

Twelve tips for patient involvement in health professions education

Citation for published version (APA):

Eijkelboom, C., Brouwers, M., Frenkel, J., van Gorp, P., Jaarsma, D., de Jonge, R., Koksma, J., Mulder, D., Schaafsma, E., Sehlbach, C., Warmenhoven, F., Willemen, A., & de la Croix, A. (2023). Twelve tips for patient involvement in health professions education. *Patient Education and Counseling*, 106(1), 92-97. <https://doi.org/10.1016/j.pec.2022.09.016>

Document status and date:

Published: 01/01/2023

DOI:

[10.1016/j.pec.2022.09.016](https://doi.org/10.1016/j.pec.2022.09.016)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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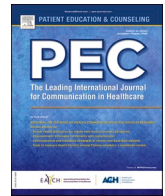
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Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

Discussion

Twelve tips for patient involvement in health professions education

Charlotte Eijkelboom^{a,*}, Marianne Brouwers^b, Joost Frenkel^a, Petra van Gurp^c,
Debbie Jaarsma^d, Roos de Jonge^e, Jur Koksma^f, Dante Mulder^g, Evelyn Schaafsma^h,
Carolyn Sehlbachⁱ, Franca Warmenhoven^j, Agnes Willemen^k, Anne de la Croix^l

^a Department of Pediatrics, University Medical Center Utrecht, Utrecht, the Netherlands^b Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands^c Department of General Internal Medicine, Radboud University Medical Center, Nijmegen, the Netherlands^d Faculty of Veterinary Medicine, Utrecht University, Utrecht, the Netherlands^e Utrecht Center for Research and Development of Health Professions Education, University Medical Center Utrecht, Utrecht, the Netherlands^f Radboudumc Health Academy, Radboud University Medical Center, Nijmegen, the Netherlands^g Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands^h Wenckebach Institute for Education, University Medical Center Groningen, Groningen, the Netherlandsⁱ School of Health Professions Education, Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands^j Skillslab, Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands^k Department of Clinical Child and Family Studies, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands^l Research in Education, Faculty of Medicine, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

ARTICLE INFO

Keywords

Patient involvement
Health professions education
Person-centeredness
Professionalism
Communication

ABSTRACT

Moving towards person-centered care, with equal partnership between healthcare professionals and patients, requires a solid role for the patient in the education of students and professionals. Patients can be involved as teachers, assessors, curriculum developers, and policy-makers. Yet, many of the initiatives with patients are isolated, small events for targeted groups and there is a lack of patient involvement at the institutional level. To support educators in involving patients, both at the institutional level and at single educational encounters, we offer twelve practical tips. This paper came about through an innovative collaboration between healthcare professionals, educators, teachers, and patients. These tips can be used as a tool to start or reinforce patient involvement in health professions education and provide guidance on how to make it a sustainable part of the curriculum. The article involves organizational conditions for success, tips for sustainable partnerships, ideas for curriculum design and proposes concrete teaching strategies. Finally, besides practical tips, we stress that involving patients in education is not business as usual, and paradoxically this needs to be acknowledged before it can become business as usual.

1. Introduction

Patients are increasingly being involved in the education of healthcare professionals (HCPs) and students.[1,2] We encourage this movement as it has clear benefits: it helps learners develop new knowledge, skills and attitudes contributing to person-centeredness, and it makes education more engaging, significant, and transformative.[3–6] Patients in turn gain understanding of their own condition, develop improved relationships with HCPs, meet peers, and feel valued and empowered.[3, 7–9] Moreover, active involvement of patients can make education more responsive to patients' needs. This aligns with the call for social

accountability, meaning education should be directed towards addressing the needs and health concerns of society.[10,11] Finally, the movement towards equal partnership in healthcare, through shared-decision making and person-centered care, should also be reflected in education. Therefore, partnerships with patients should form the basis of health professions education.[3].

Although the importance of patient involvement in education is widely acknowledged, it still seems difficult to accomplish sustainably in health professions' curricula.[12,13] Many of the initiatives with patients reported in literature are isolated, small events for targeted groups.[3] There is a lack of coordinated longitudinal programmes, and

* Corresponding author.

