



Report 2 of 4

**Birmingham Changing  
Futures Together**

# **Evaluation of Every Step of the Way Experts by Experience and Systems Impact**

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Revolving Doors Agency / March 2019



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## Abbreviation Key

Throughout the report we have at times abbreviated the names of groups or people involved, and services, please see below for details:

ES	External stakeholder
IS	Internal stakeholder
EBE	Expert by Experience
BFCT	Birmingham Changing Futures Together
ESOW	Every Step of the Way Programme

# Background: Fulfilling Lives Evaluation

# 1

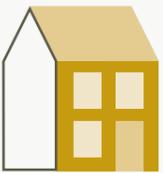
## Birmingham Changing Futures Together

Birmingham Changing Futures Together (BCFT) is one of twelve Fulfilling Lives: Supporting People with Multiple Needs sites funded by The National Lottery Community Fund. The BCFT programme aims to improve the lives of people experiencing multiple and complex needs, across Birmingham. BCFT defines multiple and complex needs as people experiencing two or more of the following: homelessness, problematic substance use, risk of offending and mental ill health. Importantly, the programme focuses on service and system change, aiming to ensure that models and approaches pioneered during the project become mainstream.

Since early 2018, Revolving Doors Agency has led the local evaluation of the Birmingham Changing Futures Together programme. This report details the evaluation of the Every Step of the Way programme. Every Step of the Way is the Birmingham Changing Futures Together user involvement and engagement programme. People with multiple and complex needs are supported, trained, enabled and empowered to participate in the BCFT programme.

BCFT programme aims to improve the lives of people experiencing multiple and complex needs, across Birmingham.

BCFT defines multiple and complex needs as people experiencing two or more of the following:

- 1  Homelessness
- 2  Problematic substance use
- 3  Risk of offending
- 4  Mental ill health

## Every Step of the Way Programme

To enter the Every Step of the Way (ESOW) programme, as an expert, the individual must have experienced at least two of the complex needs listed above in the last 5 years. They can be referred to ESOW by a support worker or a peer but in many cases they self-refer. Once they have met the necessary criteria they are inducted by both ESOW and BCFT. In the ESOW induction they complete the necessary paperwork and also complete a Personal Development Impact Plan (PDIP) which identifies their short and longer term personal and professional goals. Each expert has an Engagement and Development worker who supports them individually through their PDIP.

Initially experts entered the programme for 18 months but this has recently been extended to two years. Each expert is offered opportunities to work with services through the programme with the aim of bringing their experience of complex needs and as service users to services, projects and policies to develop them so that they work better individually and across the system. The aim of the programme is to support the experts in their development while impacting on wider system service change across Birmingham.

'They really appreciate the support that they get from us. They enjoy coming in. And I think it all helps the way that they feel. And our relationship building has been fantastic as well. Because you have to start with that ....You've got to invest in the person before they can actually take things forward'.

External Stakeholder

## Research objectives

- 1 To gain an understanding of the experiences of Experts by Experience in the ESOW programme.
- 2 To explore the impact of Experts by Experience on individual Birmingham services.
- 3 To understand the system wide impact of Experts by Experience.

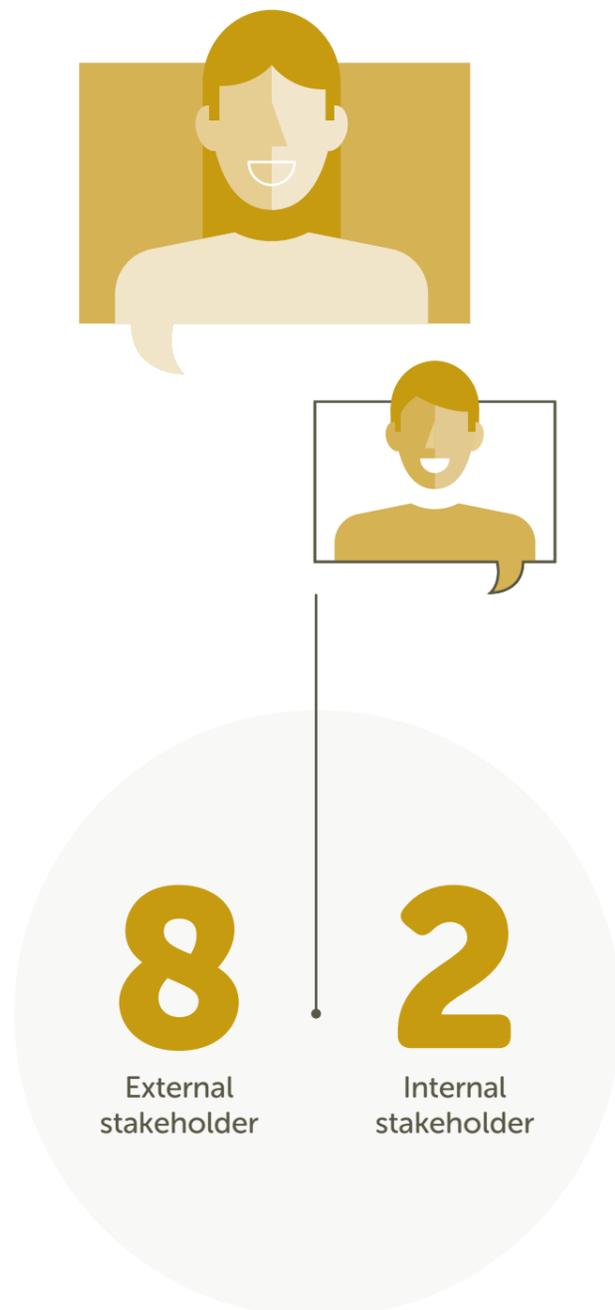
# Our methodology

# 2

## Stakeholder Interviews

Ten semi-structured in-depth interviews were conducted over the telephone with both internal and external stakeholders who had worked with the Experts by Experience. Eight interviews were conducted with external stakeholders and two with internal stakeholders. The two internal interviews were conducted with individuals managing the ESOW programme at either the operational or strategic level. External stakeholders were a varied group coming from small and national charities, an NHS service and local government and offering a range of opportunities to Experts by Experience (See Appendix A for a table describing the external stakeholders interviewed).

A topic guide (See Appendix B) exploring the opportunities offered by external stakeholders, the impact of those opportunities locally and the wider system impact, guided the interviews. In addition, the two internal interviewees were asked about how the programme worked, legacy and their view of impact on services and the wider system. At the start of the interview each of the interviewees were taken through the reasons for the interview, their rights during and after the interview, storage of data and the recording of the interview. They were then asked if they agreed to take part and for the interview to be recorded. All interviews were transcribed by a professional transcriber and analysed for themes. Verbatim quotes have been anonymised to protect the identity of the respondents.



