The EOLAS Project

The design, delivery and evaluation of a peer and clinician led information programme on recovery and mental health difficulties for users of services and family members

A collaborative venture between users of services, family members, practitioners and academics.

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EXECUTIVE SUMMARY

The current emphasis within Irish mental health service policy is on promoting a partnership approach between users of services, families and practitioners within an ethos of recovery. One strategy to promote this philosophy is the development of peer led educational interventions for both users and family members. The literature suggests that peer led programmes can have positive outcomes in terms of enhanced knowledge, empowerment and support. To date, the majority of programmes evaluated tended to be developed by practitioners and delivered either through the use of a clinician or peer model. In addition, there is a dearth of studies evaluating collaborative peer and clinician led educational interventions for people experiencing mental health difficulties or educational interventions developed in partnership with users and family members, which is the focus of the EOLAS project.

Aim of the evaluation

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (schizophrenia and bipolar disorder) for users of services and family members in the HSE Kildare/ West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

Methods

Collaborative principles guided all stages of the project. To identify the information needs of users of services and family members, a number of focus group interviews were conducted with the users of services, family members and clinicians. Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres. Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users of services or family members), who were recruited from within the service and attended a two day training programme.

This evaluation used a sequential mixed method design, involving the collection of both quantitative and qualitative data. Data were collected using pre and post course questionnaires followed by an integrated qualitative component to explore participants', facilitators' and project workers' experiences and views of the programme. In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. In addition, 25 family/friends completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. In total, 34 interviews were conducted with users of services, family members, facilitators and project workers.

Key findings

- Overall, it can be said that the EOLAS Project was a success and achieved its key objectives. All participants would recommend the programme and nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) of the programme as high or extremely high.
- While a number of the survey instruments did not show statistically significant changes, findings from the interviews suggest that the programme had a number of positive outcomes, including increases in perceived knowledge, empowerment and support. Both group of participants spoke of leaving the programme with a 'better understanding' of either their own or another's mental health problem. In addition, users of services, in particular, spoke of feeling more empowered to question practitioners about their care and treatment.
- It was clear from the interviews that participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.
- Findings indicate that participants valued the various teaching strategies used, including discussion groups, activities and information sheets. Hearing other people's stories was also considered a helpful learning strategy. However, some participants were of the view that they lacked time within sessions to address the content in-depth or to allow for discussion and sharing of views and experiences. Other issues that appeared to impact negatively on learning and group dynamics were the low numbers on some of the programmes, the open nature of the group, the changing of facilitators and the manner in which some of the learning materials were used.
- Both family members and user participants were of the view that the EOLAS Programme should be available to everybody immediately when they attend the mental health service, as part of an everyday quality service.
- One of the core differences between the EOLAS Programme and other programmes evaluated in the literature was the dual nature of the facilitation as it incorporated both peer and clinician facilitation. Survey participants generally agreed that having a user of services/family member as a facilitator on the programme was a positive experience (79%; n = 23). Interview

participants valued the role of each facilitator for different reasons. In their view, peers had credibility by virtue of self-experience and provided hope and inspiration. In contrast, the clinicians came with 'clinical expertise' that they also valued.

- Although the involvement of peers appeared to foster new understandings as people started to appreciate the person 'on the other side of the fence', findings also indicate that due to a variety of reasons, including insufficient preparation of facilitators around power dynamics, the valuing of clinical expertise over self-experience, and insufficient strategies for co-facilitation, on occasion, traditional power dynamics prevailed within the group. Consequently, the clinical facilitators were positioned as the 'leaders', with clinical knowledge being seen as more valuable than the voice of self-experience.
- Previous published studies appear to confine the delivery of programmes to people who had received a very specific diagnosis, with a reluctance to combine people from different diagnostic groups. This study demonstrates that combining people with different 'diagnoses' offers a promising approach, especially when there may not be enough potential participants to make organising diagnosis-specific groups a feasible option.

Recommendations

Bearing in mind that the written materials (information leaflets and facilitator manual) for the programme have been revised and subsequently evaluated by a cohort of users of services and family members, the researchers make recommendations under a number of key areas:

- The revised programme should be offered to users and family members both within and outside the Kildare/Wicklow services to cater for those who did not get the opportunity to attend and consideration should be given to providing all users of services and family members with relevant written information based on the EOLAS Project handouts immediately when they attend the mental health service as part of an everyday quality service.
- Subsequent programmes delivered should give consideration to expanding recruitment strategies, extending the duration of sessions and using additional creative teaching strategies.
- Future training programmes of facilitators should provide opportunities for in-depth discussion and reflection on the inherent power differentials between clinicians and peer facilitators and explore strategies of how to minimise such issues. In addition, future training programmes need to incorporate awareness raising exercises that would emphasise the unique and valuable contribution peer facilitators bring to programme delivery.
- The revised facilitators training programme should be given recognition by an appropriate accrediting and training body.
- In view of the unique needs of family members, consideration should be given to providing family members with information on support groups and accessible counselling services, and appointing a key worker who would act as a 'mediator' between families, users of services and mental health services.
- The revised programme should be further evaluated using a larger cohort of participants to ensure that statistical findings are robust. Further testing of the quantitative measures to identify those that would be most suitable in evaluating the efficacy of the EOLAS Programme is required. In addition, there is a need to evaluate the long-term benefits of EOLAS and to test the effect of different modes of delivery of the information programme, such as peer and clinician led face-to-face delivery versus online delivery.

