

Factors Influencing Attendees' Engagement with Group Psychoeducation: A Multi-Stakeholder Perspective

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Abstract

Background: Psychoeducation provides a range of benefits to service users with severe mental health illness and their family members. A lack of engagement with mental health services may lead to poorer outcomes and increased healthcare costs. Few studies have explored the problem of engagement in relation to group psychoeducation from a multi-site and multi-stakeholder perspective.

Methods: The aim of the study was to explore the factors influencing service user and family engagement with group psychoeducation programmes. The study design was qualitative descriptive. Data were collected through individual and focus group interviews with key stakeholders (n=75) involved with the programme within 14 mental health sites in the Republic of Ireland.

Results: Enablers and barriers to engagement were identified at participant, provider and programme level. Motivated participants and clinicians, peer co-facilitation and support, and skilled and responsive facilitators were some of the factors which enhanced engagement. Barriers to engagement included a lack of motivation and readiness among participants, concerns related to stigma and confidentiality, a lack of support for programme participation within families, group discomfort, issues with accessing transport, the time and length of the programme being unsuitable for some participants and a lack of capacity among clinicians.

Conclusion: Findings from the study illustrate the multifaceted nature of engagement as well as provide a greater understanding of the multifactorial influences on engagement. Strategies to enhance engagement should therefore reflect a multipronged approach. At the outset of programme implementation, organizations should address their readiness to engage, conduct local needs assessments to anticipate individuals' needs and plan accordingly in order to maximize engagement, and bolster facilitators' engagement skills through the provision of training and mentoring opportunities.

Background

The distress associated with mental health problems such as schizophrenia or bipolar disorder is well documented from the perspective of the person experiencing it [1, 2] as well as from family members' perspectives [3, 4]. A central pillar underpinning evidence-based care for people with such a diagnosis is the provision of psychoeducation. Psychoeducation as an evidence-based intervention is included in international and national clinical guidelines on the care of people experiencing psychosis [5, 6]. Numerous randomised controlled trials and systematic reviews attest to the clinical and recovery benefits of service users engaging with psychoeducation, including decreased relapse rates, increased awareness of symptom triggers and warning signs of distress, strengthening of self-efficacy, hope and sense of empowerment as well as greater utilisation of mental health services [7–9].

A high percentage of people experiencing psychosis continue to live with or are in regular contact with family members, who not only provide emotional and practical support but play a significant role in accessing services when someone becomes unwell [10]. In light of this the provision of education to family members is also considered best practice [6, 11]. Positive engagement of family members with psychoeducation programmes not only enhances their knowledge of mental health problems and the supports available, but has been linked with interrupting negative patterns of interaction between the person and family members [12–16]. In addition, psychoeducation has been shown to positively impact carer burden, coping capacity and problem solving in crisis situations [17]. Consequently, supporting engagement of service users and family members needs to be a central pillar of all psychoeducation programmes. A lack of engagement in treatment among those with mental health difficulties is a significant problem [18]. Previous research indicates that at an individual level, factors such as male sex, younger age, greater severity of illness, diminished functional capacity, having a diagnosis of schizophrenia or schizoaffective disorder [19–25] and comorbid mental health and substance use conditions [22, 25] are associated with higher rates of attrition and disengagement from mental health services. Perceptions about the efficacy of treatment [25] as well as the quality of the interactions between clients and providers [25, 26] can also inform decisions about whether or not to engage.

Engagement with a psychoeducation programme is not just about enrolling, recording attendance and attrition, but rather is a dynamic, co-constructed process [27] that moves along a continuum from initial recruitment to sustained active participation with the programme. In line with this thinking, engagement focuses on buy-in and emotional investment from service users and families [28] as well as the facilitators' role in building collaborative relationships [29, 30] and supporting engagement through their facilitation style [27]. The National Alliance of Mental Illness [25 p. 79] not only emphasises the importance of individuals' forging alliances with providers but draws attention to the importance of considering engagement within the context of family and wider supports.

While a significant body of work exists on the benefits of delivering psychoeducation, few studies specifically explore factors that influence engagement with group psychoeducation post-intervention. The studies that have reported on aspects of engagement suggest that participant, provider and intervention factors have an influence. These include participant factors, such as mood of service users [31], competing demands [31, 32], difficulties in group situations, and concerns for confidentiality [10]. Provider-related factors include clinicians' belief in the value of group psychoeducation [33] and skills of facilitators in supporting participant engagement [31, 34]. While these studies provide useful insights, they are limited by small sample sizes (7–18 participants) and in many cases exploring factors that influence engagement was not the primary aim of the

study. In addition, the studies collected data from one site and one stakeholder group, such as facilitators/programme leaders [33–35], clinical staff and agency directors [35], service users [31] or family members [32], thus potential differences or conflicting perspectives between participants and facilitators were not examined. Given the benefits of psychoeducation, and the potential for poorer health outcomes and increased healthcare costs associated with disengagement [18, 22], understanding factors that influence engagement is critical.

This paper aims to address this research-to-practice gap by generating evidence on factors that influence attendees' (participants') engagement from a multi-site and multi-stakeholder perspective in order to identify and develop strategies to increase engagement. The focus of the paper is on the perspectives of those either participating or directly involved in delivering a psychoeducation programme rather than the views of higher-level policymakers. The data which this paper is based on is part of a larger funded study into the structural, cultural and systemic processes that have enabled or hindered the adoption, implementation and sustainability of group psychoeducation programmes within the mental health system [36-reference inserted after review].

Methodology

Aim

The aim of this current aspect of the study was to explore the factors influencing service user and family engagement with group psychoeducation programmes, called respectively the EOLAS Programme for Service Users and the EOLAS Programme for Families and Friends (EOLAS is the Irish word for knowledge). The content, format and delivery of the EOLAS programmes are co-designed, co-developed and co-facilitated by service users, family members, and clinicians [37-Inserted after review]. The EOLAS Programmes were first piloted in one mental health service in Kildare in 2011 and, following positive evaluations [38-40-Inserted after review], were extended to 14 further mental health services around Ireland.

Methods

A qualitative descriptive design was considered appropriate as the focus of the study was to 'understand a phenomenon from the perspectives and worldviews of the people involved' [41 p. 2].

Data collection

Data were collected through semi-structured, interviews guided by an interview schedule and audio recorded with permission. Potential participants were given the option of participating in either an individual or focus group interview. The team developed an interview schedule to guide data collection on participants' views of the factors they believed enabled or hindered the implementation of the intervention and part of the schedule included the topic of barriers and enablers to attendees' engagement (Additional File 1). To ensure consistency in data collection the same schedule was used for both the individual and focus group interviews and reviewed by some of the research team after the first round of interviews. Two members of the research team (RM and JB), who were not well known to the participants, collected the data between late 2018 and 2019. Both interviewers were female; one was a postdoctoral researcher with extensive experience in qualitative research and the other had an academic education in psychology.

Recruitment

Based on their ability to inform the study objectives, a purposeful sample of participants were selected from 14 mental health services involved in delivering the intervention. Emphasis within recruitment was on interviewing groups 'deemed rich in information for the purpose of saturating the data' [42 p. 255]. Potential participants (co-ordinators, facilitators, programme participants) who had previously provided consent to be contacted by the project team were sent an information brochure, together with a letter requesting them to contact a member of the research team if they were willing to participate. The information brochure contained the aims of the research and information on data collection and the consent process. Once a potential participant made contact, all questions were answered and a time for either an individual or focus group interview was arranged. Interviews were either conducted face-to-face or by phone, depending on participants' preferences, and took place in a hotel, mental health service or university. Interview duration varied between approximately 30 minutes to one and a half hours. Fieldnotes were recorded after each interview. Participants were informed that they could review the transcripts if they so wished, but no participant took up the offer.