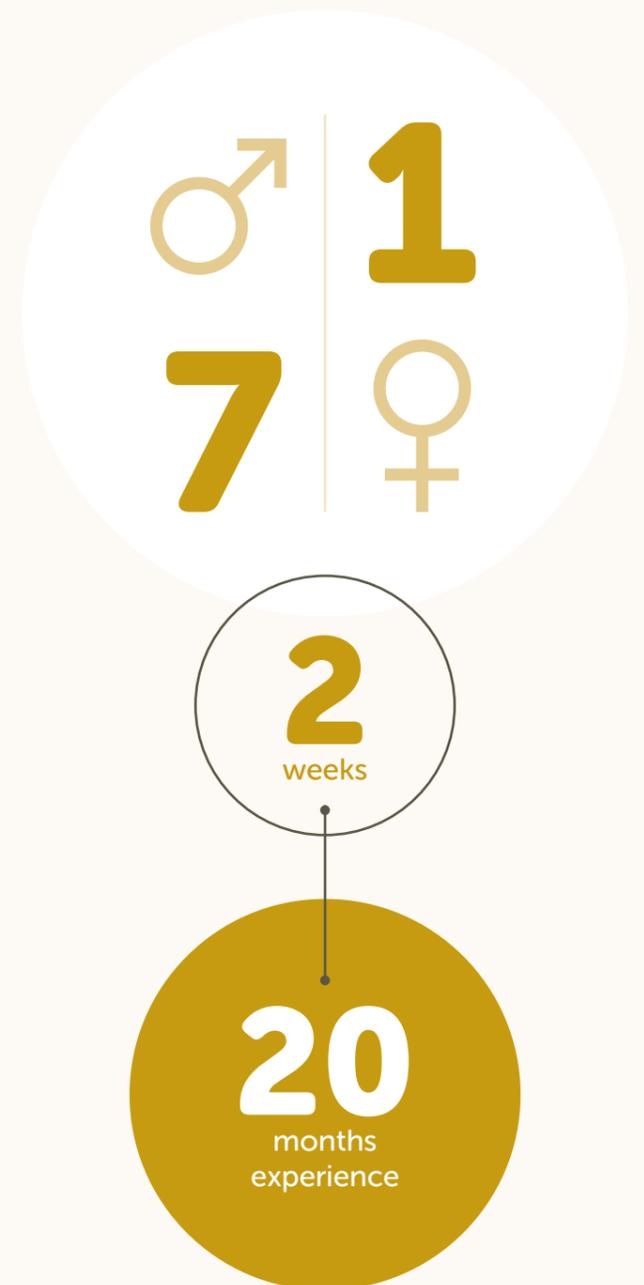
## Focus Group

A group of Experts was recruited by ESOW staff on behalf of Revolving Doors Agency. There were 8 participants in total; all but one was female. The focus group was held in BVSC offices in Birmingham.

The length of time that the participants had been acting as Experts differed considerably ranging from 2 weeks to 20 months. Given there is a cap on the length of time that Experts can volunteer for (24 months), we were able to glean the perspectives of Experts who had been volunteering for almost the entire possible range of time. There were 3 Involvement Champions in the group. Involvement champions start out as EbEs at ESOW, to get to IC level they need to demonstrate that they have a greater understanding of the overall outcomes of the programme. Therefore the opportunities they attend are ones that are on an ongoing basis which requires a more strategic input i.e. at Birmingham City Council, BCFT Core Group etc.

All participants were given information sheets and these were read aloud by the researcher before commencement of the discussion. All participants were given the opportunity to ask questions and signed a consent form to confirm they were happy to proceed. The group discussion was audio-recorded and lasted 74 minutes. It was steered by a Topic Guide, attached as Appendix C. The recording was transcribed verbatim with all proper nouns and other identifying comments removed. Direct quotes have been included throughout this write up, all in italics. Most participants were also volunteering for other organisations alongside ESOW and brought these experiences into the discussion.

The remainder of this report will describe the findings from the analysis of the interviews and the focus group.



# Findings: Stakeholder Interviews

## 3

### Views about how the Every Step of the Way programme works

Overall the stakeholders interviewed were positive about ESOW and in particular about how Experts by Experience were supported. There was a sense throughout the interviews that ESOW was somehow different from similar schemes being run by others.

**"I think they've had a lot more training than what some of ours with lived experience have had. Every Step of the Way has quite good in terms of building confidence and giving them capacity. (ES)"**

**"With Every Step of the Way... it's kind of more structured and opportunities are sort of brokered for people... there's a much bigger group involved. The packages of support that they get from the staff at Every Step of the Way seems to be really thorough and really kind of person-centred. (ES)"**

There was a lot of appreciation from the stakeholders about how well supported the Experts by Experience were. But also a sense that the ESOW workers went the extra mile to ensure that the opportunity was feasible and worked.

**"(Meeting) was in XX and Every Step of the Way people and their members of staff came as well just in case there would be an issue. I mean that was really good and really supportive. We felt very supported by Every Step of the Way with that. Because that lady in particular can be quite volatile." (ES)**

**"Because of (what).... Every Step of the Way do with people obviously...they have a lot of kind of self-awareness and understanding. And they just bring such a level of honesty and openness with them." (ES)**

But that is not to say that there was no criticism of how ESOW operated. In particular, both internal and external stakeholders noted that they did not get more from the opportunities offered to Experts by Experience by exploring what the impact was.

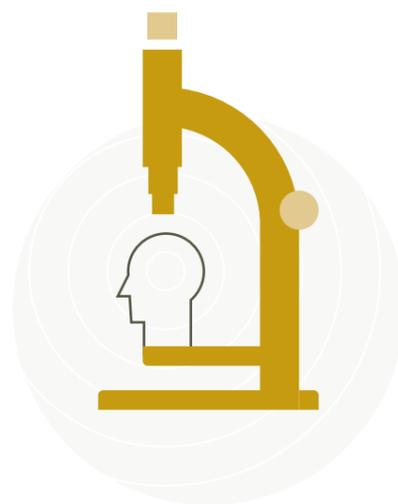
**"What they should be striving to achieve? At the moment I feel like it's very much, we set up opportunities and Experts go. But then that's where the connection ends with Every Step of the Way.....So, I feel like they do the middle work. Get people to an opportunity, but after that they don't see any responsibility in kind of following up and seeing how the co-production went at the meetings."**

**"After that initial one it would be (good for ESOW to say) 'you know they haven't heard from you for a little while, oh what's going on, can we be of any help?' You know just that follow up again you know."**

One issue that emerged was the ESOW brand was not clearly defined. A significant number of the stakeholders interviewed did not remember that ESOW had supplied the Experts by Experience for their opportunity.

**"...The packages of support that they get from the staff at Every Step of the Way seems to be really thorough and really kind of person-centred."**

External Stakeholder



### Stakeholder views of working with the Experts by Experience

There was an overwhelming positivity about the Experts by Experience – their preparedness, work ethic and desire to change the system stand very clearly out.

**"It's as though they've researched things. They don't just do it. They've looked into it and what could be the best effect of it and what's the likely outcome of it.... So, that's always quite useful. The ones I've come across as well are all, as I've said, they're really quite dedicated. They by and large, work hard." (ES)**

**"A positive impact. They worked really quite hard and several of them spent the whole day there and... I mean what I've found is, is I know a lot of the people who go through Every Step of the Way are very motivated, um, very passionate about what they do. And very passionate about making a difference. You know, making things better for others." (ES)**

There was also a clear sense from stakeholders that the Experts by Experience were personally and professionally developing through this work – not surprising given the effort ESOW put into supporting individual Personal and Professional Development Plans – and several commented that they would, in the right circumstances employ them.

**"it's very clear that they get a lot of.... nurturing... and I've known some of them from kind of when they were very fresh into the program and I've seen them ....months and years on ... coming to strategically relevant meetings and they are contributing in an incredibly meaningful way." (ES)**

**"He's going to be a perfect... we would love to employ him after. That is actually our goal." (ES)**

**"I didn't know it was Every Step of the Way. I thought it was just Birmingham Healthy Minds. (ES)"**

This in itself is not particularly worrying as ESOW is part of a much bigger brand – Birmingham Changing Futures Together (BCFT) but no one mentioned BCFT either. Though the Birmingham Voluntary Services Council (BVSC) was known but is seen as a very large organisation to infiltrate to find the person you wanted to connect with.

**"... so, I think if anything, the blockage would have been a little bit BVSC..... because it's so big, I mean it took me a while to find out the right people (to talk to about Experts by Experience)." (ES)**

There was also a sense that they may well be missing opportunities because of the lack of brand awareness.

**"How they promote themselves, especially within the Local Authority (is important), because ultimately the bulk of the services that people will be accessing will be run or commissioned by the city council, so I think a bit of greater integration into the council would be very beneficial...we got a bit lost finding them in the first place, once we'd engaged with them it was fine." (ES)**

**"Yeah, yeah, they can promote more. Definitely they can promote more." (ES)**

Throughout the interviews stakeholders underlined that they did not want the exercise of working with Experts by Experience to be tokenistic. There was a recognition that while Experts by Experience brought their 'story' to the table they also brought a less structured way of working plus an honesty and insightfulness that brought fresh ideas to the discussions.

