

Patient involvement in medical professionals' education - A survey for patients and patient organisations

About this survey

What is the survey about?

Through this survey we hope to gain a better understanding of how common it is for patients (individual patients or patient organisations) to participate in continuing professional development / continuing medical education (CPD/CME) activities, what kind of activities they participate in, and what their experiences are like, as well as get patients' recommendations on how to improve this.

Who is the survey for?

The survey is meant for individual patients, patient advocates and experts, family members, informal caregivers, or representatives of patient organisations.

Who is the survey for?

You do not need in-depth knowledge on the topic to complete this survey. Even if you or your patient organisation has never participated in CPD/CME activities, you can still give your opinion about some aspects of it.

How much time will it take?

This survey consists of **xx** questions, some of which have tick-box options. It should take around **15-20 minutes to complete**. Parts 3 and 4 are optional. Please do try to answer all the questions if you can; in our analysis we can only take into consideration completed surveys in order to have reliable and comparable results.

Can I see the questionnaire before answering?

To prepare your answers in advance or to consult with colleagues, you can take a look at the questionnaire in pdf format [here](#).

What is the deadline for completing the survey?

The survey is open until **XX xxx 2020**.

How will you protect my data and privacy?

You are under no obligation to participate in this survey. If you choose to do so, your replies will remain anonymous. EPF is managing the survey, and we will treat the results as strictly confidential. We only ask for information that is needed to analyse the results, for example "demographic", country and disease-area information. This will also remain anonymous. No personal information will be published.

By completing and submitting this survey you are providing your informed consent.

How will the survey responses be used?

We will use the survey results to identify gaps and need for further actions as well as planning specific activities towards increasing patient involvement in CPD/CME.

We will publish a summary report of the survey results, which will be freely available on EPF's website. The report will include information in a non-identifiable form.

We may wish to conduct personal interviews at a later stage to gain more information. For this we will always ask for permission separately. Completing this survey does not oblige you in any way to participate in further activities.

More questions?

If you need additional information about the questionnaire or clarifications on the content, please do not hesitate to write to: policy@eupatient.eu

Thank you for your support!

The EPF Secretariat

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Background – why we are doing this survey now

One important factor in ensuring the high quality of healthcare is that healthcare professionals have the right skills, knowledge and attitudes to practice person-centred care – including shared decision-making, listening, supportive and effective communication, empathy and partnership.[1] Across Europe, the health workforce is in transition and countries will need to plan for new skills and roles, such as coaching and advocacy, to be able to better address the needs of patients with chronic conditions.[2]

Patient organisations' role in shaping the basic and continuing education of professionals has until now been unrecognised and under-used. EPF calls for embedding patient involvement in all professional education.

Patients can be involved in professional education in many ways. At the most basic level, patients' stories are increasingly used as learning material. Sometimes role play is used or patients are invited to speak of their experiences in person. However, advanced roles such as having patients as “co-teachers” or having them involved in shaping teaching curricula are still rare.

For an overview of patients in undergraduate education, please see this recent article by Stijntje Dijk, Matthias Wienold and Edwin Duijzer in *BMJ Open*. For a discussion of patients' roles in other contexts, see pages 18-22 of the EPF Congress report plenary session “Patients as teachers – what can patients teach professionals?” organised in collaboration with The BMJ.

What are CPD and CME?

EPF started a collaboration with BioMed Alliance in 2019 on promoting high-quality continuing professional education (CPD), of which patient involvement forms one important element.[3] Continuing professional development, sometimes called continuing medical education (CME), is an important area of education to keep the skills of already practising physicians up to date.

Both CPD and CME aim to keep doctors' medical practice up to date. It is the ethical duty and professional requirement of a physician to constantly update their knowledge and undertake training in areas such as knowledge, skills, safety and quality, communication and teamwork, for example. Competencies go beyond purely medical knowledge and include other areas such as ethics, social and personal skills. Practising professionals need to gain a certain number of “credits” each year to fulfil this requirement.