Ethical approval and access to participants

Ethical approval for the study was granted by the University's Research Ethics Committee and the ethics committees of the services involved. All participants received written and verbal information about the study and provided written consent prior to the interviews.

Profile of Participants

75 people participated in the study, 42 in one-to-one interviews and 33 in focus group interviews. Participants included EOLAS co-ordinators (n = 16), EOLAS facilitators (clinical n = 12; peer n = 25), programme participants (n = 16) and other key stakeholders (n = 6). More detailed information

on the profile of interviewees is given in Table 1.

Table 1
Overview of interviewees by role in EOLAS and method of data collection

Role in EOLAS	Individual interview (n)	Focus group (n)	Demographics and Background Information
EOLAS Clinical Facilitators	2	10	<i>Gender:</i> F = 10; M = 2 <i>Profession:</i> Nurse = 6; Social Worker = 4; Occupational Therapist = 2 <i>Years working in MHS:</i> Mean = 15.58, SD = 8.93, Range = 4–29 years <i>Years involved with EOLAS:</i> Mean = 4.5, SD = 2.38, Range = 1–6 years <i>Number of EOLAS programmes delivered:</i> Mean = 3, SD = 1.83, Range = 1–5
EOLAS Coordinators* *12 had experience of facilitating the EOLAS programmes	7	9	<i>Gender:</i> F = 11; M = 5 <i>Profession:</i> Nurse = 8; Social Worker = 7; Psychiatrist = 1 <i>Years working in MHS:</i> Mean = 16, SD = 11, Range = 3–40 years <i>Years involved with EOLAS:</i> Mean = 3.43, SD = 1.89, Range = 1–7 years
EOLAS Peer Facilitators	11	14	<i>Gender:</i> F = 15; M = 8 <i>Background:</i> Family Member = 11; Service User = 14 <i>Number of EOLAS programmes delivered:</i> Mean = 2.29, Range = 0–7 <i>Number of facilitators currently facilitating EOLAS:</i> n = 18
EOLAS Participants	16		<i>Gender:</i> F = 11; M = 5 <i>Background:</i> Family Member = 12; Service User = 4 <i>Length of time since EOLAS completion:</i> < 1 year = 8, > 1 year = 7
Other Key Stakeholders	6		<i>Gender:</i> F = 2; M = 4 <i>Background:</i> EOLAS Steering Group members = 3; Project Workers (former and current) = 3

Data analysis

Interviews were transcribed and uploaded to NVivo12 for analysis [43]. To enhance the rigour of the qualitative analysis, data were analysed independently by more than one person on the research team (RM, CD and AH). The analytical process moved through several coding phases. The first round of analysis was completed separately for each group of participants. All data for one group was open coded for ideas and concepts around attendee engagement using the following headings: organizational, provider, intervention and participant factors. Once this first round of analysis was completed for all groups, codes were compared across groups for similarities and differences in views and merged into three themes: participant factors, programme factors, and provider factors (Fig. 1).

Results

Participant related factors (Theme A)

A number of participant related factors were identified as impacting uptake and engagement with EOLAS, namely, individuals' motivation to move forward in their recovery, level of readiness, stigma, confidentiality concerns, family dynamics, pool of potential participants, and access to transport (Table 2).

Table 2
Data to support each theme

Codes: CO = Coordinator; CF = Clinical Facilitator; FF = Family Member Facilitator; SF = Service User Facilitator; FP = Family Member Participant; SP = Service User Participant; SH = Stakeholder; II = Individual Interview; FG = Focus Group Interview	
Theme A: Participant related factors	
A1	[...] We all had the same reason as wanting to move forward in our lives and wanted to take steps to ground ourselves well and wanted to know more about mental illness in order to develop coping strategies and to liaise with the mental health teams and professionals more beneficially. SP3 (II)
A2	CF11 (FG): Whereas the families seemed to be really, they had no. CF12 (FG): Crying out for it [information]. CF11 (FG): And they were like. CF12 (FG): Sponges, absolutely. CF11 (FG): And wanted to come forever. And wanted to come every week and never wanted to leave and I'm getting support and this is great.
A3	[...] once we'd heard about it we were keen to learn as much as possible. We always were asking questions if you like at the hospital (Laughs). [...]. The minute I heard about it I decided oh absolutely we have to do that. FP12 (II)
A4	And I was seeking some support for myself, so I was on a waiting list for eighteen months and I repeatedly would ask when are they running it [EOLAS programme] out? FP9 (II)
A5	[...] we knew that it was a good thing, the whole idea of support groups. FP2 (II)
A6	Well you see they would be appropriate in the sense of the criteria, they would have either one of the diagnoses but the motivation and then they just don't turn up. CO4 (II)
A7	Yeah, because you hear a lot of the time, you know, people are crying out for the information, they're looking for the support, they're looking for the education and then when it's offered you've nobody, you know [...] CO12 (FG)
A8	We did a service user survey on,, what other interventions they would like and they were looking for other alternative supporting therapies and once you offer them, you literally could have a yoga group, it's free, it costs like a gazillion tons of money to go to a local yoga group and they still won't go,, you know [...] sometimes it is just person specific to why they're not going. CO13 (FG)
A9	But in the spring when she [family member with mental health problem] was in hospital I was saying to the people that were organising the service user group.. I says are you going to ask [name of person] and she says, yea her but she probably won't go because she's not interacting even with the OTs.... But they did ask and she didn't go to it. FF8 (FG)
A10	I suppose they [service users] don't want to sign up for anything, we find it hard to get them to change, make one little change, you know to their routine or their week. CO16 (II)
A11	[...] we have families like asking for support all the time, but for some reasons there's, like I had four people who said yes but haven't turned up to EOLAS CF10 (FG)
A12	And there was loads of cases like that. People that we thought were prime candidates and would've really benefitted from it. No interest in going, didn't really. And people who we'd good relationships with. And we were selling it to them and this is great and trying to tell them, no interest. Or would say they'd come and wouldn't turn up [...] CF11 (FG)
A13	Yeah and it's very hard I suppose to get people interested in it as well because when you get better and when you get out of hospital, you're kind of thinking I don't want to associate with that [...] SF4 (II)
A14	Q: Had you known about it [EOLAS], you said your mother was involved in it before that. Had you known about it from her? Had she told you little bits about it? A: She did it but that was like a few years ago and I just had no interest in hearing. I was off meds that year and I wanted nothing to do with mental health just because I wanted to kind of convince myself I'm past all that. And I just wasn't open to listening to it. SP2 (II)
A15	I know service users get very disheartened. Because they say, oh that's another group, a fly by night. And that's why people don't get involved. Because so many things have come to the wall over the years. FF11 (FG)
A16	I did sort of feel you know the service users, in one setting or another had heard a lot of the information before. And the buy in from them was a little bit more difficult. They wouldn't always come back, they'd be but I've heard this a hundred times. You know they weren't as interested. CF11 (FG)
A17	I suppose he's [husband] living with this since he was fifteen and he feels you can't teach him any more about it. So, yeah, so no, we, since – in the first few weeks when we were going and, and as I say, he did enjoy it, but he just dropped out of it then after two or three sessions. [...] For the programme itself, it was very good, but for me, I suppose I didn't really learn anything new during it [over the years had done a lot of reading on family member's diagnosis]. FP8 (II)
A18	And there was somebody that was referred, who actually was given a referral [...] it wasn't an appropriate referral, because the person was in a position maybe within their journey where they were finding things quite challenging. SF1 (II)

