

Developing opportunities for people with diabetes to engage in Improvement Champion activity: a practical guide for diabetes teams

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Received: 29 March 2021

Accepted in revised form: 11 June 2021

Abstract

By sharing their unique lived experience of using diabetes services, Experts by Experience can provide health care professionals and services with a valuable opportunity to enhance their practice and significantly improve service delivery. Despite an established evidence base in other areas of health care, and emerging evidence that engaging in Expert by Experience activity can beneficially impact people living with diabetes, this important area of practice is still very much neglected in routine diabetes care and the number of people who are able to access this opportunity is small. This paper, written by a team of people who have either acted as, or supported people to become, Experts by Experience, offers practical guidance to diabetes teams to assist them in supporting individuals to engage in this powerful activity while maintaining psychological health and healthy boundaries. Copyright © 2022 John Wiley & Sons.

Practical Diabetes 2022; 39(1): 30–33

Key words

Expert by Experience; service user involvement; patient leadership; Improvement Champion activity

Introduction

An Expert by Experience (EbE) is someone who has personal, lived experience of using health, mental health, and/or social care services, or caring for someone who uses those services.¹ Also referred to as Patient Leaders, Service User Representatives, and Patient Advocates, EbEs hold an essential and unique perspective on the service they use, and this perspective can be utilised to gain a fuller understanding of how services are currently delivering care, and how they could be improved. The evidence base for the benefits of EbE input to services is well established and clear: involvement can make services more effective,² make the professionals delivering the service more empathic and inclusive,^{3,4} improve the impact of training sessions^{5,6} and improve the impact of professional conferences.⁷ This evidence has led to EbE involvement being listed as a national policy priority^{8,9} and models of patient leadership are beginning to emerge across the UK.²

As depicted in The Patient Leadership Framework¹⁰ (see Figure 1), EbE

involvement can occur on a variety of levels, with differing goals and focus. While EbE involvement can provide high value in all types of activity, for the purposes of this paper we have focused on 'Improvement Champion' activity where the EbE's role is given high status, similar to a key note speaker at a conference. This type of activity can be a powerful and highly symbolic act that is often emotionally impactful for those who witness it. Improvement Champion activity is varied, but some examples include:

- Presenting about lived experiences at a staff training day/conference.
- Attending and inputting into service development meetings.
- Sitting on interview panels.
- Assisting in developing curriculum and delivering training sessions for student health care professionals.

The role of the EbE within diabetes services is still not well established, and the number of those people who are invited to engage in formal EbE activities within the diabetes health care system is small. At a recent large international online conference for