**"just working with people who've got such interest and insight on the system and the work that we're doing. Just building a relationship with them has been great." (ES)**

**"We want to sort of see how it evolves. What the experts think is the best thing. Although, that freaks me out slightly... ..I've seen how not, kind of, taking over and imposing a plan on people has meant that we've come up with things that we wouldn't have come up with.... it's all been quite emergent and it's been exciting." (ES)**

**"Definitely,(they are well trained) and you could tell because they were all considered and thoughtful, it wasn't just coming up with you know things that were unworkable, they were quite measured so yeah that was good." (ES)**

**"To be honest, this was one of the better groups I've worked with because... the questions ... were respectful ..... I've been in some engagement meetings where people are challenging you as a person.....they were all respectful and all put their points over and everyone contributed." (ES)**

**"just working with people who've got such interest and insight on the system and the work that we're doing. Just building a relationship with them has been great."**

External Stakeholder

### Stakeholder views of the impact of working with the Experts by Experience

The interviews were very positive about working with Experts by Experience and stakeholders were easily able to articulate the impact they could see on the Experts by Experience themselves. However, when questioned about the impact on services or their own work although they really wanted to describe meaningful impact, most found it difficult to pin down what the tangible outcome of the work had been. There were a few small process examples. One stakeholder described changing how a meeting was run as an impact and another described changes to the methodology of undertaking a survey.

**"Whenever there's an expert by experience present, officers will do their utmost to kind of cut back on jargon and use very plain English."** (ES)

**"There are a lot of changes to be honest with you. I mean some of them were only small. Some of them are bigger. Our service user survey gets changed due to the consultation that we have.... it was suggested that we have an online version rather than the paper version. So, it changed the survey monkey. We are now getting 43% return rate as compared to 23% with a paper survey."** (ES)

Others acknowledged that it is perhaps too soon to see impact and that just the fact that Experts by Experience were involved was an impact in itself. While others could identify changes to how they worked with service users.

**"I feel it's yet to be determined. But it's at least meant that there has been expert involvement throughout the writing of that strategy. So, the strategy hasn't been released yet ... we'll know more once it has, but there is at least... expert involvement in the writing of it."** (ES)

**"And we'll meet at a place which is best for the patient. Sometimes it's in the hospital around their ward beds. So, when they're going out to be discharged, everything's already set up and in place. Oh, yeah definitely. We have changed our way of thinking."** (ES)

**"His feedback has made so much positive changes towards our paperwork. It's really good. Only he could have given us that insight. I couldn't... I don't think we could have done that ourselves."** (ES)

Having said that there was some evidence that the Experts by Experience were making an impact at a potentially higher level. For example, the involvement of experts in discussions about poverty and education policy led directly to one school making changes to its uniform policy. This particular example may well have further impact as its findings have been circulated to schools across Birmingham.

**"And there a school....it's a direct result of what we have talked about... regarding the cost of uniforms and how difficult it is. They are going to source their uniform from the local Sainsbury's."** (ES)

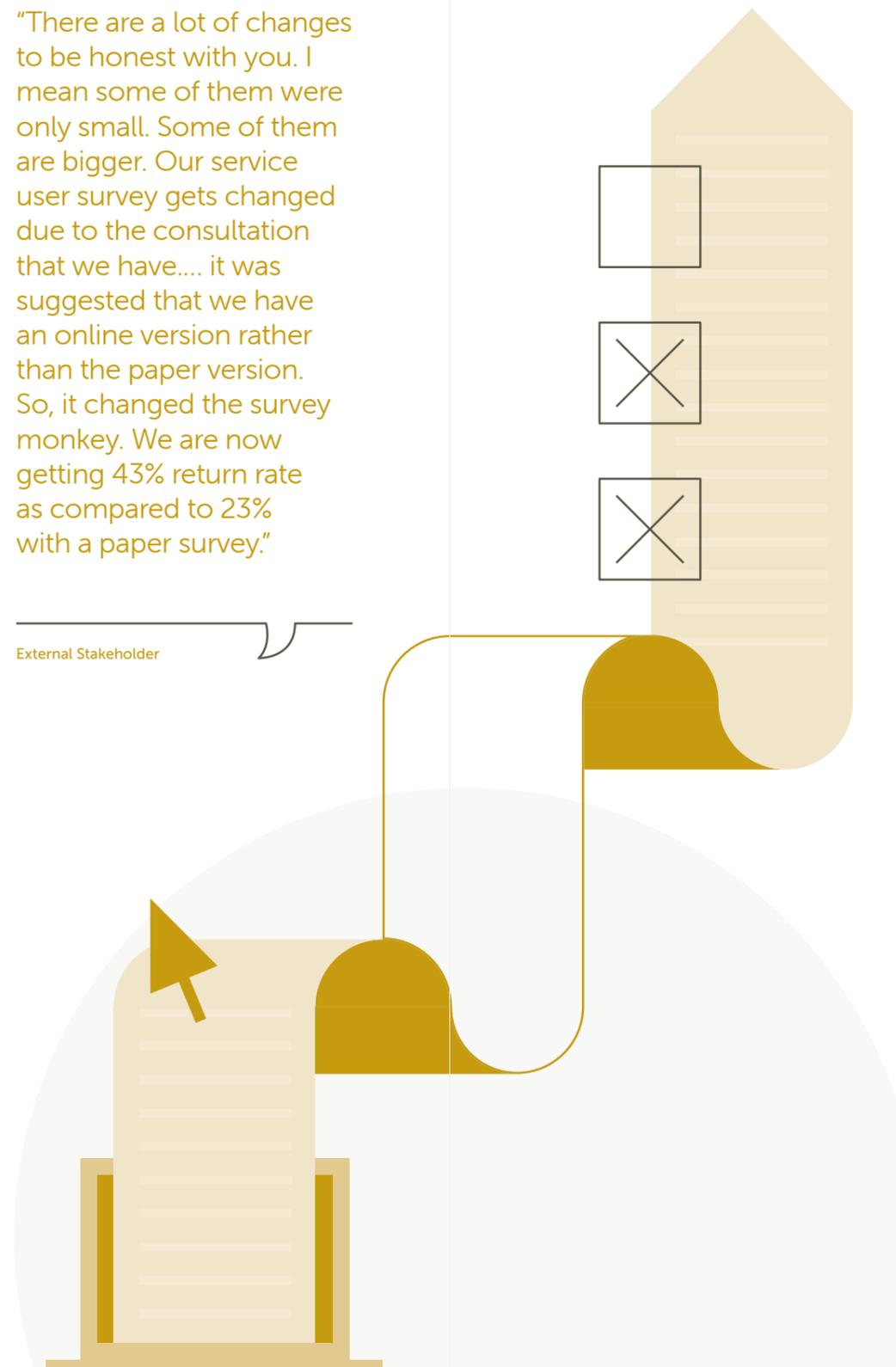
**"Talking about their experiences and a film (we developed with Experts by Experience) was shown... (to) a head teachers conference in Birmingham... and then that would be pushed out further by the guy who is the head of the Birmingham Education Partnership. He got a copy of the films now he can push the out to all of the head teacher's...Well I think that we would see that as a very positive outcome from the opportunity that we had to present these films... you know rethink what you are doing and how you are doing it with the kids who fall through the gap."** (ES)

Another had worked with Experts by Experience to judge public health initiatives in a Dragon Dens style competition where the stakeholder believed they had real influence on what was commissioned.

**"...the experts by experience ... heard out a load of commissioners and senior managers from various teams pitching proposals to rectify a whole series of things around complex needs and homelessness etc. ...at that Dragons Den scenario. (It)really did kind of steer public health (in) a number of initiatives so they, the experts by experience flatly rejected some of the proposals that were going forward ... that the authors were hoping would remedy situations and they were just very clear, that wouldn't work for me, I can only speak for myself, that wouldn't work for me for these reasons... and that then broke out into workshops and generated work**

**"There are a lot of changes to be honest with you. I mean some of them were only small. Some of them are bigger. Our service user survey gets changed due to the consultation that we have.... it was suggested that we have an online version rather than the paper version. So, it changed the survey monkey. We are now getting 43% return rate as compared to 23% with a paper survey."**

External Stakeholder



**streams so that, that was one example where that direct impact really did go into very real work streams."** (ES)

Many of the stakeholders spoke about their belief in having Experts by Experience built into their work. One stakeholder, who had never worked with Experts by Experience before, was now promoting it throughout their large charity as the way to work.

**"I think it should be embedded more in the council really."** (ES)

**"I work for a company who've got loads of different other organisations attached to us. I'm going to my meetings with my other manager and my peer. I'm sharing this information (about) how much he benefits our service...., they're seeing this person... the Peer Mentor. So, they're thinking, 'Oh, this is a really good idea'. They've asked me, how did you get on board? How did you train him? And I've said, 'We've used Every Step of the Way'."** (ES)

While external stakeholders struggled to articulate impact, internal stakeholders were much clearer about what they saw as the impact of Experts by Experience.

