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Purposeful involvement of experts by experience

Summary

Background: There is growing requirement from professional bodies in the United Kingdom (UK) that health and social care education must include the voice of Experts by Experience (EbE). Active steps have been taken at international level in order to truly embed their involvement. In parallel with this development, there is compounding evidence collated globally that links interprofessional education (IPE) to improved health outcomes. Since involvement of EbE plays a central role in IPE there is an increased expectation for teachers to be able to successfully involve EbE in IPE and other health education.

Issue: Whilst there is some guidance available to teachers on how to involve EbE in pre-registration health and social care education, less guidance is available on how to involve EbE in complex educational interventions, such as IPE. Hence the need for faculty development.

Approach: The Centre for Interprofessional Practice (CIPP) has involved ~350 EbE in a variety of IPE since 2005. This review draws on their insight to identify a number of practice points for teachers who wish to involve EbE in IPE, or as part of their specific profession's education. The practice points are endorsed by EbE and discussed in light of initiatives and evidence reported by others in the literature. To help contextualise and make use of these practice points they were grouped according to the Presage, Process, Product (3P) model. This paper can inform faculty development aimed at new or senior educators, and our insights are equally applicable to both uni- and interprofessional contexts.

Introduction

Experts by Experience (EbE) are defined as “people who have experience of using, or caring for someone who uses health and/or social care services”.¹ Initiatives that include their voice in health and social care education are reported across the globe and active steps are taken to encourage further involvement.² In the United Kingdom (UK) professional bodies now require that EbE are involved in health and social care education to better address today’s complex care needs (Table 1).³⁻⁵ Indeed their participation has shown to help students develop their interpersonal skills, empathy and attitudes.⁶ Benefits to students’ academic learning and ability to link theory to practice have also been demonstrated.⁷

Table 1: UK Professional Bodies standards around EbE contribution to teaching. Please note that the term “service user” refers to EbE in the context of this paper.

Standard	UK Professional Body
“Approved education institutions, together with practice learning partners, must ensure programmes are designed, developed, delivered, evaluated and co-produced with service users and other stakeholders.”	Nursing and Midwifery Council ³
“Service users and carers must be involved in the programme. By ‘involved in the programme’ we mean that service users and carers must be able to contribute to the programme in some way”.	Health Care Professionals Council Standards ⁴
“The development of medical school curricula must be informed by medical students, doctors in training, educators, employers, other health and social care professionals and patients, families and carers.”	General Medical Council ⁵

Another common feature in healthcare curricula are opportunities to learn with students from different professions, and EbE where possible, during interprofessional education (IPE). This is welcomed by the World Health Organization, which states that IPE helps optimize health outcomes.⁸ These increasingly important components of health and

social care education require teachers to help students build partnerships with students from other professions and EbE. However, some educators find these expectations challenging.^{9,10,11}

Some advice is available on how teachers successfully involve EbE in their uni-professional teaching¹², which has helped move away from the 'wheeling in' of patients.¹³ Further to existing advice on EbE involvement, guidelines are also available to help educators develop IPE,¹⁴ which is notoriously multifaceted. Whilst involving EbE in IPE adds a unique richness to learning, it also adds an additional layer of complexity, and as a consequence, teachers need appropriate preparation.

At the Centre for Interprofessional Practice (CIPP), we have involved EbE (n~350) in a wide variety of IPE since 2005. Box 1 gives a flavour of their views on how prepared they felt.