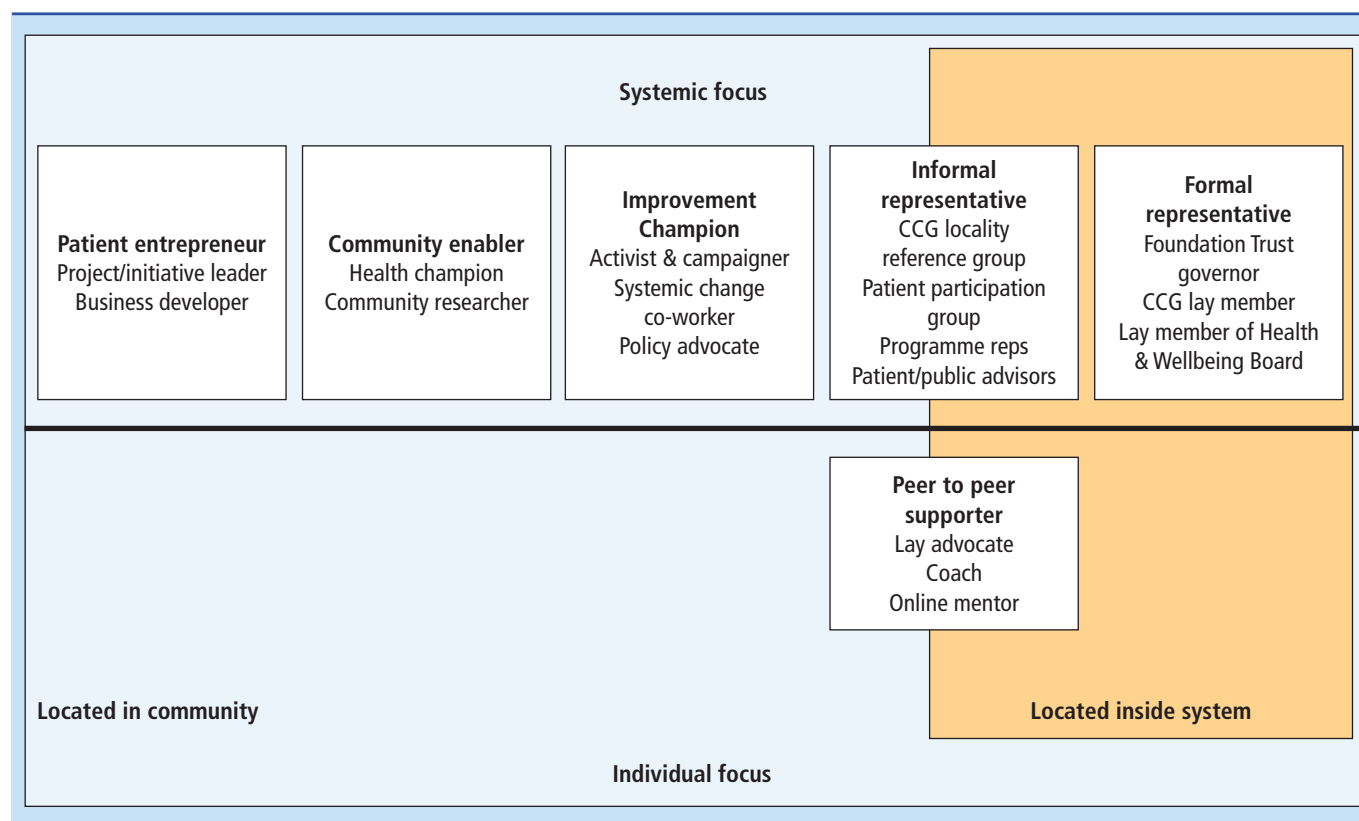


Figure 1. The Patient Leadership Framework¹⁰

diabetes professionals, only six of the 165 listed speakers were presenting in an EbE capacity.¹¹ These are issues that urgently need to be addressed as they result in less routine EbE involvement (with fewer benefits for services), a lack of diversity of views and the potential to breed resentment within the diabetes community if some individuals are perceived as being given more opportunities than others. This is particularly pertinent given the high level of inequality in access to health technologies for people living with diabetes in the UK.^{12,13}

Given the benefits that increasing EbE input into diabetes services is likely to have, and the need to increase the numbers of people involved, it is important to understand the impact this activity can have on EbEs, and to foresee any potential support needs. A recent qualitative study¹⁴ conducted by one of the authors of this paper (BA) and supervised by another (RS) found that engaging in Improvement

Champion activity was a positive experience for young adults with diabetes, and that it led to a feeling of empowerment in multiple facets of their lives. These included psychological empowerment (e.g. building self-respect, having the opportunity to tell one's story), social empowerment (e.g. changing dynamics with health care professionals, becoming part of a community) and empowerment over diabetes management (e.g. motivating improved self-management). The study was able to identify that there are factors that can act as facilitators or barriers to the benefits that a person obtains from Improvement Champion experience. We have combined these factors along with our experience of acting as Improvement Champions (CO and SC) and supporting people to become Improvement Champions (RS and SC) into the practical points below that can assist staff in supporting people with diabetes into Improvement Champion activities.

Who makes a good Improvement Champion?

While some people may already have experience in public speaking about their diabetes it is essential that this is not the only criterion for further involvement, and that diabetes services are continually seeking to diversify and develop the pool of potential speakers. Services should seek to ensure representation from people with a range of ages and backgrounds, and particular efforts should be made to ensure representation from groups that are often overlooked by society (e.g. ethnic minority groups, the LGBTQ+ community, people with learning disabilities, people from disadvantaged socioeconomic backgrounds, young adults).

