

EPF Survey Report on Patient Involvement in Continuing Professional Education

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

Introduction

The transformation of healthcare systems by technological and scientific advances, such as digitalisation, are changing the relationships and roles of patients and healthcare professionals. The health workforce is in transition and countries will need to plan for new skills and roles, such as coaching, shared decision-making and advocacy, to be able to better address the needs of patients with chronic conditions.¹ The high-quality and patient-centricity of healthcare relies on healthcare professionals who have the right skills, knowledge and attitudes to practice person-centred care – including soft skills such as active listening, supportive and effective communication, empathy and partnership.²

Healthcare systems can place people and patients at the centre of healthcare by, among other things, involving patients more in the training of healthcare professionals: patients and family members can contribute both to basic and continuing education activities; their roles can range from sharing their personal stories to actually teaching professionals, to shaping institutional training curricula.

Patient involvement in professional education was one of the areas identified as a priority in EPF's Patient Empowerment Campaign in 2015.³ EPF also addressed this theme during its 2019 EPF Congress on Meaningful Patient Involvement, where there was a plenary session focused on "*Patients as teachers – what can patients teach professionals?*", co-organised with The BMJ.⁴ Moreover, this topic has been on the EU Health agenda since the State of Health in the EU companion report (2019)⁵ recognised the need for the involvement of patient organisations in developing new skills for healthcare professionals.

The present survey focuses on continuing professional education (CPE) for healthcare professionals. For the purposes of this survey, it also includes Continuing Medical Education. CPE activities aim to maintain, develop, and increase the knowledge and skills of healthcare professionals. CPE activities may take place in a variety of formats and scenarios, such as live or virtual events/workshops, publications, online programmes, courses, or others. They may happen both in medical and/or in academic settings. The aim of the survey was to gain insights into our members' experiences of involvement in CPE activities. Insights generated from the survey will inform EPF's further advocacy work in this area.

Survey participants

The survey was conducted online from 24 November 2020 to 31 January 2021. It was drafted and distributed by the EPF Secretariat. The surveyed population was approached via e-mail. The survey was also disseminated via other communication channels (internal newsletters to EPF Members, and

¹ 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

² "Future EU Agenda on quality of health care with a special emphasis on patient safety". Final opinion, EXPH, 9 October 2014, p. 71.

³ More information on this is available here: <https://www.eu-patient.eu/policy/campaign/PatientsprescribE/>

⁴ The journal's online page is available here: <https://www.bmj.com>

⁵ This document is available here: https://ec.europa.eu/health/sites/default/files/state/docs/2019_companion_en.pdf

EPF’s social media channels). EPF Members who received the link to the survey were encouraged to further forward it to their members (i.e., individual patients or patient advocates, and/or family members of a patient). Responses were collected and analysed with the assistance of the web-based tool SurveyMonkey.⁶

This survey collected 89 responses. These comprise responses submitted by individual patients, patient advocates or family members, and responses on behalf of patient organisations from EPF’s membership⁷ comprising national coalitions and disease-specific patient organisations. Due to technical reasons, the results do not always specify the respondent’s category (more information is given in the “conclusions” section, at the end). When it was not possible to classify the responses received by category of the respondent, all responses are treated and analysed together.

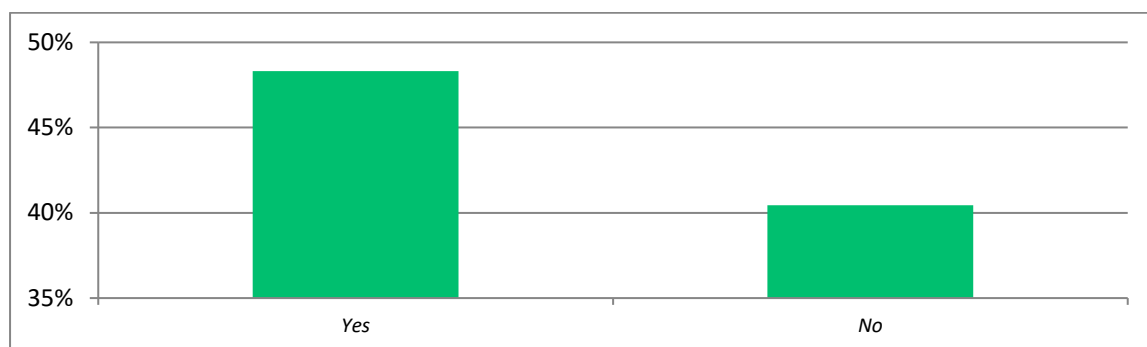
All questions provided participants with a series of possible answers (sometimes they could choose all options that applied, while other times they could only pick one), and whenever relevant, respondents were given the possibility to add additional input in a free-text form.