E-mail address: m.c.l.eijkelboom@umcutrecht.nl (C. Eijkelboom).<https://doi.org/10.1016/j.pec.2022.09.016>

Received 16 May 2022; Received in revised form 26 September 2022; Accepted 29 September 2022

Available online 1 October 2022

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participation at the institutional level or curricular development remains rare.[3,4,7,11] Moreover, potential harms of patient involvement should be taken into account, in order to prevent negative experiences for patient or students. Such risks can arise from stigmatisation, tokenism or from a lack of structure or confidentiality in teaching sessions.[3,4] Therefore, guidance for educators on how to involve patients is necessary.

We employ a broad definition of patient involvement in education: the active involvement and engagement of patients in the education of (future) HCPs, both formally and informally, in all sorts of roles, using their unique experiential knowledge of living with disease, illness or disability and receiving healthcare.[3,14,15] Patients can fulfil various roles in different levels of involvement, as described by Towle et al., Table 1.[3,16] Level 2–6 are taken into account in these twelve tips for education.

For the sake of clarity and in lack of a better alternative, we use the term patient, despite its controversial nature.[3] With the term patient we mean all people who suffer from health issues, use or are in need of healthcare services, as well as their caretakers and family members.

The purpose of these twelve tips is to offer practical guidance for educators on how to involve patients in their education. Tips 1 and 2 regard conditions for success: which organisational conditions are needed for patient involvement to succeed? Tips 3–6 are about sustainable partnership: with whom and how do you collaborate? Tips 7–8 concern curriculum design, and tips 9–11 are practical tips for teachers in the workplace. We encourage you, after reading this article, to start with tip 12.

2. Methods

2.1. Development of tips

The development of these 12 tips was an iterative and collaborative process. First, we held a round table session at the 2020 online Netherlands Association of Medical Education conference. Twenty-two participants (students, patients, educators, and HCPs) were present and constructed tips through a brainstorm exercise. Second, we clustered these tips and presented them in an online shared document to participants of the conference session who wanted to join this collaborative project. Thirteen participants provided feedback and comments on the first draft and shared relevant literature, after which the tips were revised. Third, we divided the tips among 9 authors (CE, MB, JF, RJ, ES, CS, FW, AW and AC) who wrote the first draft of each tip in pairs, using literature and their own experiences with patient involvement. Drafts were saved in a shared online document, which enabled authors to continuously share literature and feedback. Finally, tips were combined and feedback on the whole set of tips was provided by senior authors who were not allocated a specific tip and an independent patient panel (6 patients). Feedback on the final version was provided by the whole

author team and consensus was reached.

2.2. Collaboration

The team of authors came from 6 different institutions in the Netherlands and are involved in healthcare professions education as patient, educator, researcher, student, and/or healthcare professional. To integrate these various perspectives and enable collaborative knowledge production, we deliberately wrote the tips in pairs of various author combinations. This approach resulted in 12 thoughtfully constructed tips (Table 2), which are built from multiple perspectives and reflect the extensive teaching and research experience at multiple universities. Each participant added literature to the manuscript that they thought to be essential to their view on patient participation. Moreover, it resulted in new valuable connections and collaborations between stakeholders who strive to enhance patient involvement in health professions education in the Netherlands.

3. Twelve tips for patient involvement in education

Tip 1: foster a culture of openness

Educational improvement and the elimination of current blind spots thrive on inviting fresh perspectives: that of patients. This requires an open culture with room for multiple perspectives and with respect for each other's interpretations and experiences. Patients have unique experiential knowledge through lived experience, which can complement the professional knowledge of educators. Yet, patients' perspectives may also challenge academic assumptions of quality healthcare.

Table 2

Twelve tips for patient involvement in health professions education.

Tip 1	Foster a culture of openness
Tip 2	Set up institutional support
Tip 3	Include patients in all educational roles
Tip 4	Aim for diversity
Tip 5	Forge bonds with patients and patient organizations
Tip 6	Appreciate patients for their educational efforts
Tip 7	Think beyond the traditional patient lecture
Tip 8	Start from day 1 and never stop
Tip 9	Teach teachers how to involve patients
Tip 10	Support patients and students in their role
Tip 11	Broaden your perspective (to complete the patient journey)
Tip 12	Just do it!