CPD is the broader concept, while CME is geared towards information and knowledge that is essential to medical practice. CPD/CME can take different forms; one very common form is that professionals attend certain sessions at medical conferences for which they get credits for CPD/CME. Sometimes professionals also do courses online or attend lectures, read articles, participate in live teaching courses or workshops to get credits. Exact requirements vary in the EU.[4]

[1] “Future EU Agenda on quality of health care with a special emphasis on patient safety”. *Final opinion, EXPH*, 9 October 2014, p. 71.

[2] *State of Health in the EU Companion report 2019* available at https://ec.europa.eu/health/sites/health/files/state/docs/2019_companion_en.pdf

[3] *The Biomedical Alliance in Europe (BioMed Alliance) brings together European medical societies at European level*. Visit <https://www.biomedeuropa.org>

[4] <https://eu-acme.org/cpd-cme-credit-system/number-of-credits-per-activity-type/> ; *Study concerning the review and mapping of continuous professional development and lifelong learning for health professionals in the EU (2015)* <https://ec.europa.eu/health/w>

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Part 1 – Demographic questions

To help us make as useful an analysis as possible, please give some information about your background.

* 1. Are you answering:

- | | |
|--|---|
| <input type="radio"/> On your own behalf (as an individual patient or patient advocate) | <input type="radio"/> As a family member of a patient |
| <input type="radio"/> On behalf of a patient organisation or network (disease-specific) | <input type="radio"/> As other informal caregiver |
| <input type="radio"/> On behalf of a patient organisation in a specific country (cross-disease umbrella) | |

* 2. What is the disease-area you are active in?

* 3. What country do you live in/your organisation operate in?

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Part 2 – Experience of involvement in CPD/CME

In this section we ask about whether or not you have been involved in CPD/CME activities, and your experiences. Please answer this section as fully as possible.

* 1. Have you/your organisation ever taken part in CPD/CME activities?

- Yes
- No
- I don't know

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Part 2.1 – Experience of involvement in CPD/CME

* 1. What was the topic of the educational activity? (tick all that apply)

- Treating a specific condition
- Diagnosing a specific condition
- Use of a specific treatment, medicine or device
- Patient safety in general
- Medication or device safety
- Communication between health professional and patient
- Shared decision-making
- Physical examination skills
- Clinical research
- Patient psychology (e.g. social isolation)
- End-of-life or palliative care
- Prevention or risk factor management, e.g. nutrition or exercise
- Rehabilitation
- Digital technology, e.g. telehealth, wearables, artificial intelligence
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

* 2. Who organised the educational activity? (if you have participated in more than one, tick all that apply)

- Medical / scientific society
- University
- Pharmaceutical or medical device industry
- I don't know
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

* 3. How did you get invited to the activity?

- Through a doctor
- Through a hospital or other healthcare organisation
- Through a patient organisation
- Information found online or in the media
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

* 4. What was your/your organisation's role in the educational activity?

- Provide patient(s) stories as learning materials, but not be present in person
- Bring patient(s) participating in person to share their stories
- Having a teaching role – not just sharing your story
- Present the organisation's own activities/more general lessons from its work with patients.
- Other / not applicable / do not wish to answer

Please describe your role in more detail if you can; for example, if you had a teaching role what did this mean?

* 5. Did you receive any training, support or information in preparation for the activity?

- Yes
- No
- Other / not applicable / do not wish to answer

If YES, please tell us who provided this, what did the training include, and did you feel it was adequate for the task expected from you

* 6. Were you/your organisation involved in designing the activity?

- Yes
- No
- Other / not applicable / do not wish to answer

If YES, Please describe how (for example co-drafting the programme, defining objectives...)

* 7. Were you/your organisation compensated for your expenses and your expertise?