Main results and discussion

This section will present the analysis of all questions. Graphs are included when useful to illustrate some responses.

1. INVOLVEMENT IN CPE ACTIVITIES

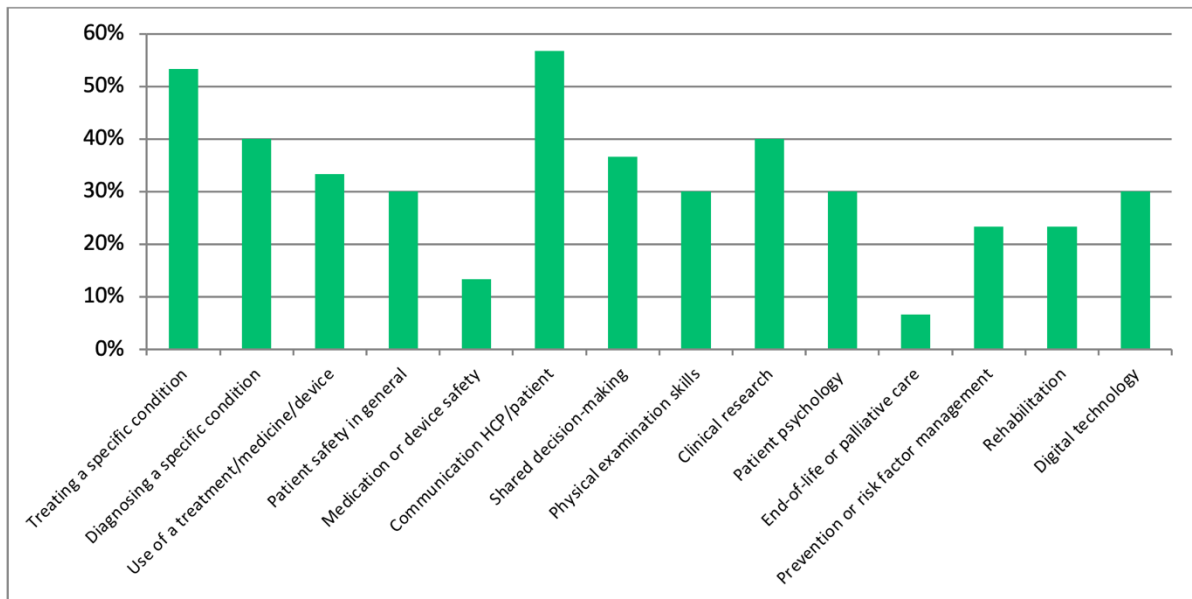
To start the survey, respondents were asked if they had ever been involved in CPE activities. Of the 89 responses received, 49% said “yes”, and 40% said “no”.



Following, respondents were asked on the topic of any medical educational activity they may have been involved in (if any). Thirty-three answers were received. More than half of those (56%) indicated that they had been involved in CPE on the topic of communication between healthcare professionals and patients, and/or on the treatment of a specific condition (53%). Diagnosing a specific condition and clinical research followed (40%). The rest of the responses are represented in the following graph.