Table 1

Level of patient involvement as defined by Towle et al.[3].

Degree to which the patient is actively involved in the learning encounter
1. Paper-based or electronic case or scenario
2. Standardised or volunteer patient in a clinical setting
3. Patient shares his or her experience with students within a faculty-directed curriculum
4. Patient-teacher(s) are involved in teaching or evaluating students
5. Patient-teacher(s) as equal partners in student education, evaluation and curriculum development
6. Patient(s) involved at the institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development for students

Patients need to be acknowledged as legitimate partners in medical curricula and feel safe, welcomed and supported to actively participate at all levels.

Faculty can foster a culture of openness by incorporating patient involvement in the central mission and vision of the educational institution. They should set the example by including patients as stakeholders in moments of decision-making, reflecting level 5 and 6 of involvement.[3,4,17,18] In addition, teachers need to be willing and able to share control of learning encounters with patients. This might mean letting go of traditional, familiar ways of teaching and supporting collaborative knowledge production through student and patient interaction (tip 9).[19] An example is the Council of Elders, in which residents present their dilemmas in caring for elder people to a group of elders. Through open dialogue between doctors, researchers and elders, novel ways of overcoming health-related difficulties are identified.[20].

Tip 2: set up institutional support

Institutional support is vital for any initiative to take hold and persist. To move from isolated initiatives towards sustained and well-coordinated programmes patient involvement should be embedded in, and supported at, the strategic, tactical and operational level of the organisation. [3] This includes support for patients, students and educators (tip 9, 10). A patient committee or advisory group within an educational institution, reflecting level 6 of involvement, can enable and safeguard institutional support and structural patient input into the educational process.[4] Additionally, to enhance effective collaboration, the dialogue about power dynamics should be addressed early, for example by beginning an open discussion about the goals and needs of both patients and students/educators. This type of discussion should take place before any decisions are made, instead of being addressed when a project has already started.[21].

For example, at Radboud University Nijmegen in the Netherlands institutional support is established on multiple levels. At the strategic level, patient involvement is part of the central mission and strategy *Person-centered Health Care* as defined by the executive board.[17] At a tactical level, a Patient Advisory Board has been instituted. They provide both invited and uninvited advice to educational directors and coordinators, on both the design and evaluation stage, to promote and embed patient involvement and person-centered education.[22] Furthermore, The Radboudumc volunteer center provides administrative and practical support to ensure patients are rewarded for their educational efforts and to facilitate their participation. These parties support both educators and patients to co-create successful and sustainable patient involvement.

Tip 3: include patients in all educational roles

Include patients in different roles in your curriculum. The majority of papers report on patients as teachers delivering education to students. However, patients can also be assessors, curriculum developers, and student selectors.[4] Patients' experiential knowledge can provide unique perspectives on students' performances, which could enrich formative and summative assessments.[23] Moreover, to make education more responsive to the needs and health concerns of society, patients should participate in curriculum design and development.[24].

Boundaries between roles can be blurred. People can have multiple identities, and multiple perspectives. After all, an educational director who has battled cancer may integrate her patient perspective when designing the curriculum. We recommend using this multiplicity of identities. At Pedagogical Sciences at Vrije Universiteit Amsterdam in the Netherlands, a lecture about building professional relationships with parents was co-taught by two child care professionals who were also mothers to children with multiple disabilities. A potential challenge of multiple identities might be to balance educational needs with authentically telling a personal story, and switching between roles of educator and patient.

Tip 4: aim for diversity

There is not one single patient perspective.[25,26] Hence, patients cannot be considered a collective group. They are individuals with unique preferences and perspectives, diverse in their health and disease status. Some might fit the 'acute patient' label for a specific time and context, whereas others might be chronically ill. Patients might differ in nationality, language, culture, affirmed gender, social-economic status, health literacy, et cetera. We should strive for diverse patient-teachers who are a reflection of society, to enable (future) HCPs in providing care that addresses the needs of all. Moreover, a variety of patients can serve a variety of educational goals and take up a variety of educational roles that suit their individual qualities and preferences.[27,28].