Box 1: EbE views on how they felt prepared for their involvement in IPE by CIPP

1. *"I am invited in to a pre-seminar meeting to discuss the contents of the day, if I have any requirements or anything that I feel could be of use on the day."*
2. *"Always had pre-meetings to discuss the topics of the training; format the training would be in; a check whether session was okay & if it raised any issues..."*
3. *"We have always been fully supported and well looked after in preparing for and participating in events."*
4. *"Very supportive; CIPP staff have always made sure that I was 'comfortable' & 'prepared' for training sessions. It can raise issues again that you'd thought were dealt with, but a team member will always check if you are okay after a session."*

5. *"I am invited to a post seminar meeting to ask how things are, how I felt on the day, how I have been since and any feedback that I feel would be of value to the CIPP team or the students that have attended the seminar."*
6. *"...follow up session to reflect on training sessions & the feedback to take forward for next year."*
7. *"I would also be happy to be involved in anything else that I could be of use to."*
8. *"I have been involved for about five and a half years and I have found each experience has been extremely well facilitated, educational, motivational and very well run."*

For the purpose of this paper, our experiences have been encapsulated into a number of key practice points for clinical educators who plan to involve EbE in their teaching. These practice points, which have been endorsed by EbE (Box 2), apply to both uni- and interprofessional contexts and can be used to inform faculty development programmes for new staff, or more experienced teachers moving into curricula design (Box 3).

Box 2: EbE endorsement of the practice points presented in this paper

An informal peer-review of this paper was carried out by EbE who have worked with CIPP for a number of years. The paper was sent to five EbE who were asked if they could critically review and comment on this paper and the practice points in particular. Some small changes were made in light of their comments. Permission was asked to use a quote from each to summarise their evaluation, and these are the ones presented below.

"What you have written is exactly how it was for me for all those years I worked with you.

Always asked for my opinion, ideas, feelings and I was always paramount to your IPL sessions.

I enjoyed doing them because not only did it help my healing process, but I know that I was assisting others to go on and continue to teach to help more...

I hope that this paper goes a long way to continue to help more people learn from the source in the correct way." Katharine, Domestic abuse survivor.

"... should allow service user/carer to decide when time is right as sometimes the experience is more real when you are in the middle of it. Just offer emotional support if needed. It can be therapeutic to share at difficult times as you know your difficult experiences can be learnt from."

Amander, EbE.

"Sharing the negative experiences ones encountered can be upsetting to recall, but knowing that CIPP are there is very reassuring. Telling students what made a difference and/or what could have made a difference can be therapeutic for EbE as well as memorable to the listener. Having CIPP support helps to build a relationship with EbE and sharing feedback strengthens this relationship and dispels any thoughts of "a tick box tokenism." Linda, Stroke survivor.

"We have seen EbE involvement in student teaching evolve over the years in response to patient/carer feedback - this reflects the 'partnership' nature of the relationship between academics and EbE." Joyce, Carer & Colin, Stroke survivor.

Box 3. Using this guidance for faculty development

This paper can be used in both uni-and interprofessional contexts to prepare new and/or experienced teachers by for example:

- Informing a training programme to prepare teachers for EbE involvement in their teaching. This can be delivered as a stand-alone event, or be part of an existing training programme.
- Informing a Master Class specifically tailored to senior educators who wish to embark on curricula design/development involving EbE.
- Adopting flipped learning approach and thus disseminate this paper, or aspects of it, to teachers prior to inviting them to: a Q&A session; describe how they intend to engage EbE and then invite to reflect on their approach afterwards.
- Acting as trigger for discussion around EbE involvement, how best to take it forward at their institution and what faculty development is deemed necessary.

Each approach should ideally involve EbE.

In order to contextualise these points they were applied to the Presage, Process, Product (3P) model¹⁵ and Figure 1 helps illustrate how they are grouped across the three phases to ensure purposeful involvement. Each of the practice points are presented below and reviewed in the light of existing literature.

Application of the 3P Model ¹⁵ to ensure purposeful involvement of Experts by Experience	
The Presage phase Before approaching EbE	<ul style="list-style-type: none"> • establish rationale for involvement • offer co-production • target the invitation • offer differing perspectives
The Process phase Preparing EbE for event	<ul style="list-style-type: none"> • discuss role and contribution • agree a partnership and gain consent • individualise support • build a relationship
The Product phase Optimising outcomes	<ul style="list-style-type: none"> • create a safe learning environment • offer to meet after the teaching event • address negative experiences or feedback • value contribution.