- Yes, for expenses only
- Yes, for expenses and also payment for the contribution
- I was offered but did not accept (please explain in comments box)
- No
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

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Part 2.1.1 – Experience of involvement in CPD/CME

* 1. Where did the compensation come from?

- Participation fees
- The organising body
- Third-party support, e.g. from industry
- I don't know
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

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Part 2.1.2 – Experience of involvement in CPD/CME

* 1. Was your involvement part of a continuing relationship with the CPD/CME provider?

- No, it only happened one time
- Yes, there is a continuing relationship with one or more provider
- There have been several one-time participations with different providers
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

* 2. How was the experience overall for you?

- Positive
- Negative
- Mixed
- Other / not applicable / do not wish to answer

Please comment on your answer if you wish

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Part 2.2 – Experience of involvement in CPD/CME

* 1. Would you like to be involved if given the opportunity?

- Yes
- No
- I don't know

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Part 3 – Gaps and suggestions for improvement

In this section we ask for your views on what might make it easier and more attractive for patients or patient organisations to participate in CPD/CME activities. These questions are optional, but we very much appreciate your thoughts.

1. What do you consider to be the most important elements or timing of patient (organisation) involvement in CPD/CME activities? (If no answer please input N/A)

2. What do you see as the major barriers to having more patient involvement in professional medical education and continuing professional development? (If no answer please input N/A)

3. What kind of training and/or information would you wish to have to prepare you for involvement in CPD/CME? (If no answer please input N/A)

4. What other factors would increase patient involvement in CPD/CME in your opinion? (If no answer please input N/A)

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Part 4 – Independence of CPD/CME

In this section we ask about your views regarding involvement of industry in supporting CPD/CME activities, in particular medical education. These questions are optional.

Medical societies have recently expressed concerns about industry involvement in medical education. Although there are legitimate and valuable areas of co-operation in education between the medical profession and the industry, in their view medical education should be provided by not-for-profit medical societies to guard against bias. Medical education is differentiated from product training.

In Europe, educational activities organized directly by industry are not accredited. The European Accreditation Council for Continuing Medical Education (EACCME) requires that "all funding from sponsors must be provided as an unrestricted educational grant, free of any attempt to influence the programme, individual sessions, subjects for discussion, content or choice of faculty members."

1. How important do you think is it that CPD/CME educational activities aimed at healthcare professionals are independent from the pharmaceutical and device industry?

- Very important
- Somewhat important
- Not very important
- Not at all important

Please comment on your answer, for example how would you define "independent".

2. Do you think there are risks of pharmaceutical and device industry involvement in CPD/CME? (tick all applicable)

- Yes. Content may be biased towards industry interests (for example, encouraging overtreatment / overdiagnosis, or bias in favour of for certain products)
- Yes. Financial conflicts of interest of the expert speakers
- No, I do not think there are risks
- I don't know
- Other / do not wish to answer

Please comment on your answer

3. Who would be your preferred partner in developing CPD/CME activities ?

- Medical /scientific society, such as a disease society
- University
- Teaching hospital / university hospital
- National public sector health institution, such as a healthcare quality institute
- Pharmaceutical or medical device company (even if these activities are not formally accredited)
- Other / do not wish to answer

Please comment on your answer if you wish

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Part 5 – Conclusion

1. If you have any further comments or wish to address any issues not covered in the survey questions, please feel free to comment here

** 2. EPF may wish to conduct interviews with patients/patient representatives at a later stage to gain more insight into the experiences, knowledge and preferences. If you agree that we may contact you with an interview request, please give your name, organisation and email address below. We will only contact you if you give us permission.*

Please do not contact me further

I agree to be contacted further

3. If you want to be contacted further, please share your:

Name

Organisation or disease-area

Email Address

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Thank you for completing our survey!

If you have not already done so, please share this survey with your network by using this link: **xxxxxx**

The deadline to complete the survey is **XX October**.

The survey report will be published and available for free on EPF website in the coming months.

For any questions or queries, please contact: **policy@eupatient.eu**