**"Where the Expert by Experience are going out on visits with In-reach Outreach, to actually utilise their lived experience to engage with potential clients. Those that are entrenched, that have not got a lot of trust in services. The experts are saying, 'Look, we want to help. We want to be part of**

**something that can change your future'. And I think that's having actually a really positive impact on the prospective clients that we're getting through the Police system. ... Sometimes the Police Officer sitting there saying, 'You know, you should really access services. It'll be good for you'. Is completely different to somebody has actually accessed drug treatment services."** (IS)

**"But their impact has been huge....we've had experts who have come into the service quite, obviously new and they've taken part in opportunities like going to the House of Lords where they've spoken directly to MP's about some of their lived experiences. There's just been a range of opportunities that they've got involved with."** (IS)

**"Beyond the Basics to be honest. Experts were crucial ... we were meeting every week and discussing the whole process of Beyond the Basics. It is about that step gap once they've had all the help from services and they're now letting them go. And you know, they made a very conscious decision from the start, that it's not about support work. It was more a guidance role. But they actually set the boundaries and the reasons they gave for it were really valid. They wanted people to no longer have that handholding...they wanted somebody to empower them. And I think if the Experts weren't involved with that at the start, it could have gone very differently."** (IS)

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Internal Stakeholder



## Stakeholder views of the system impact of working with the Experts by Experience

If articulating the impact on their own work was difficult describing system impact was even more difficult. To some degree this is to be expected. The early years of a new programme are about getting processes right and that is where attention will be. As a project beds down impacts should start to emerge.

**"If I'm being completely honest with you. I know the value out there. But if you would say to me to quantify it, I wouldn't know where to actually start by saying. 'You know what, to an individual, their lived experience story will have had a massive impact. But, on systemic change, we've yet to see how that one voice has fully changed the landscape.'" (IS)**

**"It's kind of ongoing. We don't know yet the final impact of that." (ES)**

Yet there was little in the interviews to suggest that stakeholders had an understanding of what systems change meant in this context. Both of the internal stakeholders expressed the view that 'hearing' the Expert by Experience voice through the opportunities offered was a major system change in itself.

**"I think they've definitely had a really valid input into all of the work streams. So, from starting off at recruitment, Experts are on the panel. Their opinion matters. Bringing the right people into the team who are going to lead the**

**team. They've got a real voice. It's really important that their voice is heard. And then even from each work stream. Every work stream has Expert involvement at some stage throughout it. From In-reach Out-reach, it's direct expert contact." (IS)**

**"Change couldn't actually happen without our experts because they are the voice. These are people that are still.... sometimes very much in their own recovery. They're much stronger in their recovery, but they are still in recovery.....But, they've made huge impact in terms of their voice. Taking part in these opportunities..... in terms of changing services in Birmingham for the better" (IS)**

Another stakeholder felt the development of the peer mentor model in services other than BCFT was evidence of system change.

**"I think that's been the most measurable systems change that I've seen because it's meant services outside of Fulfilling Lives are commissioning that model and having Peer Mentors and Lead Workers in their service. So, that, yeah, that's really direct impact in Birmingham." (ES)**

At an individual service level there is clearly evidence that Experts by Experience has shaped services and service delivery. There is some evidence that this is beginning to trickle

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Internal Stakeholder

**"It's really difficult to isolate an instance where, you know expert by experience said this and subsequently we did... yeah... because nothing happens in isolation, so it would be a contribution with a group dynamic but clearly, clearly things have been influenced by opinions."**

External Stakeholder

out across the system but as yet it has not had enough traction to impact the system more widely. Capturing impact was a key theme of all the interviews.

**"I think that captures it (would be) great to be honest because I think, it's that bit of, how do we capture to know? ... But it's making sure that the stakeholders that we keep constant contact with them. I know that there's gaps and flaws within what we're doing at the moment. There's areas of things that we need to pick up. That we need to be better at." (IS)**

In many ways, asking stakeholders about systems impact felt like a surprise question that they could not really answer.

**"Difficult for me to say (about system change) because I'm not involved enough, but I'm sure there could be." (ES)**

**"I think the different elements of the programme that involve experts can seem to be an outsider (to the programme), it may be totally different, because I've said, I don't work for them. So, there may be a plan around this." (ES)**

This may be explained to some degree by the programme, while established, is still young. Services using the Experts by Experience are also invariably looking at that individual project or issue rather than the wider system. As such, some work may be needed to focus on what systems

change is for BCFT, but this must filter right down to the frontline for culture to change.

**"I think there never has been any focus on it to be honest and I think that's partly due to everyone on the project. You know, the first four years is about involving... getting experts on board. Getting them, you know, just involved. And now the culture is shifting. Which means that the culture needs to change...we now need to look at what outcomes we want to get. What the system change actually looks like and how we can shape towards that outcome." (IS)**

The one key theme that did emerge from the interviews is how difficult it is to capture quality evidence of systems change systematically without adding more burden. It certainly is not undertaken on any regular level and so is not part of the consciousness of stakeholders around this work.

**"I do think time would really help with that.... whoever is going to benefit from involving experts should dedicate equal time resource to it where they have time to build relationships and spend time having difficult conversations and reflecting when things haven't worked and... because a lot of the time I think people have sort of parachuted in to consult on something.... but I think**

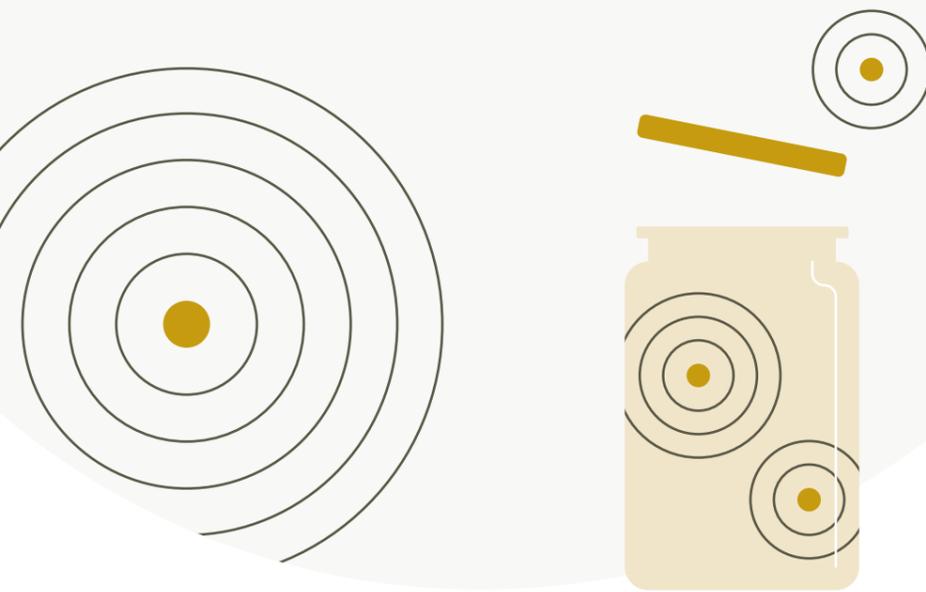
**there's not then time for that reflection afterwards to say like, 'what do we think the impact was? That's one thing I think would help. Kind of taking the evaluation of it more seriously.'" (ES)**

**"(It's), a bit of a bear trap really is that it's often very difficult to ... just capture and document these you know little instances where there's been a change in direction or a change of thought or a change of opinion... perhaps leading to... you know something specific in a policy." (ES)**

**"It's really difficult to isolate an instance where, you know expert by experience said this and subsequently we did... yeah... because nothing happens in isolation, so it would be a contribution with a group dynamic but clearly, clearly things have been influenced by opinions." (ES)**

**"That is effort... the big problem for you in trying to identify impact is A, it's early days, but B, it's not coming back to you in a form you can digest." (ES)**

**"Yes, I think with the help at the programme. It is slow, we all know that. We know that we can't evidence, you know, system's change. Probably not even some of it in the life of the programme." (IS)**



"I think we need to start capturing (impact) better. Because like you say, there's things going on ... there've been changes but we don't know what they are..."

