CME. We are hopeful other CME providers will challenge themselves to take such steps using their own methods. Our organisation and physician contributors, along with our readers, have been supportive, and we continue to expand this collection of topics, with

the intention of positively impacting patient care and expanding the role of patients as educators in healthcare.

## Acknowledgments

We wish to thank the patient authors who have written about their healthcare experiences in UpToDate, including Bruce D Rosenblum, who provided valuable feedback on this article; Janet Damaske, who worked on an earlier version of this article; and Denise Gilpin, Vice President of Content Editing, for her contributions and support of this work.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## References

- [1] Towle A, Bainbridge L, Godolphin W, et al. Active patient involvement in the education of health professionals. *Med Educ*. 2010;44(1):64. doi: [10.1111/j.1365-2923.2009.03530.x](https://doi.org/10.1111/j.1365-2923.2009.03530.x)
- [2] de Wit MP, Abma TA, Koelewijn-van Loon MS, et al. What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT? *J Rheumatol*. 2014;41(1):177. doi: [10.3899/jrheum.130816](https://doi.org/10.3899/jrheum.130816)
- [3] McMahan GT. Learning together: engaging patients as partners in CPD. *J Contin Educ Health Prof*. 2021;41(4):268. doi: [10.1097/CEH.0000000000000388](https://doi.org/10.1097/CEH.0000000000000388)
- [4] Wykurz G, Kelly D. Developing the role of patients as teachers: literature review. *BMJ*. 2002;325(7368):818. doi: [10.1136/bmj.325.7368.818](https://doi.org/10.1136/bmj.325.7368.818)
- [5] Caron-Flinterman JF, Broerse JE, Teerling J, et al. Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. *Health Expect*. 2005;8(3):253. doi: [10.1111/j.1369-7625.2005.00337.x](https://doi.org/10.1111/j.1369-7625.2005.00337.x)
- [6] Patient perspective. Post TW, ed. UpToDate. Waltham, MA: UpToDate Inc. [cited 2023 August 18]. Available from: <https://www.uptodate.com/contents/table-of-contents/primary-care-adult/patient-perspective>
- [7] Chu LF, Utengen A, Kadry B, et al. "Nothing about us without us"-patient partnership in medical conferences. *BMJ*. 2016;354:i3883. doi: [10.1136/bmj.i3883](https://doi.org/10.1136/bmj.i3883)