Some patients are underrepresented in education because they are hard to reach or identify, for example patients who are ashamed about their literacy skills or who face poverty. Programs that represent only a select demographic group, risk the unintended message that the needs of only a privileged few reflect the needs of all.[25] On the other side, interactions with people from marginalised populations can encourage more positive attitudes towards these people and overcome stigma and stereotyping.[1] If a target group is under-represented throughout your curriculum, seek collaboration with patient-organizations or community-based groups to connect to those patients, and explore what is necessary to engage them. Practical tips on how to engage community partners in a medical school are described by Marjadi et al..[18] If there are practical barriers in reaching patients, think of creative options like video-conversations or visiting these patients outside of the educational institution in a place where they feel comfortable. An example is the community clerkship at the Utrecht University Medical School in the Netherlands, where medical students participate at, for instance, social community teams or organizations that support migrants.[29].

Tip 5: forge bonds with patients and patient organizations

To achieve sustainable patient involvement, it is important to forge bonds and stay connected with patients and patient organizations. Patient organizations can help recruit patients, as many have quick access to their members through online forums or newsletters. Next, make patients feel part of a community, whether they are involved at the institutional level or share their experience in the classroom. For instance, by sending an official welcome letter and inviting them to teacher meetings. Formally establishing peer support groups for patients can make them feel part of a community of patient-teachers.[30] The University of Leeds in the United Kingdom has a large patient community, which offers advice, peer-support and informal social gatherings to enhance a sense of belonging and ownership.[31].

When building relationships with individual patients, consider their educational role. Longitudinal and continuous bonds are needed with patients who are involved in curriculum development or at institutional level (level 5 or 6). Whereas this continuity might be less important with patients who share their experience in the classroom (level 3), where the focus might be on presenting diverse patients and perspectives.

Lastly, bonds are being forged when a relationship is reciprocal. Discuss with patients or patient-organizations what their goals for participating are and make sure the needs of both learners and patients are met.[18] Moreover, appreciate patients for their educational efforts (tip 6). At Maastricht University, a student- and patient-led organisation is dedicated to recruitment of patients and keeping close contact with patient organisations, as well as organising workshops and informal annual get-togethers for the participating patients as a form of forging reciprocal relationships.[32].

Tip 6: appreciate patients for their educational efforts

Show gratitude and appreciation to patients for their educational efforts. Reward patients for their efforts and communicate back what their input yielded. A fair rewarding system contributes to equal partnerships. Rewards can come in all sorts of forms: tangible like money and gifts, or intangible like symposia, trips to the museum or thank-you letters.

Rewards should be customized. They should be in line with a patient's educational role and the amount of effort a patient puts in. For a patient providing feedback to an intern at the hospital, a simple 'thank-you for the feedback' might be fair. For a patient who developed a whole course, the appropriate reward may equal market rates. Rewards can have drawbacks, for example financial rewards could cause problems for patients who receive state benefits.[11] Therefore, rewards should also be customized to a patient's individual circumstance. Moreover, receiving a salary and thereby becoming part of the institution could make patients feel restrained in their authentic voice. That being said, rewards are meant for the time and effort a patient puts in. The expenses a patient makes, for instance travel and parking costs, should be covered at all times.

A nice way of combining both tangible and intangible approaches of rewards might work best. For example, at the University of Groningen: instead of facilitating staff, students take the responsibility of thanking the patients after an educational encounter where they interviewed patients. They report their learning benefits from the patient's input and hand over a gift voucher.

Tip 7: think beyond the traditional 'patient lecture'

Traditional learning encounters with patients involved focus on patient lectures or bedside teaching, where patients function as passive objects through which teachers can illustrate aspects of diseases.[15] However, patients can support a wide range of educational objectives. These could address communication, physical examination, technical, organizational and interprofessional skills, or knowledge about (living with) a disease and quality of care.[7] As there are various aspects that learners can learn from and with patients, there are various ways and environments to learn with patients.[33].