External Stakeholder

## Legacy of the Every Step of the Way programme

The interviews with both internal stakeholders focused on the potential programme legacy. Though one external stakeholder also felt legacy was an issue to address, particularly in terms of how it supported the Experts by Experience going forward.

"I think it's just now, at this point in the project..... it's about all the projects, kind of turning their eyes to what comes next and making sure that everything they have done has...a lasting impact ...how do we get the experts ready for what comes next and ensure that everybody doesn't just kind of drop off the radar once Every Step of the Way isn't there." (ES)

For internal stakeholders keeping the spirit of the programme alive was important.

"My only fear is that, when the programme ends, I hope it just doesn't become a tick box. I'm hoping that services will go on to add... keep that value alive." (IS)

"I think the expert pool that we have, has had a massive difference on people's ways of thinking....embedded, kind of different ways of approaching things which I think is massive. So, for example,

even the fact that Birmingham City Council say that, you know, we want somebody with lived experience to be part of any standards that we put together, would have been unheard of before. Changing Futures has really championed it. So, I think there really is a legacy that could be made in regard to the co-production side of things and the Experts using their voice to champion it I suppose." (IS)

In this scenario capturing impact at both service and system level becomes paramount to evidence why the ESOW programme has value.

"I think we need to start capturing (impact) better. Because like you say, there's things going on ... there've been changes but we don't know what they are. It kind of stops at the door if you get what I mean. The expert's gone through the door. The door's shut behind them. We're all a little bit oblivious to what's going on." (IS)

Birmingham Mind are keen not to lose what they have built in ESOW. To this end they are in the early days of developing a Community Interest Company which will build on the foundations ESOW has achieved.

"We, don't want to sort of lose that (what we have achieved) so we are thinking of working with the Experts to set up a Community Interest Company.... It's sort of like being consultants so to speak. Because they are now, you know. They are consultants and they don't get paid.... Obviously well before the programme comes to an end. Because we see the value and we don't want the voice just to be lost." (IS)

In the case of both internal stakeholders the ambition was to normalise Experts by Experience in the workplace.

"I think what I'd like to see is that lived experience is just the norm in a work place. That it isn't something that's extra special and extraordinary. It's just part of, within voluntary organisations, within statutory organisations...if someone is doing something about a community, that lived experience is part of that discussion. ...In ten years' time I'd like to see it embedded that it's now the norm. Not that it's unique." (IS)

"Because of (what).... Every Step of the Way do with people obviously... they have a lot of kind of self-awareness and understanding. And they just bring such a level of honesty and openness with them."

Photo credit: Elliot Brown, www.flickr.com/photos/elli-brown/

External user - Views about how the ESOW programme works , See page 8

# Findings: Focus group

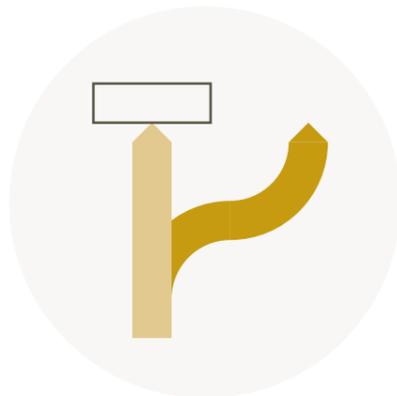
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It had been previously found that Experts by Experience found it difficult to identify the impact they had made on the work of other organisations (Birmingham Changing Futures Together Annual Report, 2017). This focus group was designed to consider whether this remained the case.

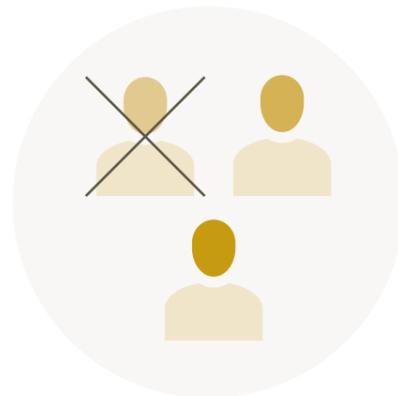
## Areas considered were;



The extent to which Experts by Experience felt they had made an impact on Birmingham Changing Futures Together Project



The extent to which Experts by Experience felt they had made an impact on wider systems change



Any challenges that Experts by Experience had experienced, including the composition of the ESOW team.



**“Even the title, Experts by Experience gives you a boost, makes you feel less of a victim.”**

Expert by Experience

The purpose of this focus group therefore was not to explore whether Experts by Experience felt empowered, supported and as though they were developing professionally and personally as this data has been captured in other learning and evaluation streams. However, it was clearly something that participants felt very strongly about and it was a running theme throughout the group discussion. It is important to raise this, as it is to the credit of BCFT, that the Experts were so intent on praising of the ESOW team and proud of their own progress.

**“Even the title, Experts by Experience gives you a boost, makes you feel less of a victim.” (EBE)**

**[my troubles] were not for nothing (EBE)**

It was a clear theme that Experts by Experience valued the fact they were part of something ‘bigger’ than regular service user involvement in something like substance misuse, or another single issue service. Experts by Experience welcomed the way that the services were trying to come together in Birmingham because they had personally needed multiple services concurrently. While service user involvement is increasingly being adopted within organisations, they feel that ESOW reflects a unique opportunity for service user involvement.

**“So, if you’re involved in something to do with addiction, it’s going to be that. If you’re involved in something to do**

**with mental health, the focus is going to be on that. So, you may dabble in the other areas, but this is the one, kind of, place that covers everything and nothing’s undervalued. Nothing’s, kind of, ‘Ooh, that’s worse’.”(EBE)**

The role of Experts by Experience was mostly perceived as helping other service users’ voices to be heard, ‘the invisible’ voices. However, Experts by Experience talked about other parts of their roles being to advise service users of what is available for them in Birmingham and to change user perceptions in big organisations. It is also to advise practitioners and managers of how services ‘feel’ and ‘work’ for users.

The Experts by Experience were proud of the training they have had whilst at ESOW; “we have the best training”, which they feel has broader implications than personal and /or professional development. A couple of examples were given, including informing other services of training on offer to ensure all services have the opportunity to access up to date and relevant training to enable them to work with service users;

**“And because I know about [mental health first aid training], I can then suggest that to [name given] who’s in charge of the choir. And you know, because she’s looking at volunteers getting trained.” (EBE)**

## Impact on Birmingham Changing Futures Together

In terms of the impact the Experts by Experience have had on the programme itself, it was difficult for participants to define this explicitly, often referring to wider opportunities or impact. They did offer examples of when they had been involved with various parts of the programme but without specific detail of how this involvement had been impactful.

For example, two of the Involvement Champions had been involved with the local evaluation, firstly by sitting on the recruitment panel and secondly through receiving training in peer research and going out to interview service users. They recognised the value of their involvement within the interviews as it put service users at ease;

**"We explain to them that we have been on the same side of the coin as them. So, there's already a connection." (EBE)**

When praising the ICAT computer system which is currently being rolled out within Birmingham Changing Futures Together, they questioned whether Experts by Experience had been given a voice in its creation. In fact, there was Experts by Experience representation when ICAT was first being discussed and the IT specification was being created. However, several years have passed and the Experts by Experience involved have since moved on so the current Experts by Experience were not aware of this involvement.

One recent opportunity given to the Experts by Experience was in the construction of new values for Birmingham Mind, and this was raised as being something of real worth;

**"They've um, five core visions and values or values of Birmingham Mind and they've asked us to give our input into how to talk about how we see the person. So we're working on that at the moment. How we all visualise respect. How we all feel about respect. What is it?" (EBE)**

The Experts by Experience spoke a little about ESOW funding coming to an end in 2021. Currently, they are participating in daily involvement opportunities and want to continue with this. They are currently working together to see if they can form their own group and for there to be a legacy beyond the life of the project. This was also referred to by an internal stakeholder when discussing legacy.

**"[Expert] got in touch with some kind of Commissioner or somebody and we're thinking about keeping ESOW up and running." (EBE)**

Experts by Experience spoke in an aspirational way of a desire to have more involvement with children's services and wanting to support mothers who were experiencing challenges from mental ill health, substance misuse, homelessness and criminal justice. It is likely to have been influenced by the composition of the group, in that the majority were mothers themselves, some of whom had lost their own children.