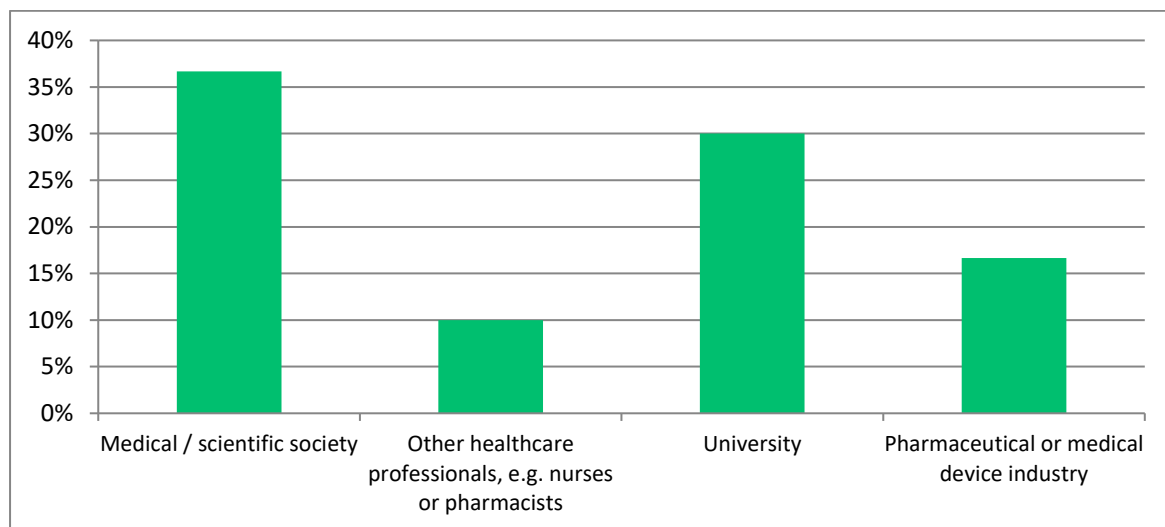
⁶ More information on how this tool works is available here: <https://www.surveymonkey.com/mp/take-a-tour>

⁷ The full and updated list of EPF Members is available here: <https://www.eu-patient.eu/Members>

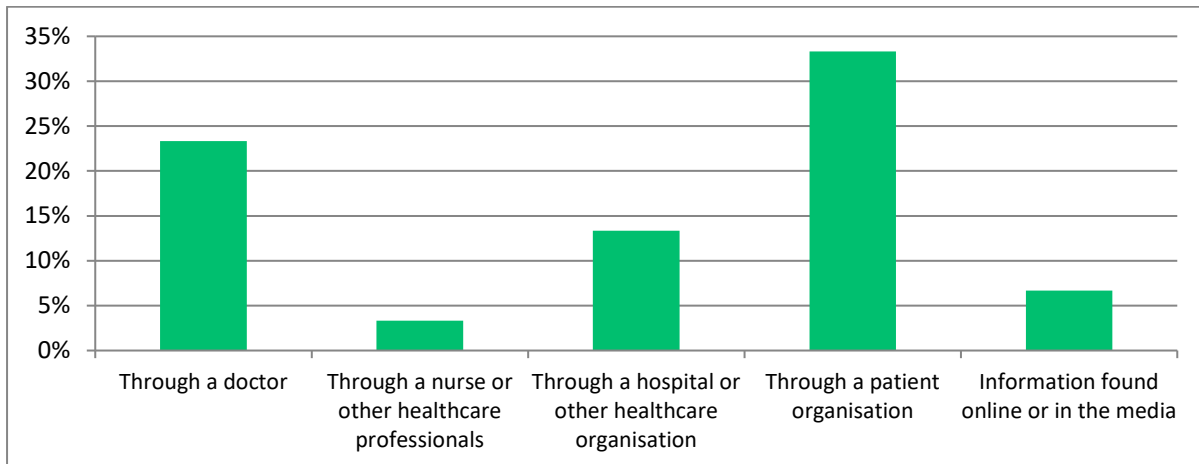


From the free-text answers, one participant indicated that she/he had been involved in CPE on the “communication and the use of E-Health possibilities”.

As a follow-up to the previous question, when asked who had organised the CPE activity, most respondents (of a total of 30) pointed out that it was done by a medical/scientific society (36%) or a university (30%). In the same vein, free-text answers reiterated that medical societies and universities are the types of institutions that organise most CPE activities. In addition, 17% of respondents referred to a pharmaceutical or medical devices manufacturer, and the remaining 10% to other professionals.