There is often misperception that EbE conference speakers need to be people who are achieving the best possible outcomes with their diabetes; however, many of the most impactful talks we have witnessed come from individuals who have lived experience

of overcoming particularly difficult issues such as eating disorders or repeat diabetic ketoacidosis. Within the study by BA supervised by RS,¹⁴ many of the Improvement Champions likened the opportunity of being able to tell their own story to the process of therapy, in that it helped them process their experiences. However, discussing one's most difficult points in life can be emotionally challenging. It is important that individuals are able to create psychological distance between what they have been through previously and where they are now to avoid triggering any potential psychological distress and/or relapses in previous issues. 'Psychological readiness' was a theme identified in the study by BA supervised by RS¹⁴ – many of those we interviewed were at a point in their lives where they had overcome the worst of their difficulties and were looking (consciously or subconsciously) to create something positive and meaningful from their experiences by giving back to the wider diabetes system and community.

Some areas to consider and to discuss with potential Improvement Champions are as follows:

- **Support:** does the person have a good support network around them?
- **Visibility:** does the person feel comfortable sharing their personal experiences with strangers? Do they feel comfortable that their talk may be recorded and put online? Do they feel comfortable that their visibility might increase as a result of the activity?
- **Expectations:** does the person have a realistic view of what the activity involves? Are they expecting this activity to become a primary source of income?
- **Preparedness:** is the person already engaged in similar activity (e.g. blogging or vlogging, supporting others with similar issues in person or online, using their experience of living with diabetes as a topic for school assignments)?
- **Resilience:** could talking about these issues have negative consequences for

the person? What would these be and how could these be managed?

- **Resources:** does the person have the time and flexibility to be able to attend meetings and events that may involve travel? Are there additional arrangements (e.g. childcare, impact on paid work/education) that need to be taken into account?

- **Realism:** does the person have a vision or opinions on how diabetes care could be improved? Are they able to share this while understanding that others may not share their views and that systemic change may be incremental?

Factors that facilitate positive experiences

Team support

Improvement Champion activity is often a courageous act that involves publicly speaking about some of the most difficult aspects of living with diabetes. It is essential that those involved feel safe and supported as much as is practically possible and, where a person has a positive and trusting relationship with them, members of the diabetes team are well placed to offer such support. When inviting people to engage in Improvement Champion activity, it is essential that the team is clear that they fully support the person in communicating their full lived experience and that there is no expectation that the person's story should be censored or edited in order to make the team 'look good'. An individual member of the team should be available to the EbE should they have any questions or concerns about the activity. If the activity involves a person speaking publicly about their own experiences, particularly if they have been difficult (e.g. living with a mental health issue), it can be helpful for the EbE to work with a team member to discuss the structure of their talk, to identify any areas that they might not feel comfortable talking about in a public forum and anticipating any potential negative consequences of speaking publicly about their difficulties.

Transferable skills

Many people will have experience in public speaking or presenting from other life areas (e.g. work or school); helping them to recognise that these skills transfer across situations can increase confidence. In engaging with EbE activity, many people also gain useful skills (e.g. leadership, consultation, team working, and/or public speaking) that can in turn enhance their own career opportunities – this can be particularly helpful for young adults and those with employment needs.

Planning

Feeling well prepared for the EbE activity is crucial in counteracting anxiety and ensuring people have a positive experience. Important elements of planning could include being able to discuss the nature and location of the event, being able to have 'rehearsals', and understanding how to use any technology involved. Diabetes specific considerations may need to include preparing for the impact of adrenaline on blood glucose levels, carbohydrate counting buffet meals, and managing the effects or travel and disruption to normal routine.

Barriers to positive experiences and how to overcome them

Tokenism

During the study by BA supervised by RS¹⁴ some EbEs recalled particularly frustrating events where their input had felt tokenistic in that they had not been listened to (e.g. staff ignoring what they were saying, or talking over them in group settings), had their experiences questioned (e.g. asking 'are you sure this isn't just you misinterpreting what happened?'), or had felt that there was very little scope for their service improvement suggestions to be incorporated (e.g. the service had already decided what was going to happen prior to EbE consultation). It is important that when inviting EbEs to contribute to an activity that the scope and the person's remit is made clear in advance to avoid potential confusion and

disappointment. While it should be implicitly understood that any professionals working with an EbE should treat the person and their views with the utmost of respect, this understanding and agreement may need to be made more explicit at times, and could be incorporated into staff training and pre-event information.