Four questions from the Cambridge Framework can serve as a tool to develop educational settings with patients involved: *Who? How? What? and Where?*[34] Consider *who* should be involved to achieve the educational objectives (tip 4). Next, consider *how* patients and students interact and collaborate. This could be a one-way information transfer from the patient to the student, or a reciprocal interaction where both patients and students learn. Also consider the duration of student-patient contact. Longitudinal contact can support the development of meaningful relationships, which in turn can contribute to the development of aspects of person-centeredness like empathy.[35,36] An example is the Health Mentors Programme, where four students from different disciplines learn together with and from a patient with a chronic condition in self-directed groups over a prolonged period.[36] Next to *who* and *how*, consider *what* content is offered and *what* activities could be performed to achieve the educational objectives. Examples are students interviewing patients about their illness experience, or patients and students working together on authentic learning tasks like creating patient information.[37,38] Lastly, consider *where* the education takes place. This could be the classroom, the hospital, the patient's home or the community. By changing the context, roles change and different learning opportunities arise. In 'Operation Homefront', third-year medical students visit families of children with special needs at home. Their written reflections demonstrate that these home visits relate to relevant competencies like respect, intrinsic motivation for learning, and communication skills.[39].

Tip 8: start from day 1 and never stop

Stimulate early and recurrent patient contact in education, so that learning with patients becomes normal, and patients are recognized as equal and indispensable partners in the learning process. In order to make patient encounters more than just fun or memorable, we recommend to concurrently offer sessions where learners are guided in reflecting on their encounters with patients, seeing the value of patients' perspectives, and integrating these with their current knowledge and perceptions.[40] By providing and raising awareness of various learning opportunities with patients, students might not only learn and develop

at that point in time, they might also learn *how* to learn with and from patients in future interactions. This could provide them with tools to become self-directed life-long learners.

One way to learn from patients is by means of feedback. Teaching students how to ask, receive and use patient feedback, can facilitate learning throughout their career. Inviting feedback from patients becomes particularly important in future practice, considering HCPs receive less and less formal feedback over time. Since patients actually observe HCPs behaviour, interacting with patients can present rich learning opportunities in daily practice.[41,42] Facilitated reflection on the received feedback can aid in making sense of feedback and transforming it into specific learning goals.[43,44].

Tip 9: teach teachers how to involve patients

Since involving patients into education might conflict with traditional ways of teaching (tip 1) and the traditional hierarchy of the doctor-patient relationship, faculty development is needed.[21] Teachers need to learn how to involve patients in a meaningful way and to accept leadership of patients in collaborative teaching.[4,21] This requires guidance in how to work with patients in partnership, and how to support patients and students in their role (tip 10). Moreover, teachers need knowledge of new ways of educating (tip 7), and skills in how to create optimal, safe learning settings where both patients and students can share their perspectives. Besides, they have to be capable of guiding emotionally charged conversations when applicable. Faculty should support teachers in their new role by investing in teacher training regarding patient involvement and providing guidelines for meaningful patient involvement from the design stage onwards.

Moreover, faculty development should focus on making teachers aware of their function as a role model. Teachers are not merely 'neutral knowledge-brokers', but act as role models in human interaction. Students learn from the observed interaction between a patient and a teacher. The latter needs to be curious, open and respectful. Teachers facilitating sessions with patients have the challenging task to deal with ambiguity, and to navigate different perspectives respectfully. This requires reflexive teacher teams and starts with awareness of their own assumptions, beliefs, and possible biases.

Tip 10: support patients and students in their role

Patient support can come in many forms and should be adjusted to the individual patient's needs and the patient's role. When patients are involved as teachers (level 2, 3 or 4), they should be supported before, during and after educational encounters. Explore the expectations of the patient to align the learning encounter with the patient's needs and preferences and prepare the patient what to expect. Discuss whether a patient needs support during the encounter and, if so, what this support should consist of. Debrief after the encounter, to evaluate experiences and adjust future encounters if needed. Preparatory teaching training can also support patients in their role. However, we must keep in mind that these programs should support patients in conveying their unique and autonomous voice, *not* to shape them into teachers who 'fit' the traditional academic world. To overcome this, Cheng proposes a peer-led model, where experienced patient-teachers mentor new-comers.[30] Moreover, peer-support networks, where patients can share experiences and advice, like the Patient Carer Community at the University of Leeds, can be beneficial.[31].

Students should also be supported and informed about their role in the educational encounter.[18] It is important that both students and patients have congruent expectations about the encounter. Debriefing with students can aid reflection and can help them process possible emotional encounters.