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A19	[...] people need to be in a really good place to do it. That I think is another kind of impeding factor, you have to be really well to do it. Because I've seen people struggle with it and I've seen people unwell [...] But you know everybody has to kind of function at a higher level. [...] people who are newly diagnosed - it's nearly too early, people are only coming to terms with the diagnoses, they might be linked in with the EIP [Early Intervention Psychosis] program. CO16 (II)
A20	[...] I suppose their readiness you know, how ready people were for it. Somebody maybe only out of hospital maybe a couple of weeks and was still on the road to recovery but probably not exactly there yet d'you know [...] Then you might have had to even say to them, you know I'm not sure you're ready yet. You know there seems to be, you know lots of adjusting of maybe medication or that you're in quite intensive psychology at the moment. You know, do you really feel you'll be able for this and will it benefit you the amount that we'd want. CF2 (II)
A21	[...] it was just having enough time for the team to identify suitable people because I mean if you have someone who is just post discharge or you know actively unwell, you know something like this for some people mightn't be very helpful. CF1 (II)
A22	Now there was actually one person, it was a couple and the husband struggled with it. And found it very stressful and didn't come to the very last one. And there is that kind of thing, their daughter was newly diagnosed. And they were in a really difficult space. CF4 (FG)
A23	And I think particularly family members, like you know yourself the family members, it's often years down the line when they're really ready for something like that [EOLAS] CO2 (II)
A24	And that is why I think maybe some people might be reluctant because they are kind of ashamed to think that some members of their family is undergoing mental treatment. FP11 (II)
A25	[...] it's such a small town [...] I it seemed to carry just that little bit more of a stigma, [...] I think it's just everyone knows everyone, that's what one lady said to me, she says everyone knows everyone. [...] one lady said I was really nervous I'd know people in here. And the others had said that they were the same, because she said 'I think if I did know someone I wouldn't say anything'. CO1 (II)
A26	You see the way it works a lot of people don't want to be – even though they know they're not well – they don't want to be there and they don't want to be around other people who are not well. I think it's, the stigma to their illness, but that's what I thought. FP1 (II)
A27	I was late diagnosed, I was 36 so I had my own stigma. You know around that so I wouldn't have wanted to have been seen to be going to clinics and if I went to outpatient appointments I used to look around. SF14 (FG)
A28	[...] we were running two groups. One in [rural town] and one in [Urban town]. And a couple of people decided that they would travel the twenty miles to other group, you know, those are just sensitivities that are there. CF5 (FG)
A29	Because I said I would go anywhere to get this service, I just didn't particularly want it in [local area], you know, I would travel to it, which I did. FP9 (II)
A30	[...] there was a lot of anxiety about the family members coming in to a room with other family members, that they were almost felt that they were, they were exposed [...], they felt very vulnerable coming in to that space and saying I, my relative has, has Schizophrenia or whatever. So there was I think a bit of a barrier to get past selling it, that this is a safe space and the, that actually meeting other families in your situation may actually have some benefits for you rather than keeping it to yourself, I explained it to them like that [...] the service users were more accustomed to being among one another, if you like, in waiting rooms and clinics and what have you, so had less of that concern about being exposed. CF7 (FG)
A31	I suppose I was worried some of this information could get back [to their relative] and would not be reported as I had said it and I wasn't sure what the reaction would be. And I was a bit fearful in that respect, so I kept it limited let's put it that way. FP3 (II)
A32	I wonder, [names town] is such a small area everybody knows everybody and I wonder if that was kind of a factor why they didn't come. CF1 (II)
A33	I know one person who said, God 15 years ago if I had have went in front of a psychiatrist about my son or my daughter or my brother or my sister, I'd been told, oh no sorry I can't discuss anything with you. Now we're saying it's ok to come in and we're able to discuss stuff openly in a group. They [family participants] found that kind of strange and I have to say you could understand that [...]. CF2 (II)
A34	We have a family member who rang up the day before we were starting and she said that she wanted, she was all signed up to do it. But her daughter wanted to come along [to the family group].. Because she didn't want her talking about her. She wanted to make sure she wasn't saying anything about her. So in the end the lady didn't come herself, you know because obviously the service user can't come to the family one. SF11 (FG)
A35	[...] a lot of families would be saying, oh I don't know about that and whether the service user, my family member would like it. And we were saying, no we won't actually be discussing anything about their care. It would be a broader picture stuff. So I suppose our family member numbers were small initially but those numbers began to grow. CF2 (II)
A36	Yea well you see, I think there is obviously a limit, in terms of the demand. Because there was clearly a neglect of people, service users and families. And some of that's been taken up now, yea. But there is, because we're fairly, we're a very rural area and the population is fairly thin. CF5 (FG)
A37	The, we've, we've run it about four times and I suppose psychosis, we don't get that many new referrals so we've offered it to all of our patients four times now who have experienced Schizophrenia or bipolar psychosis and we've kind of run out of people now on our books, some people just don't want to do it, point blank - so we haven't run it in I'd say eighteen months, whereas before that it was every year. CF9 (FG)