**"And I've always felt, in fact I left Social Services because I felt that people weren't being listened to and they wouldn't let us do any work with families. You know, around prevention. And then, I went on the other side of it myself." (EBE)**

When asked if this idea might translate to action, they all agreed that if they raised it with the ESOW manager they would be supported. However, at that time they had not taken it further. It was extremely positive that Experts by Experience felt very supported as an independent group at BCFT, and that if they had an idea for where to make an impact they would be confident to take this forward, with one participant saying; "There's nothing I cannot do". Another said;

**"We have an Expert by Experience meeting basically, so we can bring that together and as a collective, we can say, but believe me if there's an opportunity. If there's a way of taking it forward, we'll be able to do that with ESOW backing." (EBE)**

There was an example given of an idea stemming from work undertaken with projects within BCFT. The team had been working with the Rough Sleepers Team and had been working in hostels and getting to know the service users. They have identified some inherent problems and are currently in the process of seeking to inform practice and to affect change.

**"We explain to them that we have been on the same side of the coin as them. So, there's already a connection."**

Expert by Experience

**"They've got no money. They don't want to hear what people really think because if they have to listen then they have to do something about it."**

Photo credit: Elliot Brown, www.flickr.com/photos/elli-brown/

Expert by Experience - Findings: Focus Group, Challenges, See page 23

## Impact on the wider systems change

Overall, Experts by Experience were excited by the extent to which they been able to speak with services about their own experiences and were excited by the possibility for change. They were proud of the sheer reach the ESOW has, with the hope that some of their contact will translate into real change. A number of organisations or types of professional were discussed within the focus group as having worked with Experts by Experience from ESOW including; Department of Work and Pensions, Prison Reform Trust, the Police Service, Psychiatrists, GPs, Youth Crime Commission and Making Every Adult Matter. They also discussed upcoming opportunities of visiting a prison and speaking with the Home Secretary.

Some examples have been included here where there appeared to be impact on a stakeholder who had attended an Expert by Experience presentation;

**"We did something in Coventry where there was a few Commissioners, Head of the Police Service were there and everything. There was only a few of us. It was at a table like this. Yeah, that was it. A board. And the copper actually come over to me afterwards and thanked me for my speech because he said, 'I'm quite bad at that'. He goes, 'Because I can hit front line situation and just look at the shit that's going on around'. Instead of looking at what that person's going through and what his potential is. And he thanked me. He said, 'I'm going to try and change my way of working'."** (EBE)

**"I went down to London to the Houses of Parliament and I got to go and sit in on the House of Lords. What was amazing was that in that break, a top Psychiatrist came to me from London University and he says, 'You know what, you're absolutely bang on, right'. And even the DWP came to me and he says. 'Well, what can we do to make things better?'"** (EBE)

**"I went myself and I gave two talks there and it was really amazing. A couple of weeks ago, somebody came to our... A Police Officer came to our building. He said, 'I absolutely loved your talk'."** (EBE)

**"We had a human rights Lawyer come to one of our EBE meetings a couple of months ago and she's brilliant...she's really trying to lobby where EBE's are going to be buddying hierarchy officials, but on the same pay."** (EBE)

As well as impacting on individuals who attended presentations, they also referred to a couple of real changes they had seen happen within Birmingham due to ESOW.

**"Just going through the homeless with the In-Reach, Out-Reach, it's to reduce the amount of numbers of clients (who) keep phoning 999. So, let's say in a certain area in Birmingham, a Police Station. We'll go out to the Police Station and we'll actually go and visit some people in their home when they're like, there's domestic violence issues or alcohol or substance misuse but, you know those individual clients that keep ringing up 999? So, what our aim here at In-Reach, Out-Reach is to go out, see if we can try and get that individual signed up to some other kind of support to reduce the amount of 999 calls being made. And that's with the Police and the Police have agreed to work."** (EBE)

**"I was speaking at a Police conference. A doctor approached me for some information about the organisation that I was referred to here through. So, I gave him my information. He then went back. Liaised with the In-Reach, Out-Reach. There's a bit of an intervention. Sort of In-Reach, reaching out to people that are on certain medications that don't really want to be on that medication any more. Can they be outsourced to a different organisation? Can they come through our doors? Can they get any support? That was a massive [achievement]..."**(EBE)

One Expert by Experience told us of a time when she reconnected with one of the individuals who approached her after a talk. She asked him "Have you implemented anything into your daily life as a Police Officer when you go out" and his answer was 'I look at people differently', which is a powerful message of hope regarding the level of impact the Experts by Experience have.

**"I went down to London to the Houses of Parliament and I got to go and sit in on the House of Lords. What was amazing was that in that break, a top Psychiatrist came to me from London University and he says, 'You know what, you're absolutely bang on, right'..."**

Expert by Experience

It was noticed that most of the opportunities the Experts by Experience chose to speak about in the first part of the focus group were not only within Birmingham but were further afield, such as in Leeds, Manchester, Bristol and Coventry. Experts by Experience felt that this was because ESOW sought change in more than just Birmingham and that these opportunities were good for the Experts by Experience professional development. One Expert felt that it was a reflection of the changes ESOW had made in Birmingham;

**"I think it's because, like, it's... what's happening is that stuff's working so well in here and Expert by Experience and IC's [Involvement Champions] are so passionate about things that have impacted services here that you're kind of trying to spread the [good work]"** (EBE)

Experts by Experience talked about working directly with service users, particularly in hostels. While this may not be affecting whole systems change, the Experts considered it as an important part of the role in terms of affecting individual service users' connection to systems, one of the aims of BCFT. It is also about spreading information throughout a well-connected network about the services on offer, something that was missing for many Experts by Experience when they were accessing services themselves.

**"I wasn't even aware until I walked in the rooms of the meetings, how many treatment centers there were in Birmingham. How many services were available in Birmingham. I was never told. ... I'm hearing about all this now, that I'm involved. I never heard about it when I was really at the depths of the depths."** (EBE)

There was an appreciation that the Core Partnership group were working well together within Birmingham Changing Futures Together, especially with the arrival of the iCAT computer system (which they Experts by Experience felt should become nationwide). However, Experts felt that the wider partnership group needed to work more collaboratively with the project. Indeed, there was no reference to them even being in a wider partnership with the project, more that they were unconnected services. This was an area of work that Experts by Experience were heavily involved in;

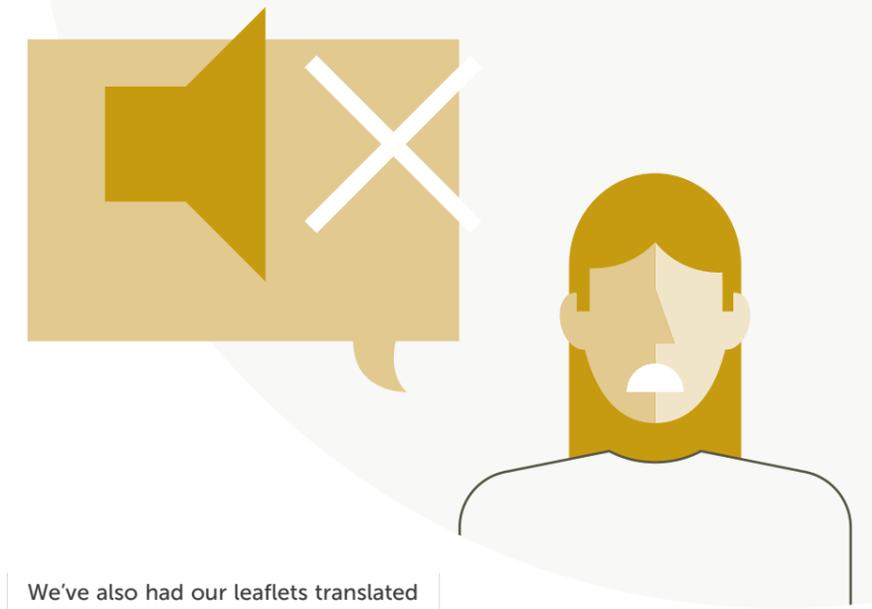
**"It is World Mental Health Day tomorrow, and we are doing a stall at a big, big conference and there's going to be lots of other stalls from different organisations."** (EBE)

Overall, Experts by Experience were excited by the extent to which they been able to speak with services about their own experiences and were excited by the possibility for change. They were proud of the sheer reach the ESOW has, with the hope that some of their contact will translate into real change.