Figure 1. The figure outlines a set of different practice points that need to be considered for each of the three phases of the 3P model,¹⁵ and before approaching EbE, to ensure purposeful involvement.

The presage phase

Establish rationale for involvement

EbE participation needs to be purposeful for all stakeholders.¹¹ Therefore, it is important for teachers to establish a rationale for EbE engagement¹² so that it is clear how they can enhance students' learning. A good way to achieve this is to align their contribution to learning outcomes (LOs). This helps to ensure EbE input is central to the learning, which may be the most important aspect of IPE,¹⁶ thus avoiding tokenistic involvement.¹³

Offer co-production

A true partnership approach, where EbE co-produce content before LOs are agreed, is a worthy goal.¹² If LOs have already been set, teachers can invite EbE to join the development of teaching content and methods.¹⁷ Their experience and knowledge will bring a unique authenticity to the teaching. Although not all EbE will opt to be part of the co-production process, they will appreciate the opportunity to be.

Target the invitation

Teachers need to involve those whose experiences can help students achieve the intended LOs^{11,17} and service user/ carer groups are likely to be in a position to suggest appropriate candidates.¹¹ Some EbE may contribute a perspective on behalf of a group of people who have experienced an area of care, others may share their own personal story. This may include describing painful memories, and therefore teachers must assess and agree with each individual what can be shared with students.¹⁸ From talking through their story, which many describe as therapeutic, most will discover whether they are in the 'right' place in their recovery from illness, dependency, or bereavement pathway.

Offer differing perspectives

Inclusion of different EbE allows students to hear divergent perspectives from people with the same condition and see patients as individuals.^{6,13} As well as providing diversity, having more than one 'expert' per student group serves as a useful backup in case of absences on the day. Spouses, carers and family members can also act as EbE, and/or provide valuable emotional support, help prepare someone with cognitive impairment, or aid someone with communication difficulties.¹² Paramount to embracing diversity is for

teachers to consider each person's emotional and physical needs, thus enabling everyone to contribute safely and effectively.

The process phase

Discuss role and contribution

Adequate and careful preparation of EbE needs to be emphasised to teachers so that they understand the importance of discussing, clarifying and agreeing the role of EbE.¹⁷ Pre-briefing meetings offer opportunities to ensure they understand their part, the purpose of the teaching session, and how their contribution fits within the course and wider curricula, as illustrated by feedback received (Box 2). Ideally, teachers should themselves arrange and/or be part of such meetings, but this will depend on the type and scale of intervention.

Most people who are keen to get involved with healthcare students' education arrive with good intentions. On rare occasions, some EbE have an agenda, or 'axe to grind'.¹⁹ In such cases, the teacher may try to address the issue and help them contribute more meaningfully/appropriately to the teaching session, or they may consider opting out of building a partnership with that individual.

Agree a partnership and gain consent

In most cases, when EbE volunteer to take part in teaching, they are somewhat apprehensive about sharing their story for the first time, or being in a higher education environment. It is therefore necessary to listen to their concerns and agree a partnership. For example, many ask how and with whom they will share their experiences, which emphasises the need to address queries around confidentiality and state that students

will be reminded to abide by the professional rules. Teachers must gain informed consent¹⁷ and clarify that EbE can withdraw at any time.

Individualise support

Some people might prefer individual sessions for support in shaping their 'story'.¹⁸ This can help EbE tailor their contribution to ensure everyone feels comfortable and confident sharing their 'story' and responding to questions.¹⁸ Others prefer to meet as a group, to share their experiences and generate discussion around how they can best support students to achieve the intended LOs.