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A38	[...] when EOLAS goes into an area initially you're picking up on all of the people who have been there for all of the generations who haven't experienced EOLAS, all right. Now two, three years in you've probably provided EOLAS to all of the existing service users and their family members. SH5 (II)
A39	I'm not sure if we have the population for EOLAS. [...] But again I think it's down to the population here in [ES06] at the moment. You know I do think it's about that. Like I mean as I said to you we've a very, like [ES06] is a very deprived area. Very socially deprived area, there's pockets of wealth and there's extreme pockets of poverty. So we've lots of, we've a huge traveller population here as well. They've settled down, you know nomadic travellers and then we've a Rohingya community here, we have all different nationalities living in [ES06]. So it's a very deprived, very poor socioeconomic group. Lots of involvement with you know Tusla, child protection, all that kind of stuff. Lots of, we've methadone clinic on site, so we've all those problems before you even start with the mental health. Do you know what I'm saying? So that affects sustainability as well. But like I mean somebody psychotic and you know might get a diagnosis or whatever, but you know their main problem is drugs. And you know how is EOLAS going to work for that person? You know it's not what they need, they need, you know the addiction, you know psycho-ed around whatever, do you know what I mean, so. That's the priority, exactly, yeah. And a lot of it we're managing crisis here. We're crisis managing a lot of people. CO16 (II)
A40	I think for first episode we, we thought we'd have higher numbers, so we don't particularly have, or, or we do, but then they're non-nationals and they move back home or they move catchment area, they don't have a family, or all those kinds of various things [...] CF6 (FG)
A41	CF11 (FG): We had one young guy who attended us. And his mam had been asking us, there's no support. There's nowhere for me to go there's nothing. EOLAS we thought, we rang, I'm not going to that why would I be going to that. We couldn't believe it. Do you expect me to be going in there on a Friday evening? CF12 (FG): Sure I can't be giving up my evening... Sure it's dark, how am I supposed to get there?
Theme B: Programme related factors	
B1	Q: And in terms of the co-facilitation aspect of the programme was the fact that there was family member who was co-facilitating it did that help? A: that was the biggest approval tick in the box, that person understood exactly where all of the rest of us were coming from [...] they totally did that if that person wasn't there it wouldn't have worked. FP5 (II)
B2	I think it was really positive to have somebody with a lived experience of it and I think the, the family and friends, it really resonated with them [...] CO6 (II)
B3	That [peer facilitator] was really good because [...] the language was very simple from the family member. You know it was always made feel at our own level, which was a good combination. FP2 (II)
B4	I think it was better having that other co-facilitator [service user] there because they were sometimes able to break that down a bit more. And also to kind of, I would just say it seems a bit more kind of friendlier. SP4 (II)
B5	A lot of people find that [peer facilitation] very helpful because the family member [peer facilitator] had a young person, a kid [child] like all the other people had, [...] I trying to say the person facilitating didn't have a spouse it was a child. So it was great a huge piece of identification with other members there which was good. FP3 (II)
B6	And I think that is the reason why EOLAS works, is because of that co facilitation. And that's who they look towards. It's not the person, the professional whoever that is. It's the person who has the son with a diagnosis of schizophrenia. CF4 (FG)
B7	Well I found that [co-facilitation] helpful as well because at least there was a person delivering the course that had mental health issues as well. So they would have insight to what it's like to have mental health difficulties and their understanding would be better as well because they'd be talking and able to relate their own experiences as well. SP1 (II)
B8	We were able to get [consultant psychiatrist] to come to do a session on medication. We had great talkers, [Name] I think came as well from [community mental health service]. So we had good speakers and people were interested in hearing them. SF2 (II)
B9	[...] the psychiatrist comes in and that's good because they [participants] can ask all the questions they want. Then, what do you call him, the pharmacist comes in and they're oh my god, they're just what does this tablet do and how does this work? You know they're really engaging with them. IES15DSUF03
B10	[...] to actually have the psychiatric team to come and talk to you on a one to one basis [...] and answer your questions, I never thought that would be possible. [...] They [fellow participants] all felt exactly the same way as me. It [attendance of a psychiatrist] appeared to have a big impact on them and they were delighted to be able to ask the questions you know. They were very vocal and they did ask whatever they wanted to know. SF2 (II)
B11	I suppose, yeah, the guy, the pharmacist and the psychologist that came in to talk to us, [...] I suppose it brought the, the top people down to our level and we were able to relate to them and it didn't feel like they were up at the top and you couldn't reach them [...] we were encouraged to tell them how we felt, so it wasn't as if, you know, that we were to be nice and kind of polite and kind of say, you know, everything is hunky dory when we know it's not and that, and asking if there's other different medication that could be offered instead of what's being given at the moment [...] FP7 (II)
B12	There is something about that consultant going in to the group and meeting people at a more egalitarian level rather than actually sitting, not literally, but metaphorically at least, sitting behind the desk and having a list of symptoms and, and if the families as well only ever meet the consultant in that context of either crisis or bad news or [...] for them to meet the consultant in a more social atmosphere and a more, a more level playing field is a really powerful thing, I've noticed that several times [...] CF7 (FG)

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B13	But you'd have to say that you know, EOLAS is about sharing. And if it's about sharing you get a certain value in three people sharing. But you get much more value if it's six or nine. You know that it just allows for a broader conversation, a broader range of experiences, a broader range of sharing. And all that you'd want from an information and education programme. Because as you would know from the previous research. One of the things people valued most was hearing others and their experiences. SH2 (II)
B14	[...] being a participant in a lot of ways supported my recovery. Because you feel like you've got something to contribute. And you see and hear other people's frustrations and sharing of their lived experiences. It was very supportive in that regard. Even though EOLAS is not therapy. It's not that it's group therapy, or intended to be or anything like that. Just having people chat and interact with each other and you know over the tea break or what have you is therapeutic in and of itself. SF7 (II)
B15	I think that it's such a good program, there's something very empowering about it. Again it might be the first time you've met someone with your diagnoses, the first time you've had open conversations about your experiences of the services, whether it's hospital or what. Like just having that kind of peer support within the EOLAS. Where you're talking to people who have shared the same experiences as you. SF14 (FG)
B16	When I went to the course, there were other family members there and I found people were very hesitant to speak [...] I remember everybody was very cautious so I felt very exposed in a way [...] FP9 (II)
B17	But he [family member facilitator] found the hardest thing was actually getting the, even though all the family members did kind of benefit a lot. But they were very reluctant to kind of come forward and kind of talk. You know they were kind of, the group was quite quiet. SF10 (FG)
B18	Sometimes they're quite happy not to speak I think. It's just that they have a contribution and I think when they go into the little groups, that was a good help. I wouldn't pry it out of them. FP2 (II)
B19	<p>Q: Did you find it when you were facilitating groups that it was hard to kind of get the group chatting and talking, or?</p> <p>SF11 (FG): It was hard, at times it was hard. It was difficult. But the good thing was when we had the break. I realised they were approaching us. And they were happy [...] I think that was very important, to have that break. And having coffees and tea and they approach they join that way, that was very important.</p>
B20	[...] but that to me would be the major drawback that I was the only one with a spouse, they were adult but they were children adults, child adult...but I know, I appreciate that it's quite difficult to set that up [a group for spouses when you are trying to get a group together. FP3 (II)
B21	<p>FP9 (II): [...] only one person dropped out of the group.</p> <p>Q: Oh that's fantastic.</p> <p>FP9 (II): That person I suppose, I felt sorry for them, it was a sibling, whereas the rest of us it was all our children that was unwell.</p>
B22	I suppose one of the things that may have had an impact is, we had 2 females and 8 males and then one female couldn't really attend due to work commitments. So we were left with one lady with a lot of males. So I feel that might have impacted her attendance going forward. CF1 (II)
B23	We saw one person drop out. But I think that person, would've been probably ten or fifteen years younger than the rest of the people that were participating. You know what I mean; you do need to have people of similar age, because they've similar experiences. FF2 (II)
B24	It's [the handbook] excellent not just to have something that people come back time after time, to have something that is a recognisable course you know an actual curriculum. FP10 (II)
B25	I've also used it [the manual] in my training a lot as well, in my work as a peer supporter now as well. I find it very helpful because in the sector that I'm in I deal with a lot of people who have psychosis and part of their diagnosis. I find it's very useful especially when someone is distressed. SF4 (II)
B26	[...] if I have a communication problem with my [family member], I go to the section on communication and I look at it and I say, well how should I approach that. That doesn't say about spending money or, if she was looking for more money from us right. But it told you how to communicate. So I do refer to the manual a lot because you never remember it all. But that's what the manual is for. FF8 (FG)
B27	<p>FP11 (II): [...] I didn't really read through it [handbook] on the programme, like they [facilitators] would just refer to it and it's up to yourself when you would go home to look back on it. I would leave the book open and say to my son did you see that page. Did you look at that you know so it triggers us to talk about different things.</p> <p>Q: Yes ok so it became like a prompt to be able to bring up certain conversations and topics?</p> <p>FP11 (II): Yes.</p>
B28	I suppose our first few ones that we rolled out there was a huge amount of referrals for people with psychosis and bi-polar disorder, but we find the content is very much more psychosis, kind of unusual beliefs, all that type of thing, so [...] sometimes when you get to the end [of the programme] you would see it in their evaluation that [...] they would just say that they found that there wasn't enough on their own [bipolar] diagnosis. CO1 (II)
B29	[...] this information [in handbook] is going to be changing, not even year by year but week by week and month by month and I don't think, I don't feel comfortable, giving people information that is so static and doesn't actually represent all of the information that's out there...I think that everybody should have all points of view and then be allowed to make up their own decision. But the information within the handbooks do not allow that. CO5 (II)