“just working with people who’ve got such interest and insight on the system and the work that we’re doing. Just building a relationship with them has been great.”

Photo credit: Elliot Brown, www.flickr.com/photos/elliottbrown/

External Stakeholder- Stakeholder views of working with the EBE, See page 9



### Challenges

Despite the positivity felt about ESOW and about the impact that can be made through this part of the programme, Birmingham City Council was perceived to sometimes be a barrier to absolute change in Birmingham. Experts by Experience felt that they were not always welcome and that the council was not working as effectively as it could with people with multiple needs; although the experts recognised that the council faces a very significant financial challenge. Never-the-less the perceived reluctance of Birmingham City Council to listen and respond to the views of experts was disappointing given the overall positivity and inclusion experienced elsewhere in the system (including Coventry City Council).

**“They’ve got no money. They don’t want to hear what people really think because if they have to listen then they have to do something about it.” (EBE)**

Another challenge to ESOW was its diversity, but they responded quickly, “it’s not for want of trying”. Experts by Experience were keen to stress that they would like to broaden their reach but struggle to recruit people from certain ethnic and religious backgrounds. It represents a challenge because Experts said the programme should not recruit people who are not ready, or lack particular skills simply because they fill a quota. They spoke of previous experiences (both personal and vicarious) where they have had to suspend Experts’ involvement due to them having difficulties. They have however been working with different communities, including those in recovery and the Muslim community directly, and are trying to collectively address this issue;

We’ve also had our leaflets translated into lots of different languages to target. Obviously, there may be a barrier with language if we did recruit someone who, let’s say, was Polish. But we would overcome that. We’ve already talked at the EBE meetings about how we would do that. How we could include someone who’s got a language barrier. And it would be a learning curve. (EBE)

I think we’ve all got a responsibility. I don’t think that should come from the paid staff. I think it’s about us. I mean, you know, when I’m at SIFA [Fireside], I’m constantly thinking, ‘this person might be good EBE. Shall I put them forward (EBE)

As mentioned, Experts by Experience spoke about the future of ESOW and about their aspirations. They felt that for systems change to really take place, they needed to do more work at a policy level. This was already happening to some extent in terms of speaking with staff from government departments such as DWP, but they wondered if their influence was being diluted by working with those on the front line.

**It’s alright for us talking to, you know, practitioners and those kinds of organisations, but you know, they’re grounds men aren’t they? They’re the ones who are delivering the service. The way the services are run...[,]... really it needs to be higher level. It needs to be towards MPs (EBE)**

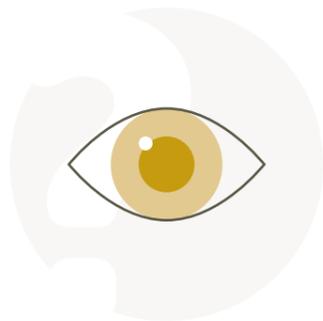
“They don’t want to hear what people really think because if they have to listen then they have to do something about it.”

Expert by Experience

# Discussion and Learning

# 5

## Learning points to consider:



### Making ESOW more visible

Overall the ESOW programme is seen by stakeholders as a positive initiative. Stakeholders described Experts by Experience as well prepared and engaged in activities. ESOW was viewed as supportive of the Experts by Experience and making real efforts to develop them personally and professionally. However, the ESOW brand was not well known across the piece with few of the stakeholders knowing what it was about. As a result, there is potential for opportunities to be lost to the Experts by Experience (and to the system) because it was sometimes difficult to know who to speak to about Experts by Experience. More importantly for ESOW is that as a result they are unlikely to be attracting a feedback loop of information that can help improve the programme and also gather the impacts they are achieving with the Experts by Experience. ESOW brand needs to be more visible and identifiable as the place for Experts by Experience in Birmingham.



### Raising an awareness of what system change means

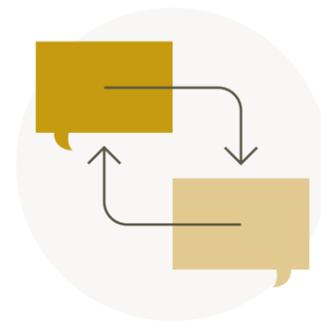
While the interviewees could talk about system change it was clear that there was not a deep understanding about what it meant in general and specifically for Birmingham. The Experts by Experience were equally unable to see how they impacted beyond individual projects. But because the Experts by Experience covered different parts of the system they were aware that their reach as part of ESOW and felt that their access to influencers had more depth when compared to other involvement opportunities. So while they could not yet see how they impacted at a system level they were aware that they were occupying a space where they could influence. Any awareness work needs to cut across all of the BCFT services and all levels of staff including the Experts by Experience.



### Capturing impact of ESOW

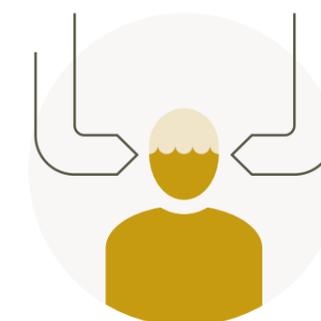
Most of the interviewees and the Experts by Experience when asked about impact found it difficult to articulate outcomes as a result of the work. All were positive about the opportunities they were offering and taking part in. Yet when probed impact was uncovered – often at a process or frontline individual service user level. These impacts are important to the development of ESOW as a service but also to the wider programme when attempting to understand the overall impact of BCFT. Most of the stakeholders had not thought of feeding back impact to ESOW when asked and most said they would go back to ESOW with their thoughts – so there does not seem to be a resistance to the idea in theory. ESOW needs to develop a methodology which systematically captures the learning from each impact as well as the outcome of these pieces of work through an impact feedback loop which involves the stakeholder and the Experts by Experience.

This report is intended to capture how stakeholders engage with the ESOW programme, explore its impact at both a service and systems level and capture lessons for the programme going forward. It also explores Experts by Experience own views of their impact across the system. The following is an account of the key issues to emerge from this research.



### Using the impact feedback loop

The feedback loop should not be seen as a static tool – because rarely are impacts immediate. Rather it should be a tool that has the possibility to revisit individual opportunities on a regular basis to capture how (or if) individual opportunities have changed services, policies or the system.



### Preparing Stakeholders for working with Experts by Experience

Thinking about the system impact of Experts by Experience is not in the consciousness of stakeholders. It might help to make it a regular part of opportunities if it was included in pre-briefs with stakeholders prior to opportunities with a definition of what it means including specifically for Birmingham. This would also place the issue at the heart of opportunities for the Experts by Experience.



### Quality controlling opportunities

ESOW have clearly sought out a breadth of opportunities for Experts by Experience with a good variety of one-off and longer term opportunities. As the programme is now established, it might be timely to quality control those opportunities and choose which to engage in as a consequence of their ability to impact on the system. This would mean ESOW vetting opportunities more deeply. This would potentially achieve two things: heighten the value that Stakeholders place on working with Experts by Experience and two allow ESOW to be more strategic about their role in the system change agenda.