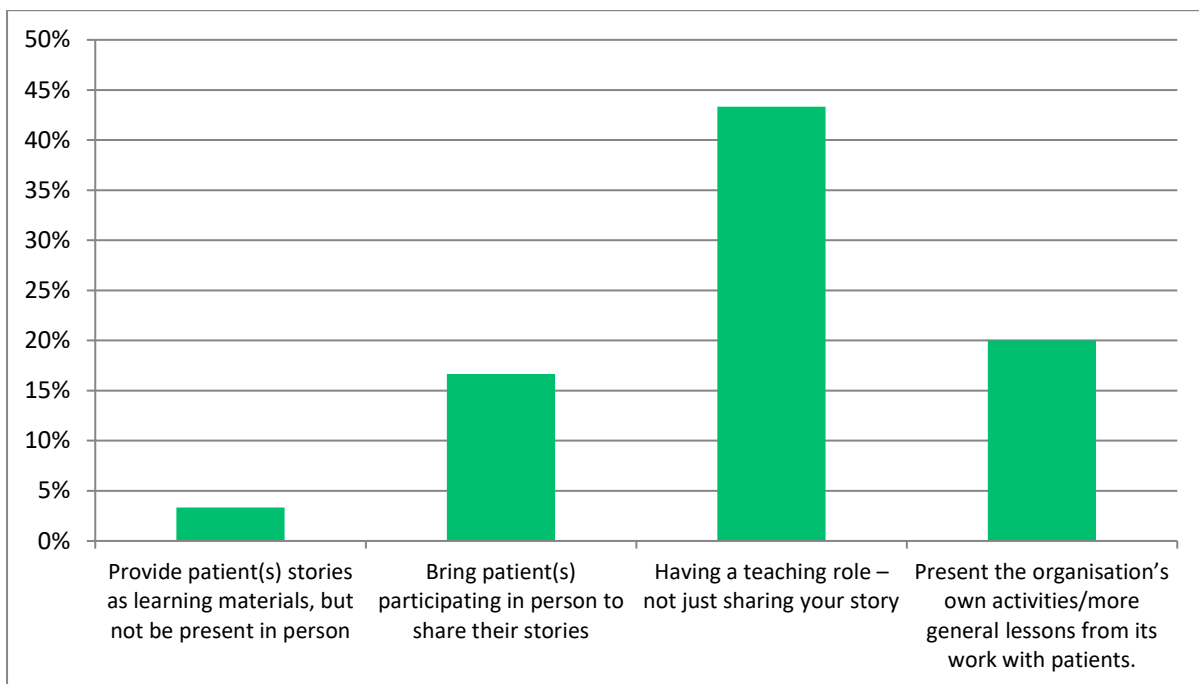


As for how respondents got invited to CPE activities, most did so through patient organisations (33%) or by doctors (23% responses). The rest got invited through a hospital or another healthcare organisation (13%), through information on the media (7%) or through a nurse or other healthcare professional (3%).



2. ROLE IN CPE ACTIVITIES

When asked about the organisation’s role in the educational activity, 40% of the organisations said that they had a teaching role (and not just “sharing their story”). Others presented the organisation’s own activities and its lessons from working with patients (20%). Seventeen percent brought patient(s) participating in-person to share their stories, and only three per cent of them provided patient(s) stories as learning materials without being physically present.



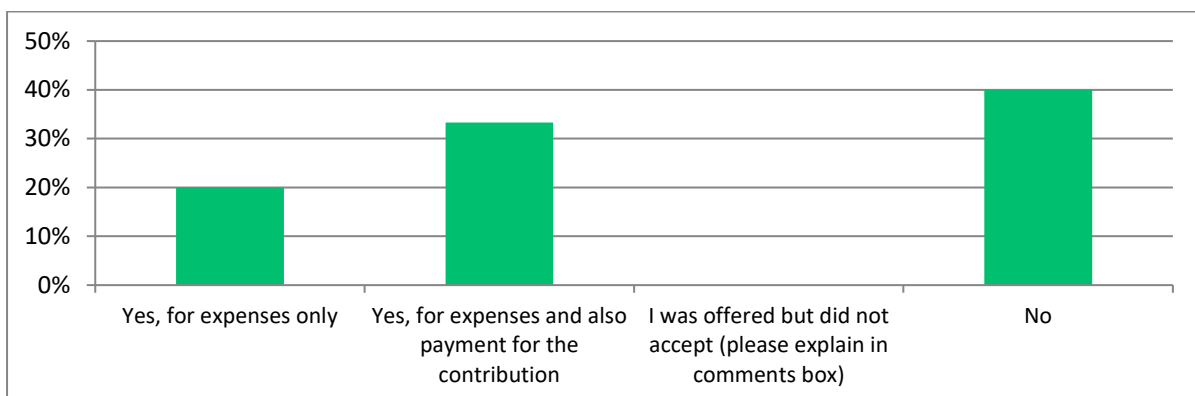
In the free-text sections, some respondents gave further insights into their responses. For example, one organisation said, “[...] teaching role means to explain the psychological situation of patients and the social and material support they can get from the health care system and the state”. Others highlighted “[w]e gave our input about the challenges of people living with food allergies and latex and how to improve the cooperation among the Health Professionals and the patients”.