CHAPTER 1

BACKGROUND LITERATURE

INTRODUCTION

In order to give a context to the EOLAS Project, the subject of the report, this chapter will review some relevant policy and research literature. The aim of the EOLAS Project was to develop, deliver and evaluate a peer and clinician led information programme on recovery from the experience of mental health difficulties (people with a medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members. The chapter begins with some policy background to user and family involvement in mental health care, as well as some background literature on the informational needs of both groups. This is followed by a section on recent trends in psychoeducational programmes, including the new, emerging area of peer-to-peer educational interventions for people experiencing mental health difficulties.

Users of services and family involvement: A partnership approach

Both national and international mental health services are moving to incorporate a more recovery-oriented philosophy into service provision. One of the core principles underpinning recovery is a shift in the paradigm of care and the relationships between practitioners, users of services and family members (Mental Health Commission 2006; Higgins et al. 2010). Indeed, various international and national health and social care policy documents have articulated a need for increased user and family involvement in the development, delivery and evaluation of mental health services (Department of Health and Children et al. 2008; World Health Organization 2010). The policy document *A Vision for Change* also reflects this collaborative perspective on service provision and recommends user and carer involvement in every aspect of service delivery with a view to enabling the recovery process (Department of Health and Children 2006). In addition, organisations, such as the National Institute for Clinical Excellence (2009) and the Mental Health Commission Ireland (2005), as well as Irish researchers (Brosnan 2006; Crowe 2006; Dunne 2006; Higgins 2008), strongly endorse partnership between users of services, family and practitioners, and consider that the ideals of a shared service approach will have positive outcomes for all.

Involvement of users of service has been linked to improved quality of health care, higher levels of satisfaction with services, increase in users' willingness to engage in treatment and improved health outcomes (Repper and Perkins 2003; Department of Health and Children et al. 2008; Higgins 2008). Similarly, there is a growing body of international evidence that recognises the importance of involving family members within the mental health services and the pivotal role played by family members and friends in supporting people with mental health issues in their recovery journey (Maurin and Boyd 1990; Rose 1996).

In addition to involving users and family members, there is an increased recognition that having access to peer support and peer groups is an important part of the recovery process for users (Mental Health Commission 2005; McDaid 2006; Higgins 2008; Slade 2009), and equally an important source of emotional support for family members (Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008; Jonsson et al. 2011). Peers, whether users of the service or family members, are considered to have greater credibility than practitioners and provide friendship, support, hope and direction, as well as encouraging development of coping skills (Resnick et al. 2004; Barber et al. 2008; Resnick and Rosenheck 2008). However, peer-to-peer approaches, although well developed and successful in other health contexts, have been underdeveloped in mental health care in general (Sibitz et al. 2007), including within Ireland.

Users of services informational needs

Despite the recognition of the rights of people who use the mental health service to have the most up-to-date information in both written and verbal format (Mental Health Commission 2005; Higgins 2008; World Health Organization 2010), the reality of every day Irish practice suggests that many services are behind in meeting the Mental Health Commission's standards on information giving (Mental Health Commission, 2005). Some of the quality standards identified include reference to users of services being "facilitated to be actively involved in their own care and treatment through the provision of information" (Mental Health Commission 2005: 30) and the importance of ensuring that information is "communicated in a way that is easily understood and made available both in verbal and written form" (Mental Health Commission 2005). Numerous studies carried out by Irish user groups and their representative organisations on users' experience of mental health service provision have highlighted a number of concerns. These include: poor communication with clinicians; lack of information relating to rights, diagnosis and treatment options, lack of choice and lack of access to alternative treatments (Western Health Board and Schizophrenia Ireland 2002; Brosnan 2006; Crowe 2006; Dunne 2006; National Service User Executive 2011).