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B30	I think the group experience it's what I'm doing exactly now, sidetracking [...]. And sometimes when you sidetrack [in the group] you get an interesting piece of information to develop. A conversation opens up. The book [handbook] doesn't dictate if you understand me, somebody says something and oh right okay, no I didn't realise that, okay FP12 (II)
B31	[...] didactic book learning is very important. But there's also a wealth of learning in terms of experience. And having a dialogue between how things are supposed to be according to the books and how things really feel, and their experience in real life. And having that kind of a dialogue back and forth, cross referencing back and forth is the most effective way to make the book useful and applicable to my life. SH1 (II)
B32	I found flipping through books could be distracting for the person next to them or the book would sometimes take away, it was like as if they needed the books to be able to talk whereas I think it would have been much more free flowing had it been maybe on a powerpoint type thing CF2 (II)
B33	But it [the handbook] can feel somewhat prescriptive at times when the conversation might lead elsewhere. CF7 (FG)
B34	[...] we had it on during the day so for some family members it wasn't practical to come during the day, which meant I suppose maybe taking time off work or d'you know that kind of stuff. CF2 (II)
B35	[...] we might've had one or two youngsters [siblings of person with a mental health issue], you know but they haven't been able to stay in the course. Because of the timing, so like availability to commit to the eight weeks which is obviously an issue [...] siblings are very seriously affected. But it just seem like they're disinclined or you know they've got college or work commitments. FF9 (FG)
B36	[...] can we be flexible in it? Is there any way that we can condense this into a shorter period of time because 8 weeks is a huge commitment. Can we run it over 3 half days for people, you know what works well for the person? [...] I think there's a better chance of getting people for shorter periods. [...] just even at weekends [...] we're actually talking about on the letter, [...] if we had the 3 options over the 8-week period, over 4 weekends whatever way we break it down, and if people don't actually fill it and send it back to us we know they're not going to be interested. [...] that's what we're thinking of going forward. And when we do get some sort of baseline and say ok the majority of people are going for this, let's just go for it. CO4 (II)
Theme C: Provider related factors	
C1	[...] you kind of need the, the key worker really to kind of go out to the service user or the family member and say come on, this is great, I'll come with you, I'll be there on the first night and all, and then they will, they might buy in because they've had a long standing relationship maybe with that person and they trust that they have good judgment in this being valuable to them, and that was really the key to kind of getting people to come along and trust that it was going to be a good process. CO13 (FG)
C2	I suppose in terms of our community mental health nurses in our area have been really, like, like you say, they really know the families inside out, so in terms of identifying the referrals with the likes of ourselves, but then doing a bit of, doing a bit of selling as well where there's a bit of reluctance or a bit of hesitance, to kind of say ah, you know, listen, you know, it'd be good for you, you know, sure go on and give it a go and, you know, a lot of, there's a lot of, I suppose it's not just for EOLAS, but in terms of I suppose just all kind of community based mental health services, there's so much that rests in that role I think, it's such a key key role. CO15 (FG)
C3	But anyway the first meeting then took place now and this is a small town. And I'm just being honest again, okay. I would've thought most of the town (Laughs) the children and the whole lot of them. Only two people turned up to the first meeting, because as said, they didn't make the phone calls. The following week [FF8 (FG)] they made all the phone calls and we had twelve. And from then on it was grand. FF7 (FG)
C4	And I think then the response I suppose to the referral is very important. Is that's actually the contact that [Name of coordinator ES10] would actually make contact and say you know, thank you for. We've got a referral in and just give them more information and organise and arrange to meet them etc. CF5 (FG)
C5	And then also you know the clinicians are really busy. And they've lots of new roles and there's things happening in the HSE. You know that is affecting you know trying to get these courses run. SF10 (FG)
C6	And the second element that's causing huge difficulty is the competition. We're doing Enhancing Teamwork, ARI [Advanced Recovery Ireland], we're doing the SRF [Service Reform Fund], we're doing EOLAS, we're doing all the kind of day to day training that each mental health team has to do. There's about ten initiatives. Staff doesn't have a, they just don't have the capacity to do it all. SH4 (II)
C7	If people are stretched in their own roles then they're not going to have the time to do the add-on bit that's actually required. SH5 (II)
C8	I thought it could've been better resourced, from the HSE perspective. So in other words it tended to be taking people, adding work onto their daily workload. Instead of saying, right we'll have a dedicated team to actually roll this out and embed it in the local area, if that makes sense. FF2 (II)
C9	[...] what I'm kind of noticing is that there's new programmes nearly coming that we're expected to be part of as an MDT [Multi-Disciplinary Team], yeah, I suppose as a sector, just, just to try and kind of keep up with this stuff [...] how you keep that on the agenda with this I suppose ever growing and ever, yeah, ever, ever increasing, populating agenda of, of programmes that are somewhat expected or, you know, so how do you prioritise and it's, you know, I do think it's, it's difficult. CO15 (FG)
C10	We have 2 people, clinicians who are trained [in EOLAS] and who will run it but they are not championing it because they are championing other things and everybody cannot champion everything. CO5 (II)
C11	I know there's here in this region there's the early intervention for psychosis and that's kind of taken over as well, which is kind of putting EOLAS in a difficult kind of position you know SF4 (II)
C12	It's [EOLAS] kind of taking a back foot in the last eighteen months because all our recovery people are gone, ARI recovery principles, they're new and exciting recovery college, yeah, and we kind of lost the momentum as a result [...] CF9 (FG)