Following up on the previous questions, participants were asked if they had received any training, support, or information in preparation for the activity. Of the 30 answers received, 47% indicated they had received some support, whereas 50% had not, and three per cent did not know. As one of the respondents indicated, *“I read some information material, which I felt was not enough. [...] I did some research through academic databases/journals for me to learn more about the process, how best it could be planned and implemented [...]”*. On the other hand, an organisation who had received support indicated *“[...] University provided details by phone and e-mail of what would be involved [...] it was all adequate and I was very well looked after. [...] I have done it for several years”*.

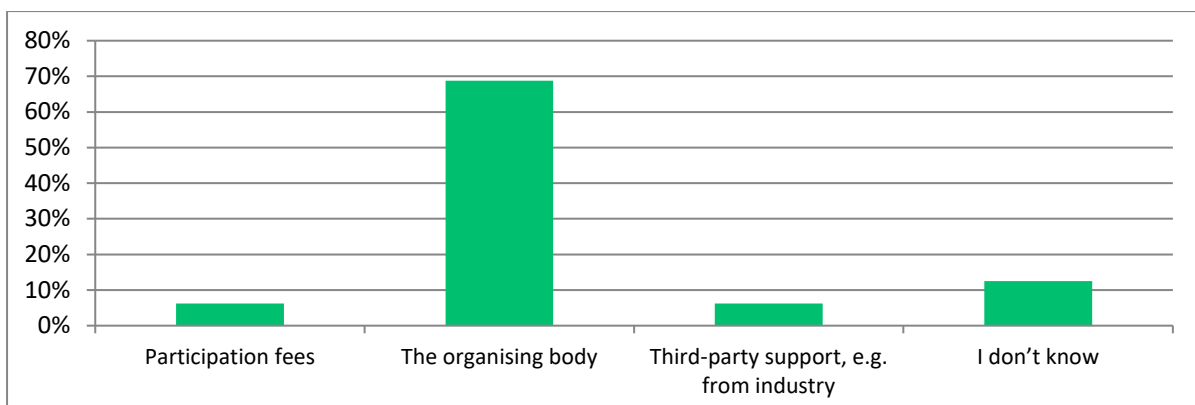
Respondents were also asked if they had been involved in the design of CPE activities. Of all respondents who responded, 50% said “yes” and the other 50% said “no”. One of the respondents said, *“I worked as a coordinator with a lady from the medical company, and the medical company was in charge of annual meetings and all the programs”*. Another respondent, in a different vein, said *“[w]e do not design the activity, but we are said to be equal partners with the doctors or scientists”*.

3. FINANCIAL ASPECTS OF CPE ACTIVITIES

When asked if they were compensated for their expenses and expertise, they answered the following (of a total of 30 replies): 40% said “no”. 33% indicated “yes”, both for expenses and payment for the contribution. 20% also said “yes”, although only for expenses.