Family member informational needs

Similarly, there is a growing body of international evidence that recognises the pivotal role that family members and friends play in supporting people with mental health issues (Maurin and Boyd 1990; Rose 1996). Gamble and Brennan (2006) identify that historically families have been as much burdened by the mental health system as by the person's mental health problem. Family members have often been (and often are still) perceived as part of the problem, if not the cause, of serious mental health issues. The reality, according to these authors, is that the treatment and recovery from serious mental health problems would not be possible without the participation of families and informal carers as they represent a major resource and support network for users (Gamble and Brennan 2006). However, to enable families to support their relatives, researchers have been identifying the importance of giving families information about their relative's mental health problem as far back as the 1970s (Hatfield 1978; Lefley 2001). In the Irish context, one of the recommendations of *A Vision for Change* is the "need to provide families and carers with support, information, and easily accessible help when needed" (Department of Health and Children 2006: 106). Furthermore, a recent report from the Mental Health Commission underlined family carers' needs for more understanding, information, empathy and respect from mental health service providers (Mental Health Commission 2005). However, Kartalova-O'Doherty et al.'s (2008) qualitative study involving 38 family carers of people who experience mental health problems highlights the short comings within the Irish mental health services. Participants within the study outlined the lack of services and support for family carers and reported receiving limited information from service providers about their relative's illness, treatment and prognosis. The participants also reported experiencing a clash between practitioners' desire to maintain the person's rights to confidentiality around diagnosis and treatment, and the families need to understand how they best can support and help their relative. Some key recommendations of this report were the need to introduce a key worker who would act as a 'mediator' between families, users of services and mental health services, and the need to provide families with information about diagnosis and other aspects of care.

Recent trends in information and psychoeducational programmes

Psychoeducational interventions are structured information programmes that focus on enhancing the emotional, social and behavioural well-being and the recovery journey of the individual who has experienced mental health problems. Psychoeducational approaches have been developed with a view to increasing knowledge and understanding of illness and treatment. It is supposed that increased knowledge has positive effects on quality of life and well-being, and enables people to cope more effectively. To date, clinician led interventions have dominated the field. Five Cochrane systematic reviews of psychoeducation and other psychosocial interventions indicate that the positive outcomes of psychoeducation, include reduction in relapse and readmission rates and improved psychosocial functioning (Pekkala and Merinder 2002; Cleary et al. 2008; Tungpunkom and Nicol 2008; Pharoah et al. 2010; Xia et al. 2011). For instance, Pekkala and Merinder's (2002) Cochrane review of 10 didactic psychoeducation programmes for people diagnosed with schizophrenia spectrum disorders reported that around 12 relapses can be avoided, or at least postponed for a year, if 100 users of services receive psychoeducation. Psychoeducation may also enhance adherence to medication, but the extent of improvement remains unclear (Pekkala and Merinder 2002). Research indicates that brief (eight to ten sessions) psychoeducational programmes produce significant reductions in relapse and rehospitalisation rates compared to treatment as usual at two year follow up (Buchkremer et al. 1997), five year follow up (Hornung et al. 1999) and seven year follow up (Bauml et al. 2007). Small effect sizes have been reported for knowledge gain (Pekkala and Merinder 2002; Rummel et al. 2005; Lincoln et al. 2007). The results for more immediate outcomes such as compliance with medication, improved mental state and psychosocial functioning are inconsistent, with differing methodologies providing different results (Cleary et al. 2008; Tungpunkom and Nicol 2008; Pharoah et al. 2010; Xia et al. 2011). In addition, the reviews do not draw any firm conclusions on the impact of psychoeducation on outcomes such as insight, medication-related attitudes or overall satisfaction with services. No standardised approach has been taken in relation to the duration of psychoeducational interventions, with programmes ranging from 1 to 24 sessions reported in the literature. The majority of previous psychoeducation evaluation studies have been conducted with users of services with durations of illness varying from 6.3 years to 14 years.

As stated, the vast majority of studies included in these reviews focus on professional developed and professional led interventions (Rummel-Kluge and Kissling 2008). In recent years, there have been some international studies examining peer led educational interventions. This section explores the existing, albeit scant, international literature on peer-to-peer and collaborative peer and clinician led educational programmes for people who experience mental health difficulties. The absence of a centralised data base makes it impossible to determine the number of professional or peer led information programme offered to users and family members within Ireland.

In total, nine relevant international studies on peer led educational interventions were located (Appendix I includes further details). Six studies were located that evaluated user led psychoeducational programmes (Rummel et al. 2005; Barber et al. 2008; Resnick and Rosenheck 2008; Cook et al. 2010; Druss et al. 2010; Pickett et al. 2010) and three studies evaluated family led psychoeducational programmes (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). There did not appear to be any studies of programmes, which were designed for both families and users of services or that were collaboratively facilitated by both family members and users of services.