Practical difficulties

It is common for many EbEs to experience a degree of anxiety about their activity, particularly if they are inexperienced or the event feels particularly important to them. While a degree of anxiety is to be expected, the activity should be a positive experience and teams need to be willing to offer support should the EbE feel anxious, or to discuss cancelling the activity should the level of anxiety be affecting wellbeing. Many EbEs feel particularly anxious about being asked difficult questions by audience members; it can be helpful to anticipate and rehearse potential answers to such questions in advance.

In circumstances where significant travel or overnight accommodation is involved, there may also be financial barriers; most conference organisers tend to pay travel expenses up to a month after completion of the event which can lead to significant out-of-pocket costs for people who may not be able to afford it – ideally, conference organisers should organise the EbE's transport and accommodation on the person's behalf in advance of the event. EbEs may also require practical support in the completion and submission of complex expenses forms.

Feelings of overwhelm

During the study by BA supervised by RS,¹⁴ some EbEs described feeling like their diabetes had become all-consuming because they were now working with it as well as living with it. EbE activity often involves a significant amount of work (e.g. developing presentations, reviewing draft documents, attending meetings) that the person will need to be fully aware of and prepared for before they agree to

KEY POINTS

- People living with diabetes (PWD) are experts in living with their condition and in the experience of using care services. Seeking PWD views and input is an essential component of service and research quality assurance and improvement
- Some PWD take on roles as Improvement Champions, where they may become involved in activities such as health care professional training or public speaking. This has a profoundly beneficial impact, both for services and for the person, and should be actively promoted within diabetes teams
- Health care professionals can assist PWD to take on Improvement Champion activities by vocalising their support, identifying transferable skills, and aiding with planning for events. Planning for common barriers, such as feeling overwhelmed, anxiety, and being able to set boundaries can also facilitate a positive experience for PWD

engage in the activity. In addition, once a person has engaged in EbE activity, they are often invited to further activities which they may feel pressure to agree to despite feeling overstretched. Feelings of overwhelm may also be exacerbated by social media as many EbEs develop a high profile as a result of their activity. This can feel increasingly intrusive if the person finds it difficult to impose limits on their level of social media interaction, and the line between personal and professional lives can become blurred.

Stepping away from EbE activity

Where EbEs have given successful talks on difficulties they have overcome and are invited to repeat this talk for new audiences, there is sometimes a risk that the EbE will start to feel that their current self is defined by their previous struggles, particularly if there were psychological difficulties involved. Ironically, what started as an empowering and liberating experience can over time become intrusive and oppressive unless the demands associated with this work are effectively managed. This can be particularly challenging if the person finds it difficult to set boundaries and say 'no' to requests, or if financial incentives or other benefits are on offer. Once again, diabetes teams can play a key role in giving people the opportunity to reduce involvement in, or completely 'retire' from, their EbE roles. This can be achieved both in continually ensuring that the

diabetes team is not making undue demands of individual people, and in ensuring that as a service they are continually seeking to recruit new EbEs, thereby ensuring throughput, an increasing pool of potential volunteers and increasing opportunities for EbEs to form their own support networks.

Conclusion

Experts by Experience (EbE) provide a rich and essential perspective that can be used for the betterment of services, and to enhance the psychological wellbeing of the EbE themselves. Increasing EbE involvement and the number of people involved in EbE activities should be a priority area for diabetes services to maximise these benefits and ensure diversity of views. Diabetes teams have a key role to play in facilitating people to engage in EbE activity; by preparing people to engage in EbE activity, then ensuring adequate support, planning and help with confidence building, teams can facilitate an extremely positive experience for those who engage in EbE activities, which in turn can be an extremely positive experience for diabetes teams. Similarly, by taking steps to avoid tokenism, practical barriers and feelings of overwhelm, teams can minimise the impact of any potential negative barriers.

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