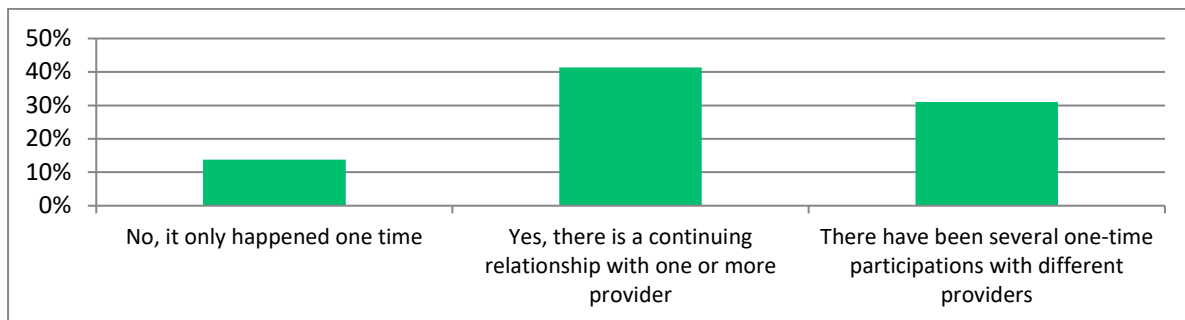


Then, when asked for the origin of the compensation, they said the following (of a total of 16 replies): 69% got paid by the organising body, 6% via participation fees, another 6% received third-party support, and the rest did not know.



4. FEEDBACK ON PARTICIPATION IN CPE ACTIVITIES

Respondents were then asked whether the involvement had been part of a continuing relationship with the CPE providers. As seen below, most respondents (21 out of 29) recognised the existence of a relationship. Indeed, 41% had a continuing relationship with one or more providers, 31% indicated that there have been several one-time participation with different providers, while 14% indicated that it had only happened one time.



When evaluating the experience, 86% had an overall positive experience, whereas 14% had mixed feelings about it. No respondent had a solely negative experience. Among the free text responses, respondents indicated *“definitely valuable and eye-opening [...]”, “I wanted to give something back. I have a rare autoimmune disease, for which the average time for a patient to receive a diagnosis is 5 years, so wanted to raise awareness of the condition. I have been involved in professional student education in other sectors too, so I enjoy the role. Treated very well, so it is all very easy”, or “a learning experience for both sides”*.

5. DRIVERS AND BARRIERS TO PATIENT PARTICIPATION IN CPE ACTIVITIES

At this point of the survey, a series of free text questions followed. The first one asked what respondents considered to be the most important elements or timing of patients (or patient organisations) in CPE. Most answers pointed towards the importance of early involvement, co-design, and recognition of the patients’ knowledge as complementary to the professional knowledge.

One respondent indicated that *“patients should be involved from the early stages, which means they should also have a say in how [...] CPE are going to be planned and implemented. Added on roles are not meaningful and just make people cynical”*. Others said that the most important elements of patients in CPE are *“the role of an expert patient. For instance, patients could share their experiences with students in a faculty, with doctors in a hospital. This interaction combines the experiential knowledge of the patient with the technical expertise of the professional [...]”* and *“Patient involvement and patient-centred health care. Communication”*.

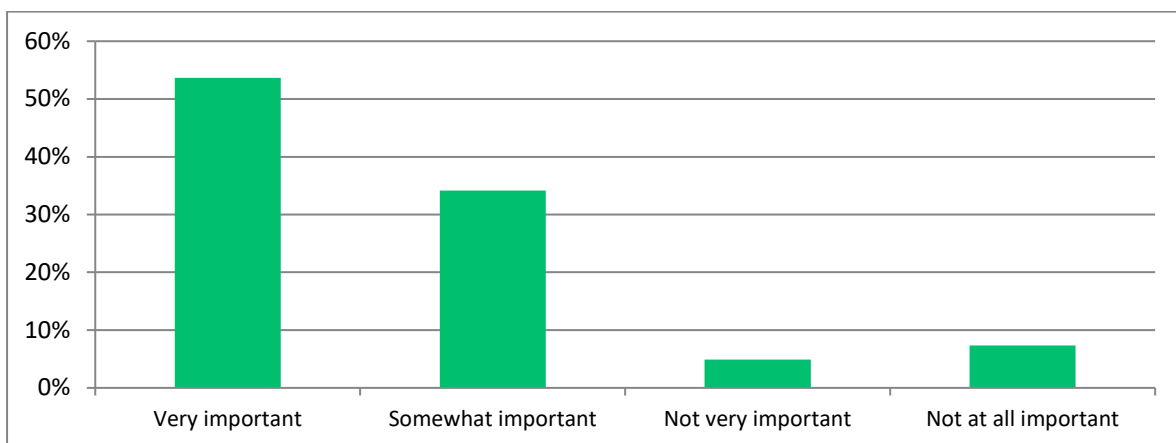
Following the previous question, respondents were asked to identify what they see as the major barriers to having more patient involvement in CPE. Most answers referred to the lack of recognition of patients’ expertise and willingness to involve patients, the time factor and financial aspects, as well as differences between patients and healthcare professionals (e.g., experience, language, and pace). One respondent indicated that there is *“little time for targeted education for the patient during*