# Appendix A

## External Stakeholders and types of Opportunities offered to Experts by Experience.

Stakeholder	Opportunity	Length of Commitment
Local Authority	Training and participation in mystery shopper exercise to explore how local businesses respond to individuals with multiple complex needs.	Training plus one-off exercise
Liaison and Diversion Service	Participation in monthly meeting for those with multiple complex needs. Setting agenda, answering questions in the meeting.	On-going
Anti-Poverty Charity	Participation in regular round tables with influencers from a range of backgrounds to influence decision makers in poverty policy.	Every two weeks. On-going.
Local Authority	Feedback on developing mental health policy.	
Homeless Charity	Recruit local peer mentor to work with clients, develop internal process and support policy development.	On-going
Coalition of National Charities	Setting up of local Expert by Experience group.	On-going
Women's Charity	Presentation by Expert by Experience.	One-off
Mental Health Charity	Mixture of opportunities including co-production of national mental health awareness conference and be-friending service.	Mixture of one-off and on-going

# Appendix B

## Birmingham changing futures together – internal and external stakeholder interviews

### Topic guide

#### Introduction

- Thanks for agreeing to take part in this interview today
- Read through and sign consent form
- As the consent forms explains, we are doing a piece of research to find out about the emerging impact of Experts by Experience (EbE) across the Birmingham Changing Futures Together project
- **For EXTERNAL STAKEHOLDERS** We are going to talk a bit about how your organisation has used EbE and how that has impacted on how you deliver your services. We will also talk a little about whether you think EbE has had an impact on any wider systems change in Birmingham. Lastly we will discuss your recommendations for the development of EbE going forward.
- **FOR INTERNAL STAKEHOLDERS** We are going to talk about how you feel EbE has been taken up, what has worked well (or not), what legacy you think will be left behind and whether service user involvement can be sustained after the ESOW project.
- We will be recording the session, *point to recorder*, so that we can remember everything that you tell us – but it's important for you to know we take confidentiality very seriously.

#### Stakeholders Use of Experts by Experience and Impact on their Services

*This section is specifically for external organisations about their experiences working with EbE including impact of specific opportunities, impact on their organisation and any system change they are aware of.*

One of the key goals of Every Step of the Way (ESOW) programme is to improve the way people with lived experience are involved in the design, delivery and evaluation of services in Birmingham. I would like to explore your experiences working with the ESOW EbE.

- Tell us a bit about your general engagement with EbE. How often have you engage EbE in tasks or projects? What sort of projects? Did they tend to be one-off or on-going? What was your overall impression of using EbE? Were there specific projects where using Ebe was better than others? Why?

#### IF WE HAVE INFORMATION FROM MIND ABOUT SPECIFIC EXPERIENCES:

- I understand that you have worked with EbE on (...). Can you tell me a little about that task? How long did engagement last for this particular task? What was the aim of using EbE in this particular project? What did you think of how EbE performed? In your view what was the impact of EbE in this particular circumstance? Where there any specific changes made to the service as a result of EbE engagement? For how people work together? For service users? Is there any changes to how you would engage with EbE in the future as a result of this particular project?

#### IF WE DO NOT HAVE INFORMATION FROM MIND ABOUT SPECIFIC EXPERIENCES:

- **IF THERE IS A LONG TERM TASK OR PROJECT:** What was the task? How long did engagement last for this particular task? What was the aim of using EbE in this particular project? What did you think of how EbE performed? In your view what was the impact of EbE in this particular circumstance? Where there any specific changes made to the service as a result of EbE engagement? For how people work together? For service users? Is there any changes to how you would engage with EbE in the future as a result of this particular project?
- **IF THERE IS A SHORT TERM TASK OR PROJECT:** What was the task? How long did engagement last for this particular task? What was the aim of using EbE in this particular project? What did you think of how EbE performed? In your view what was the impact of EbE in this particular circumstance? ? For how people work together? For service users? Where there any specific changes made to the service as a result of EbE engagement?
- What has had the most impact on your service? Why?
- Would you consider using EbE again? If yes, why? If not, why not?

Continues overleaf >

# Appendix B continued

## Impact of Experts by Experience on Birmingham Changing Futures Together Systems Change

This section is specifically for BCFT ESOW coordinator and Birmingham MIND manager about their views on EbE influence on the wider BCFT project.

One of the main aims of EbE involvement in service design and delivery is to not just to impact on individual services but to be involved in all areas of the BCFT project.

- Can we start by discussing how well you think EbE has gone? What are your reasons for thinking this?
- How have EBEs shaped the design and delivery of The Birmingham Changing Futures Together project as a whole? (PROMPT for Examples)
- Do you think there has been a wider impact for BCFT through involving EbE in service delivery and planning? **If yes**, in what way? What is the scale of the change? **If no**, why do you think that?
- What effects on service users will the EbE have had? What plans are there for future opportunities?
- Can you think of any specific examples where you think the system has been impacted **positively** by the involvement of EbE? Did processes change? In what way? Did people work better together? Were there identifiable changes that benefited service users?
- Can you think of specific examples where the system has been impacted **negatively** by the involvement of EbE? How did it impact on processes? Did it impact on the way people worked together? Were there identifiable negative outcomes that impacted on service users?
- Are there are plans to ensure there is a legacy of service user involvement beyond the life of the programme?
- Looking back on the project what are you proudest of? Is there anything you would do differently?

## Recommendations for EbE programme

This section is specifically for external organisations about their experiences working with EbE.

- Could the use of EbE in service design and delivery have impacted more on your service? In what way?
  - Would you work with EbE in your service again? Why? Why not?
  - If not what are the key things ESOW needs to address to persuade you that engaging EBE is a worthwhile endeavour for your service?
  - If yes, in what way? Could you/would you be more ambitious about using EbE?

- Could the use of EbE in service design and delivery have impacted more on the wider system?
  - How could EbE impact more on the wider system? If yes, in what way?
  - If not what are the key things ESOW needs to address to make a system level impact?
  - Is there more the BCFT services could do to ensure EbE learning is impactful?
- If yes, in what way? Could the wider system be more ambitious about using EbE?
- What was good about working with EbE?
- What was negative about working by EbE?
- Do you wish to feed back any recommendations to ESOW?

## Wash-up Questions

This section is specifically for external organisations about their experiences working with EbE.

- Can we speak briefly about your experience with EbE/ Lived Experience prior to the ESOW programme? Had you used EbE before in your services? If yes, what was the experience like? Did it impact on your services? What did you learn from those experiences? How does ESOW EbE compare?

**Thank you. This work will be written into a short report for BCFT. It will also be combined with other information/learning we find on other aspects of the BCFT programme (e.g service user perspectives) into annual report. Both will be available through BCFT.**

# Appendix C

## Birmingham Changing Futures Together – Every Step Of The Way Focus Group

### Topic guide

Total 90 minutes

### Ice-breaker and baseline understanding re ESOW aims

- To kick off let's go around the room and all introduce ourselves
- Just tell the group why you wanted to be involved in the ESOW programme and what you think is unique about ESOW

### Involvement of Every Step of the Way on service design, delivery and evaluation across Birmingham

- One of the key goals of the Every Step of the Way programme is to improve the way people with lived experience are involved in the design, delivery and evaluation of services in Birmingham
  - To what extent would you say the Every Step of the Way programme has achieved this? Why/Why not?
  - Do you think involvement in these things (ie service design, evaluation) happens *more, less or the same* as it did before you joined ESOW?
  - Can anyone share any examples of them being directly involved in helping to design or evaluate services in Birmingham?
- What kind of effect do you think your involvement had on the service?

### Impact of Every Step of the Way on wider Birmingham services / systems change

- I want to understand what sort of impact you think the Every Step of the Way programme has had on the wider system of services in Birmingham. This could include the the way services work together, the way people think, the culture, etc
- How do you think your involvement in Every Step of the Way has impacted on the way services are run as a whole system across Birmingham?
  - What activities have you done that have had most impact on changing wider system?
  - Can you think of any specific examples? Probe re processes and/or people/

- How, if at all, has your involvement changed the way people with multiple complex needs in Birmingham are supported?

- How could the ESOW programme have more impact on the system? Why?

### Involvement in designing Birmingham Changing Futures Together itself

- How involved would you say experts by experience are in the planning and organisation of the Birmingham Changing Futures Together programme itself (of which ESOW is a core part)?
- How is it different to other projects or programmes you have been involved in within Birmingham?
- In what ways could ESOW or Birmingham Changing Futures Together improve?

### Diversity in ESOW

- I want to briefly discuss diversity in the ESOW programme in terms of gender, ethnicity, ability and age
- To what extent would you say the ESOW programme is inclusive of people from diverse backgrounds? Why?
  - How could the ESOW programme be more inclusive?
  - Are there any particular people from ethnic groups or backgrounds in Birmingham that you think ESOW has struggled to involve? Why?
- What could be done to overcome this?

### Final thoughts

- Do you have any final thoughts you would like to share?
- Thinking about everything we have been discussing, what do you think is the most important thing that we have discussed that you think Birmingham Changing Futures Together need to think about regarding the Every Step of the Way programme?





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