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C13	In [county in ES15] [...] it boils down to the consultants over there, like they have totally refused to engage with. And I think it's because they have been chosen as the pilot site for the first episode. And they see the behaviour family therapy as fitting that block, even though the person who does that training in the service wants EOLAS, you know she's saying well I think it complements it and we should be doing it. We haven't, we've made constant representations to the consultants over there with absolutely no response. CO3 (II)
C14	Yeah there's a little bit of that [competition with EIP] here alright, yeah there would be yeah. Yeah there would be that element, now in saying that some of the facilitators on the EIP [Early Intervention Program] program would be involved with EOLAS and would be involved in the family carers. So there would be loads of conversations had but there's probably very little doing and you know action, there's very little action and you know yourself and I know myself, you know the heart is really in what they're doing all the time, so there wouldn't be that level of commitment. CO16 (II)
C15	I think there is a bit of the service users and [Name of coordinator in ES10] will be able to tell you more. But definitely the service users and family members being asked to attend both [EOLAS and ARI] CF3 (FG)
C16	[...] it's the same family members, service users [...] And I think we need to be conscious of that and they're being pulled for, for everything. CF10 (FG)
C17	[ES06] which had been very involved in recovery colleges and all that. There was lots of competing demands and where they ran programmes there were small numbers. And there was limited success. SH1 (II)
C18	[...] it's not advertised enough. FF3 (FG)
C19	But it definitely needs more visibility. You know if it's out there a bit more, people will go looking for it. SF10 (FG)
C20	So I think it's a visibility within services issues, more than an EOLAS visibility issue. And I think it's up to the services to work on increasing that visibility. SF1 (II)
C21	And I don't think an awful lot of people really know about it, I don't think there was that, there was that much information out there that it was going on like to family members and service users. FP1 (II)
C22	You see I worked as a [names place of work and role]. So I would have done facilitation skills, interviewing and coaching, you know and developing things. So I suppose it's an area that I would have been fortunate enough to be involved in. So listening and just making sure, sometimes by not saying anything by not interrupting and to get out of the way of the discussion, can be the best way to facilitate. FF1 (II)
C23	Yeah, and I think it's important that the facilitator would be a little bit open to sharing like their, so say the last girl [peer facilitator], she was a little bit more boundaried about her own stuff, so we're gently trying to say if you feel comfortable sharing something, because people get a lot more out of that, so, whereas the first person – maybe because I knew him better as well, but he had been on an inpatient unit for seven years and he's been in community now for probably the last seven and there was people like going what, you were in there for seven years, are you serious like, you know, and actually with him sharing that kind of stuff it really helped people, and being honest [...] CF10 (FG)
C24	I suppose it really would be down to focusing on the facilitators and their ability to facilitate [...] it is an education group with a process, a piece. The education is actually minimal, most of the time it's just setting up the conversation and the topic but not necessarily offering any particular information and having a process through this to have the conversation and through hearing what the group is saying the facilitators will have or should have the ability and the knowledge to offer and signpost the required information. So that's how your group can deal with any subject, about anything and can be sustainable into the future because the group is then set up to adapt to the people that are in the group. You know psycho education only works if you are giving and offering the right information at that point in time. CO5 (II)
C25	FF10 (FG): [...] I'm not a lover of worksheets and you know things like that so I avoid those things like you know and you know I don't think people, especially that have come together for the first time ever, you know are particularly comfortable either maybe sitting down. You've literacy issues and you've everything. Whereas if you can sit and chat you know whatever. Q: Yea it takes that barrier down? FF10 (FG): Yea and I mean I'm sure EOLAS don't want you going. And they have said this, they don't want you going too far off the scale which is fine. But within reason anyway I think, I'd say most facilitators feel quite confident, or at least flexible in terms of. And the more you do it the more flexible you might get. (Laughs).
C26	But you need knowledge of how to facilitate. Do you know and how to do that well and co facilitate and developing you know just an expertise to be able to understand that the dynamics and how to work with it and all that sort of stuff. [...] I mean we're confident in the product but at the end of the day, access to it is through the facilitation and your experience of the product is going to be as good as the facilitation. Do you know what happens in the room. And that's where the facilitation training is key. SH1 (II)
C27	The huge strength of it [train the trainer training] was we covered the course content largely and I suppose the facilitators we as facilitators were being trained as to how to deliver those modules. So we were actually going through the course and in a kind of an intensive way and we got trained to facilitate that and how to do deal with you know difficulties that might arise in it. So that was useful [...] FP6 (II)
C28	But one of the things when we did the training. An emphasis was sort of that it's not about you, or your mental health experience or your story. It's more about the people [participants], The people in the room. So it's not an opportunity for you to talk about yourself. So it's more to get them to talk about themselves. SF10 (FG)

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C29 I got on well with both the clinicians that were there. Because I would've done a lot of work with them kind of before EOLAS. So we were pretty comfortable working with each other. And I suppose it kind of; it probably makes the rest of the group that are there feel more relaxed. Because we kind of were able to bounce off each other. And it seemed quite smooth. So I think definitely having kind of to get to know the other person you'd be working with is kind of quite important. Just so you can, you get to know each other's style. SF6 (II)

C30 [...] you do need to get together and get to know each other. And kind of, you know feel comfortable and feel safe that you're on the same wavelength. And kind of, we had a few, well we had obviously I met him a few times before. And you know we did work very well together, like I mean I liked him. And kind of we liked each other's company. And he was able to relate to stories about his own experience you know and that was really so helpful. And like his competence was so reassuring you know. Because I suppose, well I would find it very hard to be with a facilitator who might kind of maybe be selling a different message. Or going kind of. Going rogue, or yea (Laughs). And I'd find that very uncomfortable do you know. And it is very important I think that you kind of understand each other. That you know that you try and support each other. Or that you pick up on each other's kind of approach and that you kind of try and kind of work in sync. CF5 (FG)

The desire of service users to move forward in their recovery and learn more about coping strategies and how the mental health services could support and help was viewed as a key enabler to engagement [A1]. Similarly, for family members, desire for information was the principle motivation to attend the programme [A2-A3]. Family members expressed a wish to learn about mental health issues and the mental health supports available. Seeking support for themselves was also a motivation for attendance [A4-A5]. Coordinators, and some family members, spoke of how a lack of motivation and interest from potential programme participants, particularly service users, adversely affected their engagement [A6]. In their view this was not unique to EOLAS [A7-A8] and sometimes reflected a broader pattern of disengagement from services [A9], or a lack of desire to change routine [A10]. Some clinical facilitators were also of the view that although family members sought support, when informed of the programme, some lacked the motivation to attend [A11-A12]. Peer facilitators in particular hypothesised that service users' lack of interest arose from people's desire to distance themselves from the mental health services once discharged from inpatient care [A13-A14], or, having seen numerous new initiatives come and go, did not want to invest time in another intervention that might not be sustainable within the mental health care system [A15]. Some participants suggested that service users and family members who were involved with the mental health services for a number of years may not see the programmes as offering anything new in terms of learning [A16-A17]. Emphasising the importance of readiness, clinical facilitators noted that service user participants who were at the beginning stages of their recovery journey, particularly those who were newly diagnosed or recently discharged from hospital, may not be well enough to benefit from the programme [A18-A21]. They also noted that families too needed a period of time to adjust to and accept their relative's situation before coming on the programme [A22-A23].

Stigma associated with mental health illness also prevented some service users and family members from engaging with the programmes [A24-A25]. Both groups spoke of the stigma that service users experienced [A26-A27], with some participants recounting how they or other participants opted to attend programmes outside their immediate locality [A28-A29]. It was noted that disclosing personal details and experiences was an exposing and vulnerable experience for participants, particularly for family members who were unaccustomed to sharing openly in group settings [A30]. Clinical facilitators noted that some family members had concerns about the confidentiality of the information they shared [A31-A32]. In addition, the concept of family engagement in mental health was relatively new to family members who had been engaged with services for a long time and who were more accustomed to being informed by clinicians that issues relating to their relatives' mental health illness could be not discussed with them (for reasons of confidentiality)[A33].

Family dynamics also impacted engagement. Participants reported that in some cases, family members experienced disapproval or anticipated disapproval from their relative with mental health issues which prevented their participation or made them reticent to participate in the family programme [A34-A35].

Some co-ordinators also suggested that the pool of people who met the inclusion criteria for the programme had been exhausted and thus there was limited on-going demand [A36-A38]. Others noted that crisis management interventions were more needed within the service rather than a recovery intervention, such as EOLAS [A39], with some suggesting that the cultural mix within the service resulted in greater instability in the cohort of users who could avail of the programme [A40]. Clinical facilitators and coordinators also noted that transport was a potential barrier to recruitment and retention, and needed to be taken into account when considering the time of day to run programmes [A41].

Programme related factors [Theme B]

Several aspects of the EOLAS programmes were identified as influencing participants' active participation and ongoing attendance and engagement, namely peer facilitation, guest speakers, group context, group make-up, manuals, and duration and timing (Table 2). While some were enablers to engagement, other aspects were perceived as barriers to depth and quality of participation.

The involvement of peers in the co-facilitation was a positive aspect of the design which enhanced participation. All stakeholder groups viewed the peer element as central to breaking down barriers, equalising power relationships between clinicians and peers, creating a friendly

atmosphere, inspiring hope and speaking a language that participants could understand and identify with [B1-B4]. Service user and family participants spoke of how the presence of the peer facilitator was reassuring as they knew that they understood what it was like to either have a mental health problem or support someone with a mental health problem [B5-B7]. The guest speaker sessions, particularly those involving psychiatrists and pharmacists, were viewed as an aspect of the programme which enhanced participants' ongoing attendance. Being provided with an opportunity to get a concentrated period of time with these practitioners, pose questions and receive answers was really valued by both service user and family participants [B8-B12].