standard medical appointments [...]” while others said that “doctors do not take patients as partners, but as users of their services. This is very much the case with older doctor generations [...]”, or that “the main barrier is not putting the patient at the centre of health care and understanding that patients have a lot of information and experience of great value to improve clinical practice”.

Then, respondents were asked what kind of training and/or information would they wish to have to prepare them for their involvement in CPE. The responses are very varied, and it is not possible to identify a common trend. For example, *“anything that would make me better understand how we can help each other in this important process”, “teaching skills, basic medical language”, or “information about the process, the participants of the discussion, and an understanding of the possible outcomes”.*

However, when asked which factors would increase patient involvement in CPE, the most repeated replies concerned financial aspects. E.g., *“remuneration”, “reimbursement of real costs”, or “allocate fees”*; among others.

Then, respondents were asked how important they think is it that CPE activities aimed at healthcare professionals are independent of the pharmaceutical and device industry. They answered the following: 54% said “very important”, 34% said “somewhat important”, 5% “not very important” and 7% “not at all important”.

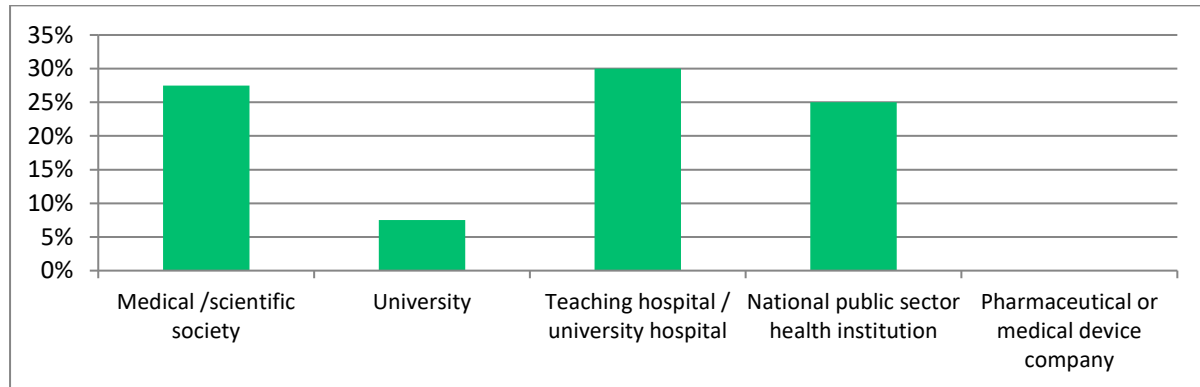


Among the free text answers for these questions, one respondent said *“all information provided by the industry should first be reviewed and fact-checked [...]”,* while another thought that the *“pharma industry have the funding and expertise to put on highly professional training and it is their corporate responsibility to give back”.*

Of a total of 41 answers, 31 respondents further believe that there are risks of pharmaceutical and device industry involvement in CPE. Out of these 31 answers, 22 indicated that *“content may be biased towards industry interests (for example, encouraging overtreatment/overdiagnosis, or bias in favour of for certain products)”*, while 9 respondents pointed to *“financial conflicts of interest of the expert speakers”.*

Respondents were then asked about their preferred partners for developing CPE activities. Of a total of 40 replies, 30% preferred to do so with teaching or university hospitals, 28% with a medical/scientific society, 25% with a national public sector health institution, and 8% with a

university. No respondent said their preferred partner was a pharmaceutical or medical device company.



Finally, respondents were invited to share any other comments or to address aspects that were not included in the survey. Most of the responses emphasised the benefits of patient involvement and referred to the relationship between patients and healthcare professionals.