The Utrecht University Medical School has a patient participation coordinator, reflecting level 6 of involvement. This is an official position, held by the mother of a child with a congenital heart disease. She can be consulted by patients, students and educators for advice and support. Moreover, to safeguard continuity in patient involvement

throughout the curriculum, she actively takes care that patient contact is ensured in all stages of the curriculum and connects the different initiatives so that they align with each other.

Tip 11: Broaden your perspective (to the complete patient journey)

We started with conditions for success, such as creating a culture of openness, followed by more practical advice. Now we continue with less of a tip and more of a mindset. Learning with and from patients means moving beyond a focus on disease and individual specialties, and towards a focus on the patient as a person. The journey a patient makes is complex and can consist of many impactful experiences and moments of connection, leading to a network of care with different HCPs and supportive staff. Therefore, besides being open to new perspectives (tip 1), the challenge is to broaden our perspective and break through individual traditional silos of medical specialties. [45].

A way to stimulate this 'broader mind' attitude in students, is to let them share patients' experiences longitudinally. For example, by matching students to patients in the first three years of their medical training, as a 'companion on the patient's medical journey'. [17,46] This allows them to experience a patient's journey, including sitting in a waiting room, undergoing diagnostic procedures and meeting different specialists. Following a patient's journey, the disease is no longer the focus, but other aspects of care and cure such as empathy and collaborating with colleagues, both intra- and interprofessionally, become important.

4. Discussion and conclusion

Moving towards person-centered care, with equal partnerships between HCPs and patients, requires a solid role for patients in the education of (future) HCPs. [1] These tips can be used as a tool to start with, or reinforce, patient involvement in education, at the level of organization, teaching staff and in individual lessons.

We will briefly consider some strengths and weaknesses of our approach. First of all, our tips were the result of combining knowledge and experiences of a diverse group of experts, in different roles, with various perspectives on patient involvement. This approach resulted in tips highly compatible with practice and at the same time supported by literature. However, we did not perform a systematic literature review and thereby possibly missed important tips. Second, these tips are based on the situation in the Netherlands, where a strong movement towards patient-centered healthcare, including patient involvement in education, is present. This facilitated the development of our expertise in this field and thereby the development of this paper. Yet, we realize that this is a unique situation, which might not be applicable to other countries with different contexts. Future research could focus on the applicability of these tips in other contexts and extend the list with context-specific tips.

Finally, and most importantly, these 12 tips are not an all-encompassing guideline and patient involvement should not be a mandatory tick box or a trick that is to be used in education. True patient involvement in education requires a change in mindset of traditional educators. The goal is person-centered care that aims at meaningful life rather than merely the absence of disease. [47,48] To achieve this goal, integration of different types of knowledge and perspectives is needed, with patients' experiential knowledge as key. This requires thoughtfully designed learning environments that stimulate integration of knowledge and attitude change, and enable collaborative knowledge production. [8, 19].

Ideally, integration of different types of knowledge leads to new levels of knowledge production, rather than reproduction of existing knowledge. This inevitably means that learning outcomes cannot always be well-defined in advance. Working towards multi-layered 'fuzzy' concepts like person-centeredness, means working with learning goals that are less precise than we might be used to. [49] We challenge you to design for empathy, caring and reflection, which enables reaching these

multi-layered learning goals and contributes to better retention of knowledge. Have a sense of direction and design for openness to enable new types of learning like transformative learning. [50].

Remember, teaching with patients is not business as usual, yet it should become business as usual. Hence, our last tip highlights not only the importance of attitude but also the experiential educational philosophy that should underline the other 11.

Tip 12: Just do it!

Conflict of interest

The authors declare no conflict(s) of interest.

Acknowledgments

We thank the participants of the round table session 12 tips voor patientenparticipatie in medisch onderwijs' at the Netherlands Association of Medical Education conference in 2020. The input this session yielded was used as a starting point of this article. Furthermore, we thank Peter van den Berg, Nicole Keurentjes-Smeets, Hans Meex, Jannie Schwillens, Marcel Verhoeven, and the other patients of the patient-panel who provided us with feedback on the first draft of the tips.

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