Teachers should consider inviting EbE with previous experience to pre-briefings to reassure newcomers. Regardless of the approach, careful preparation is key to help calibrate content and emotions.¹⁸

Build a relationship

Building relationships with EbE based on mutual trust is instrumental for successful engagement and continued participation.¹² It enables individuals to raise any queries or anxieties they may have, or other matters in their life that may affect their participation. Similarly, teachers need to be able to diffuse challenging conversations and/or share their concerns about the way someone contributed to an event.¹⁸ During IPE, this may occur if someone is overly negative about one profession. Furthermore, some EbE with a professional background in health, or social care, have a tendency to 'slip back' into their professional role, which is not always helpful.

The product phase

Create a safe learning environment

Further to preparing EbE, students too need to be primed by, for example, teachers informing them about the event in advance so they can voice concerns if a topic resonates strongly with them. At the event, teachers should communicate a 'safety warning', which signposts students to available support services - should any of them be affected by what they hear. In the context of IPE, this also allows students to prepare for their role as a representative of their profession.¹⁶ Giving them a task prior to the session can help students think about questions they might like to ask.¹⁸

Creating a safe learning environment for all is key to teachers facilitating IPE.²⁰ Despite preparation, EbE may still find it overwhelming, or have an emotional reaction to an unexpected question¹⁶, which requires them to leave or stay afterwards to de-brief.

Offer to meet after the teaching event

De-briefing after a teaching event is likely to be very important to ensure the wellbeing of EbE. Immediate de-briefing provides an opportunity to discuss any impacts they may have experienced. The need to offer these was emphasised by an EbE at this university, who reported that the emotional impact of talking about his alcoholism was such that he left the session 'needing a drink'.

Later de-briefs offer an opportunity to receive feedback from EbE; what they felt went well, what did not work well, and their ideas for improvement (Box 2). Here, the teacher can share students' feedback to help EbE appreciate their valuable contribution, and also understand how they can optimise input.¹⁶

Address negative experiences or feedback

Careful preparation will minimise situations that need undoing later.¹⁸ EbE appreciate honest and constructive feedback,¹⁶ and it is therefore imperative for teachers not to lose focus of the main purpose of their involvement in the context of education. Hence, it is important to also convey negative comments from students. In IPE, such comments are often linked to EbE having shared bad experiences related one profession. To maintain relationships with EbE, addressing such feedback sensitively on a one-to-one basis before sharing learning with the wider group may be more appropriate.

EbE engagement is an ongoing process and teachers can help to nurture confidence^{17,19} and effectiveness over time by continuing to offer support and maintaining an open dialogue.

Value contribution

Valuing people's contribution is key to preserving good relationships with EbE.¹² In recognition of their input, certificates can be awarded and monetary remuneration, including the amount and process, needs to be clear upfront.^{11,18}

Teachers need to appreciate that for most EbE the 'small things often make a big difference' - from a warm greeting and 'tea and biscuits' offered on arrival, to appropriate acknowledgement of their role. Teachers' investment in EbE is likely to pay off by them wanting to return, as illustrated in feedback received (Box 2).

Concluding remarks

The practice points presented here are aimed to guide the development of training for teachers to help them to successfully involve EbE in health and social care education, may it be as part of IPE, or when they teach one profession.

Insights presented here derive from a long-term collaboration with a number of EbE, teachers and students over many years. Hence the authors feel confident of their authenticity and value to others, especially after the paper was informally reviewed by EbE who have been part of this journey and looking to existing studies and initiatives reported in the literature, some of which are mentioned here.

The 3P model is intended to facilitate understanding of the different phases of purposeful EbE involvement and the importance for teachers to consider the 'product' before embarking on the 'presage' phase. Therefore, please note that although presented in chronological order, any training should convey the importance of teachers planning all phases before approaching EbE. Training also needs to bring clarity around responsibilities, in cases where teachers cannot commit to all aspects and thus require support by other faculty.

A number of suggestions have been provided as how this paper can be used, but the key message is that all teachers, regardless of seniority, need preparation in order to purposefully involve EbE. It is necessary for this interaction to mirror that of IPE, so that the different 'experts', including EbE, teachers, trainers and students can learn "with, from and about each other". That way, this way of approaching education becomes purposeful for all.

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