

# **Experience Based Co-design (EBCD)**

### Frequently asked questions

#### What is experience based co-design?

Experience-based co-design (EBCD) is a method for working with groups of people who have experience of accessing support and services and with staff that deliver services to make improvements or design new services together. It draws on knowledge and ideas from design sciences and professions where the aim of making products, buildings or environments better for the user is achieved by making the user integral to the design process itself.

In a health or social care setting, EBCD focuses on how people move (or are moved) through the service and how they experience and interact with its various parts, including front-line staff. Unlike user-centred design and service redesign, the focus of experience based co-design is not only to improve, redesign or create a service, but for people who will receive support and care from the service to work with staff to 'co-design' the experience of using and delivering the service.

EBCD is a participatory quality improvement approach that uses ethnographic methods such as indepth interviews and participant-observation to collect and understand experience.

The EBCD approach has 6 broad steps, as shown below:



#### Find out more at:

https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/

#### Why use an EBCD approach to service improvement or redesign?

Co-design can be a catalyst to shift the balance of power, responsibility and resources to a more equal partnership between professionals and the people who receive health or social care services, by involving them in the design and improvement of their own services.

Co-design of services also has the potential to deliver a major shift in how we provide health, social care and other public services, in ways that make them much more effective, more efficient, and therefore more sustainable and person-centred.

Using Experience Based Co-design provides a clear approach and structure to meaningful involvement of people in a robust and systematic way that has the potential to make public services genuinely better and more efficient. This approach focuses on maximising positive outcomes defined in terms of added value to the service user and staff, rather than merely effectiveness and minimising costs.

#### What costs are involved in an EBCD project?

Implementing EBCD is largely an investment of time to facilitate and co-ordinate the process, but it typically includes the following types of cost:

- Project management/Facilitation (typically 40 percent whole time equivalent (wte))
- Travel expenses (for patients and carers to attend the interviews and events as per NHS or other partner organisations involvement or reimbursement policies)
- NHS staff time (to participate in observations, interviews and various events)
- Event venue accommodation and catering
- Equipment and/or external expertise if this isn't available in-house (i.e. video and/or editing expertise).

#### How is an EBCD project managed?

Ideally an EBCD process will be led by a project team that includes a project manager or coordinator, key members of staff from the service and improvement support staff. This group are responsible for how the project is organised, creating and sharing information about the project, and defining information governance and consent guidelines for the work. This group should also include a key senior person who is committed to the process and is influential to raising the priority within the organisation or across partner organisations.

This project team can be strengthened by including representatives from relevant 3<sup>rd</sup> sector, service user support groups, other public or independent services that may have a role in the care or support journey being explored by EBCD, and public partners.

#### How do you get people involved?

An EBCD improvement project offers a real opportunity for the people who use or deliver a service to get involved and make a difference. However, before people get involved it is important to think about what is needed from them and in what ways being involved could be a positive experience for them. This helps in generating useful communication messages about the project that can encourage people to participate.

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It is also helpful to find ways to make it easy for people to participate. To do this, firstly explore traditional communication methods such as information leaflets about the project, posters, media communications, newsletters and service user groups or networks.

Other approaches can include involving staff who provide care or support in inviting participation. These individuals may be able to simply ask people they see routinely in their work if they would like to participate and provide them with information at an appropriate time.

You may however find that in some instances you must go to where people are to encourage involvement, for example going along to a local parent and toddler group, patient support group, charity organisation, community centre or GP practice.

#### What if the people you need to involve are viewed as vulnerable?

There are already good examples of where vulnerable people have been meaningfully involved in EBCD projects. However, where this is the case there needs to be a great deal of sensitive consideration and thought given during the planning stages about how these individuals will be involved safely, ethically and legally. People being viewed as vulnerable should not discourage us from involving these people as they are arguably in the most need of assistance to have a voice in how services are improved to meet their needs.

Services working with particularly vulnerable groups, such as people with communication needs and those suffering from mental health problems, may choose to draw on pre-existing meetings or groups, or to run drop-in conversation groups for a period of several months or more before commencing the EBCD work in order to support people to contribute effectively and to build trust.

If someone you consider vulnerable chooses to become involved you may need to consider the person's age or ability to consent.

Sometimes the consent of a carer, parent or guardian will be required. When it comes to working with young people and vulnerable adults we would seek the consent and participation of the young person or vulnerable adult along with their parent, guardian or carer. The process of consent, how it is facilitated, and who provides it for vulnerable people, has to be very carefully thought through and planned by the project group. This should be led by local consent and information governance policies.

#### Example EBCD case study

#### How many service users and staff need to be involved?

There are no maximum limits to the number of people from either the service user or staff group that can be interviewed, although where possible 6 interviews from each group is a comfortable minimum number.

You may need to make local decisions based around segmentation of people who access the service and the range of care pathways that people may experience.

Where possible, this process encourages an equal participation of staff and people who use the service within the co-design events. Depending on the ratio of people who use the service there will normally be between 5 and 15 participants from each group at each event.

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#### Why do you film people?

The most resource-intensive stages of the process are interviewing and filming people who receive care or support and then editing the interviews into trigger films. The trigger film is a very powerful tool that establishes priorities, motivates staff, and gives people who have experience of using the service a voice. It enables people to give the message in their own words rather than having others talk on their behalf. On film, people who have experience of using a service often talk more frankly than they might otherwise and this can have the biggest impact on identifying meaningful improvement priorities.

<u>Listen Learn Act: Harnessing the power of personal stories (NES)</u>

Digital story telling guidance (IRISS)

#### What is required for information governance and confidentiality?

It is clear that EBCD is a service improvement model that would not normally be bound by some of the restrictions placed on true 'research'. However it is important to ensure at an early stage this has been discussed and confirmed with the person(s) responsible in your organisation for Research and Information Governance.

The EBCD process ensures that consideration is taken around confidentiality of its participants and that where it is required written informed consent is obtained for all media produced that features the participants.

Your service's organisational experts in information governance and confidentiality should provide the local policy and guidance on GDPR, consent, and involving and filming staff and people who use the service, as well as any information governance documentation that needs to be completed and signed-off by the organisation prior to commencing work on an EBCD project.

#### Basic concepts of Data Protection (GDPR)

#### What if the people who use the service or staff don't want to be filmed?

It is possible to use other methods such as audio or written feedback to ensure the voice of people who use the service and staff are heard within the process. However, these methods do not deliver the same impact within the co-design event, so where possible the use of filmed experiences is encouraged. The trigger film is a very powerful tool and central to the methodology.

#### What if the improvement ideas are costly?

Improvement ideas co-designed between staff and people who use the service are in many cases cost neutral, however during the events where ideas are generated all participants should be made aware of any financial constraints of the service and this supports realistic prioritisation of improvement ideas.

It is essential to involve the right senior staff and to identify a budget-holder at the very start of an EBCD project. This needs to be a person that is central to championing the project at all levels, being able to give or negotiate permissions for people to get involved and give their time, influence from the top and negotiate for required financial support, where needed.

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#### How long does EBCD take?

Experience Based Co-design typically takes between 6-18 months to complete. The six month timeline is based on an accelerated approach which uses national trigger film resources rather than conducting and recording interviews with people currently accessing a service or receiving care or support.

<u>Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement</u>

#### Contact us

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