Notwithstanding the challenges that individual participants experienced around opening up within a group context, the discursive part of the group sessions was considered vital to engagement and provided an important mechanism for peer support. The opportunity to share experiences and learn from each other in a supportive environment was viewed as an enabler [B13-B14], and may be the first time that a person has had the opportunity to talk to someone with the same diagnosis as themselves [B15].

However, some facilitators observed that a lack of participation by some family member participants made it difficult to engage the group as a whole and possibly deterred other family members from opening up [B16-B17]. Facilitators and participants also noted the importance of facilitators using responsive strategies to engage participants who were reticent about contributing to group discussion, such as breaking out into smaller groups and having tea breaks [B18-B19].

Participants also perceived that bias in some groups' demographic make-up negatively impacted engagement. Most family groups comprised parents, with spouse or sibling participants being in the minority, which inhibited engagement [B20-B21]. Others commented on how gender imbalance and age differences within service user groups may also have impeded engagement and contributed to attrition [B22-B23].

Service user and family member participants regarded the manuals as being a useful source of information on a range of topics. Having the manuals was important not just as a guide to the programme [B24], but served as a useful reference point for information after the programme ended [B25], with some family members using the manual to facilitate communication within the family after the programme ended [B26-B27]. In contrast, a small number of the co-ordinators felt that their content was too narrow in focus to be able to address all participants' experiences [B28-B29]. Where the manuals were used as an aid to stimulate discussion, this was perceived as better serving the purpose of engaging participants and allowing valuable insights to emerge from the group [B30-B31]. In contrast, an over-reliance on the programme manuals could hinder engagement by closing down vital conversation [B32-B33].

In addition, the duration of the programme and timing was a barrier for some, as some people could not commit to the eight-week programme due to obligations related to family, work and education [B34-B35]. One participant suggested that greater flexibility in the programme design, such as allowing it to be completed in shorter blocks of time, as well as ascertaining participants' preferences regarding the length of the programme in advance, could help to maximise engagement [B36].

Provider related factors [Theme C]

Provider related factors centred on the engagement of clinicians and on facilitator skills (Table 2). Recruitment of participants was facilitated by local champions who had well established relationships with and knowledge of service users and families as they were able to promote EOLAS to them and encourage their engagement with it [C1-C2]. Several facilitators highlighted that a key enabler to recruitment was the involvement of motivated clinicians who contacted people who had been recruited to EOLAS before the commencement of the programme, in order to maximise attendance at the first session [C3-C4].

An absence of engagement with EOLAS on the part of clinicians adversely affected potential participants' access to and engagement with EOLAS. Research participants identified several reasons for this lack of engagement. In some services, inability to recruit enough participants was identified as a challenge. Workload, lack of protected time, and involvement with other initiatives [C5-C8] impacted some clinicians' capacity to engage with the recruitment process. Clinicians noted that where there are a multitude of recovery initiatives in addition to EOLAS, it is difficult for clinicians to keep EOLAS on the agenda [C9-C10] as some services and clinicians prioritised and invested their time in other initiatives [C11-C14]. While clinicians were of the view that the competition between recovery initiatives diverted potential participants away from EOLAS and depleted the recruitment pool [C15-C17], family member and service user facilitators were of the view that it was a lack of awareness and visibility around EOLAS, rather than a lack of participants or need, that contributed to the lack of participant engagement [C18-C21].

Facilitation style and skill were identified as being instrumental to engaging participants. Facilitators identified that good communication skills and an openness to sharing personal experiences were required to cultivate rapport and successfully engage participants within the groups [C22-C23]. Participants also spoke of the importance of facilitators having the ability to adopt a flexible approach to facilitation in order to engage responsively with participants' informational and emotional needs [C24-C25], as well as the importance of the training provided to the facilitators [C26]. Many of the facilitators expressed the view that the training, and in particular the exercises and role play, not only enhanced their understanding of the programme content and facilitator role but imbued them with confidence and increased their readiness to actively engage with participants during the delivery of the programme [C27-C28]. While the co-facilitation model did at times result in differences of perspectives

and was experienced as a challenge, facilitators highlighted the importance of the clinical and peer facilitators working in harmony to promote a positive group atmosphere and not allowing difference of opinion or perspective to become a focal point of tension [C29-C30].

Discussion

Even under optimal internal organisational conditions, a key challenge facing mental health practitioners is connecting and engaging with service users who experience psychosis and their family members. The findings from this study highlight how the challenges of connecting and engaging with service users/family members is not simply located within participants' attitudes, personal preferences, and the wider context of their lives, but also encompasses a wider issue of how facilitators' perspectives and skills, and the internal characteristics of the programme and model of delivery can enhance or constrain engagement.

It is noted in other literature that clinicians as 'gatekeepers', sometimes limit access of service users and family members to evidence-based interventions [44]. Murray-Swank et al. [45] noted how a lack of invitation from clinicians was a barrier to family participation with Ingvarsdotter et al. [33] commenting on how some clinicians were 'selective' in their recruitment i.e. only informing people they thought would attend and avoiding people they felt would be uncomfortable within a group. While these issues did not emerge as a major issue in the delivery of the EOLAS programmes, organisational issues such as the multiple recovery programmes being simultaneously run with services, heavy workloads and a lack of protected time adversely impacted clinicians' capacity to dedicate time to promote the programme and engage with potential participants. These barriers require greater organisational leadership in the effective management of resources in order to enhance clinicians' capacity to promote the intervention and increase its visibility to potential participants as well as to members of the multidisciplinary team. Greater visibility of the programmes among potential participants may result in them seeking out the programme rather than waiting for clinicians to initiate engagement.

The findings also highlight how successful engagement of participants in psychoeducation interventions is not a once off event but required time to build the relationship between clinicians and service users/family members, as well as a willingness by clinicians to engage continually and to follow-up with participants. The importance of establishing relationships with potential participants in order to improve service users' and families' understanding of interventions and to address any concerns is also highlighted elsewhere [25,33]. Outreach work with service users and families is important not only to build rapport, provide information and address any barriers, but it enables clinicians to assess individuals' readiness and ability to engage in the intervention. Outreach encounters also offer valuable opportunities to address differing perspectives on factors which inhibit engagement and to explore ambivalence and the pros and cons of attendance. Additionally, clinicians can use this opportunity to identify, explore and resolve family dynamics which this study found inhibited some individuals from engaging in the intervention. Sherman & Fischer [46] also found that service users were opposed to their family taking part in a group education intervention for fear that their personal issues would be discussed outside of the group causing them embarrassment, while service users in Lucksted et al.'s [47] study expressed discomfort with the thought of family members talking about them in their absence. This opposition highlights the importance of clinicians emphasising to service users the value of family education in supporting families to learn skills to cope, problem solve and understand the experience of severe mental health illness [46, 48].

Issues around stigma and confidentiality were also highlighted as being barriers to engagement. To assuage these fears and create a safe environment, assurances around confidentiality should be explicitly and repeatedly outlined during recruitment and as an ongoing part of the programme. In addition, the findings highlighted that some individuals have difficulties being emotionally vulnerable and disclosing personal feelings in a group format. Similar difficulties have been reported in other studies. Family members and carers in Petrakis et al.'s [32] study reported that discomfort in social situations and revealing emotions and personal experiences, and having competing commitments all acted as barriers to participation in a group intervention, with clinicians in this study identifying fear of the unknown, difficulties communicating emotions and logistical challenges around time and location as inhibiting engagement. Similarly, other studies reported that feelings of stigma, embarrassment and discomfort, as well as the presence of domineering group members, were challenges to engagement in group psychoeducation interventions [31, 46, 47]. While facilitators in our study identified the importance of small group work and informal group chat as potential strategies for engaging more reticent participants, it must be recognised that group psychoeducation interventions may not be suitable for all individuals. Therefore, alternative formats, such as individual one-to-one psychoeducation, should be available to accommodate individuals who are not ready to engage in group work in order to ensure that they receive the support they require.