For example, one respondent said *“when I want a makeover done on my house, I bring in professionals, but I expect my needs and wishes to be central to the relationship. It is the same with the patient/doctor relationship - the doctor is brought in for their expertise, but the patient still wants and needs to be involved. [...] The involvement of patients and patient advocates in training will go some way to redressing the current imbalances in the relationship between patients and health service providers”*. Another respondent stated *“we believe that there are positive changes in the role that patients should play in the future of health, and we believe that collaboration with physicians is essential and the best way forward”*, while others thought that *“we need an academic degree of -professional patient by experience- to share our experience and expertise”*, or that *“the patient community has a lot to learn in this area. Need to understand the needs of the system better and to put a value on the role of the patient perspective”*.

Discussion and conclusion

The major findings that could be extracted from this survey, is that CPE of healthcare professionals is very important for all respondents. If used correctly, it is also a way of placing patients at the centre of healthcare, as it enables them to share their experiences and expertise with healthcare professionals and healthcare providers who, in turn, need them to better tailor their work to patients’ specific needs and expectations. Surveyed patients do value building a relationship with their healthcare professionals, as they think that when this happens their needs are met better. Thus, patient involvement in CPE activities should be promoted and invested in as part of healthcare professionals’ continuing education throughout their careers.

When it comes to the drivers of CPE activities, patient organisations stand out as the main actors encouraging patients, their families, and carers to participate in CPE activities. In addition, patients value CPE activities positively. Most likely this relates to the level of trust that patients have in the organisations that represent them, as well as on patient organisations’ proactiveness.

The major organisers of CPE activities are medical societies and universities. That may have to do with the allocation of resources that these types of organisations may have at hand, but also with the conflicts of interest that may arise from industry funding (some of the free-text answers pointed towards this). While most CPE participants acknowledge having a relationship with the organisers, all participants also point out that organisers' independence from the pharmaceutical industry is important. The latter would not only ensure the independence of the CPE activities organisers when deciding what is needed by the healthcare workforce, but also their accountability to the patient community.

The question of resources also echoes the demand that participation in CPE activities should be compensated for patients; this could help ensure that none is excluded from participating and thus increasing the diversity and inclusivity of the patient voice. Financial compensation for their time and expertise, not only for their expenses, is also considered the most important factor that would increase patient participation.

Fostering patients' involvement in CPE activities requires the acknowledgement of patient experience and information as expertise. Some respondents reported imbalances in the relationship between patients and healthcare professionals, a lack of recognition of patients' expertise and a lack of willingness to involve patients, which, in turn, hinder patient participation in CPE. The time factor is also important in involving patients in CPE activities. The timing of participation matters, with early involvement and co-design of CPE activities considered as key elements of patients' involvement, while lack of time and busy schedules were described as barriers. Finally, patients could benefit from training and/or information to prepare them for participation. Although there was no agreement on the type and form of training, this survey showed that there was a demand for it.

The limitations of this survey are two-fold. Firstly, due to a technical issue, while collecting survey responses, groups of respondents could not be categorised for most questions (i.e., individual patients or patient advocates; patient organisations or networks that are disease-specific; patient organisations in specific countries, operating as cross-disease umbrella organisations; or family members of a patient), which makes it difficult to draw concrete conclusions and/or recommendations applicable to each of them. Thus, generalisations resulting from this survey can only apply to the EPF membership as a whole and the topic of CPE in general. In addition, the representativeness of the results is limited to the number of respondents that participated. Thus, definite generalisations cannot be drawn from the results of this survey. Nevertheless, the results are in line with previous EPF surveys and member consultations, and we can therefore consider them reasonably valid as a basis for future work with our members and/or for drafting recommendations in this area.

Ultimately, this survey serves as a testimony that, despite inherent shortcomings of current patient participation in CPE activities, such as imbalances in the relationship between patients and healthcare professionals or lack of preparation, there is a willingness in the patient community to advance patient involvement in CPE activities. Issues relating to funding by industry or universities/medical societies, the design of the participation process and how to encourage patient involvement will require further investigation. The results of this survey will therefore be used by EPF to support the ongoing activities and further develop our work in this area, in consultation with our membership.