Like several other studies [10, 31–32, 46], our study found that the timing of the programme in relation to work and other commitments, as well as access to transport, impacted whether individuals could engage. To address these issues, a needs assessment should be conducted in order to ascertain individuals' preferences regarding the timing and duration of an intervention as well as any needs they have in relation to transport. In addition, study findings point to the need to explore alternative routes to inclusion, such as self-referral to a co-ordinator who could then inform the potential participant about the programme, as well as the need for organisations to conduct local needs assessments routinely in order to ascertain the need for psychoeducational interventions given the target cohort for EOLAS in some areas was not sufficient.

While greater flexibility in delivery might make it more convenient for service users and families to engage, the challenge for manualised psychoeducation programmes such as EOLAS is to identify the ways in which it can be adapted while at the same time ensuring that the fidelity and efficacy of the intervention is preserved. Irrespective any change should follow a systematic process, informed by implementation science literature [49, 50]. One possible adaptation that has demonstrated utility in terms of overcoming some of the personal and practical barriers encountered to service user/family engagement is telehealth [22] and this should be considered for the EOLAS programmes, especially given the challenges currently being experienced in delivering group learning experiences while respecting the limitations of social distancing imposed by the ongoing COVID pandemic.

Bearing in mind that any adaptation to a programme is a finely balanced task requiring trade-offs and compromises, this study shows that there are some aspects of group psychoeducation which are integral to participant engagement and should be promoted and preserved; namely peer co-facilitation, the opportunity to share experiences with and to learn from the group, as well as the opportunity to engage with mental health professionals, but with valued clinical input being delivered in conjunction with lived experience in a way that respects the value of both sources of expertise .

Similar to other studies, peer involvement which is central to all mental health policy [5,51] was shown to be important for enhancing participants' engagement with the programme [22, 52]. Peer involvement was a key mode of engaging participants and sourcing experiential knowledge and peer support. This group process of sharing stories and the sense of collective experience is beneficial to families and service users in terms of reducing isolation and increasing knowledge of mental health issues [31, 32]. However, the study findings do point to how in-group differences (whether family participants are spouses, siblings or parents) may disrupt the communal feeling and mutual identification within the group which is core to engaging participants in shared learning. In these circumstances, providers' skills in facilitation are critical to cultivate a rapport and communicative space that facilitates group sharing and learning. The kind of knowledge pertinent to spouse, siblings and parents may also differ, therefore, it is also important for facilitators to take this into account during the facilitation process, as this study highlights how, facilitators' responsiveness to participants' informational, emotional and practical needs facilitates engagement.

While didactic learning is a useful component of psychoeducation, (particularly in the sessions addressing diagnosis and psychotropic medication), interactions between participants and clinicians proved engaging and beneficial for participants in terms of them being able to access professional knowledge in a more empowered setting. The session on pharmacology was also explicitly highlighted as an important part of the programme in Petrakis et al.'s [32] study. While the study findings provide a multi-site, multi-stakeholder perspective and provides useful insights to inform actions to strengthen engagement, they need to be considered in light of the following limitations. In addition to the potential for interpretative, selection and recall bias, the views presented do not reflect what inhibited engagement of those who didn't attend the programmes. Neither does the sample represent racial and ethnic minorities, and given the evidence that these groups experience more barriers when attempting to engage with services and are more likely to receive poorer quality of care [53, 54], this is an area that requires further attention as the EOLAS programmes evolve.

Conclusion

Findings from this study illustrate that lack of engagement is not simply due to participant factors but a combination of factors that exist at varying levels of the ecosystem. In addition to highlighting the importance of organisational readiness and leadership, the findings also point to the importance of conducting local needs assessment to inform the design of responsive recruitment and engagement strategies as well as strengthening the capacity of facilitators through sustained training opportunities and accessible mentoring support. While clinicians' capacity in terms of skill and time was found to be critical in inspiring initial engagement, it was the synergy of peer involvement, facilitator skill, programme content, group process and group composition that was harnessed to sustain engagement with the intervention. Hence, any potential local adaptations to the intervention need to be evaluated.

Declarations

Ethics approval and consent to participate:

Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin [Reference Number: 170901] and the ethics committees of the services involved. Participants were provided with verbal and written information about the study, and gave both verbal and written consent to participate in the study. In addition, the principle of process consent was applied by the re-searchers at each encounter.

Consent for publication:

Not applicable

Availability of data and materials:

The datasets generated and analysed during the current study are not publicly available due to privacy concerns but are available from the corresponding author on reasonable request.

Competing interests:

The authors have no conflicts of interest to declare.

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Authors' contributions:

All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors and all authors have contributed and are in agreement with the manuscript.

Designed study (AH, MM, LD, PG)

Data collection and analysis (RM, JB, CD, AH)

Drafting and commenting on paper (AH, RM, CD, JB, MM, LD, PG)

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Figures

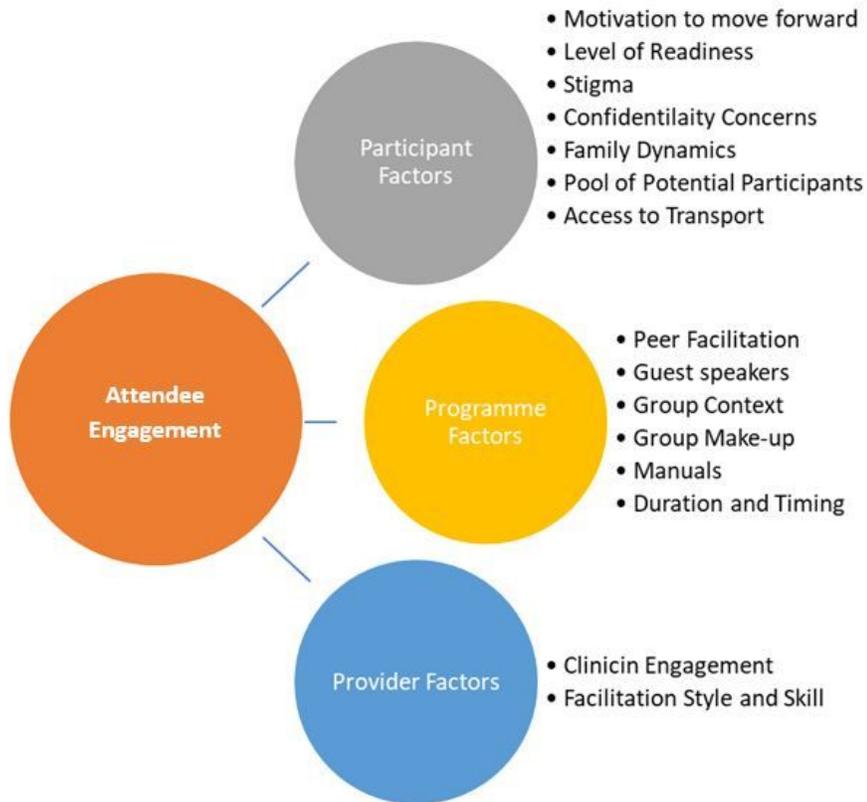


Figure 1

Factors influencing participant engagement with EOLAS

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