Resnick et al. (2004), Resnick and Rohenheck (2008) and Barber et al. (2008) evaluated the 'Vet-to-Vet' programme, the peer-to-peer intervention for U.S. war veterans, across different settings and employing varying methods. Rummell et al. (2005) conducted an evaluation of a user led eight session programme in an open psychiatric ward of a university psychiatric hospital in Munich, Germany. In contrast to the bio-medical model underlying the Rummel et al. (2005) intervention, Cook et al. (2010) examined a recovery-oriented seven day Wellness Recovery Action Plan (WRAP) programme among 381 participants from two states in the USA. In a similar vein, Pickett et al. (2010) evaluated the eight week Building Recovery of Individual Dreams and Goals (BRIDGES) programme among 160 participants across the USA. Within the literature on family-focused programmes, Pickett-Schenk

et al. (2006; 2008) evaluated the family led educational intervention 'Journey of Hope', albeit in different contexts using different methods and populations. Dixon et al. (2004) examined a 12 week 'Family-to-Family Education Programme' based in Maryland, USA.

Findings from the evaluations suggest that peer user led psychoeducation enhances well-being, as measured by both recovery and traditional clinical tools. It was reported that these programmes result in significant improvements in hopefulness (Pickett et al. 2010), awareness of warning signs and symptom triggers (Druss et al. 2010), improved use of wellness tools, crisis planning, social support, and in taking responsibility for wellness (Cook et al. 2010). In addition, findings have also shown fewer psychiatric symptoms (Rummel et al. 2005), decrease in maladaptive coping (Druss et al. 2010), and improved self-advocacy, empowerment and recovery (Barber et al. 2008; Resnick and Rosenheck 2008). Furthermore, peer family member led education for family members resulted in a marked improvement in caregiving satisfaction and increased knowledge of mental illness, the mental health system and self-care (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). The evidence, thus, indicates that peer-taught programmes, whether user or family member led, are feasible and that peer facilitators serve as credible and positive role models.

The programmes reviewed were largely designed by practitioners and had little or no user input in their development. Thus, users of services or family members who attended the programmes were positioned as 'receivers' of expert, pre-packaged knowledge. The content of the programmes generally addressed areas such as symptoms of schizophrenia, causes, pharmacological and psychosocial treatment strategies, relapse prevention and the role of family support. The duration of the programmes tended to be one to two hour sessions and were typically conducted for eight weeks. Most of the programmes reviewed were highly structured and highly scripted manual-based programmes (Dixon et al. 2004; Pickett-Schenk et al. 2008; Druss et al. 2010).

The majority of the studies did not detail the specifics of the teaching methods employed on the programme, with the exception of the Vet-to-Vet programme (Resnick et al. 2004; Barber et al. 2008; Resnick and Rosenheck 2008), which used a non-prescriptive, discussion format. The focus of each session involved the reading and discussion of an established curriculum of recovery-oriented publications. The Vet-to-Vet programme appeared to be the only intervention in the literature that explicitly employs service-user involvement at a partnership level in both the development of the programme and the learning tools used on the programme (Resnick et al. 2004; Resnick and Rosenheck 2008).

There appeared to be a trend of co-facilitating involving two facilitators across the various educational interventions (Rummel et al. 2005; Pickett-Schenk et al. 2008; Druss et al. 2010). In all cases, both facilitators appeared to be either two family members or two users of services. The educational interventions delivered to both users and family members tended to be delivered more to people with a diagnosis of schizophrenia spectrum disorders, rather than bi-polar (Rummel et al. 2005; Barber et al. 2008; Resnick and Rosenheck 2008; Cook et al. 2010; Druss et al. 2010; Pickett et al. 2010). There also appeared to be a tendency to provide programmes that were disorder-specific and which did not 'mix' people with different diagnoses.

Many of the studies simply stated that the facilitators were trained without detailing the training procedures that were undertaken (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). The exception to this was Rummel et al. (2005) who employed a five step training programme to train two users of services co-facilitators, with a physician present at the beginning of training. The first step involved the trainee facilitators attending the psychoeducation group as participants for a complete programme, while observing and noting the facilitators' skills. The second step involved the trainees attending four training workshops over a two month period. The next step involved the two trainees facilitating several sessions together while being observed by a physician. Following this, the two trainees moved onto facilitating several sessions without being supervised by a clinician. The final stage in the training programme was the recruitment of new facilitators from cohorts of participants who had completed the psychoeducational group. The presence of a physician during the training of the facilitators may have been due to the fact that the majority of the participants on the programme evaluated by Rummel et al. (2005) were still in-patients in an 'open psychiatric ward'.

Summary

The current emphasis within Irish mental health service policy is on promoting a partnership approach between users, families and practitioners within an ethos of recovery. One strategy to promote this philosophy is the development of peer led educational interventions for both users and family members. The literature suggests that peer led programmes can have positive outcomes in terms of enhanced knowledge, empowerment and support. To date, the majority of programmes evaluated tended to be developed by practitioners and delivered either through the use of a clinician or peer model. Due to the differences in methodologies, participant profiles and programme content, it is not possible to compare the differential effects and outcomes of the clinician led with the peer-led approach to psycheoeducation. In addition, there is a dearth of studies evaluating collaborative peer and clinician led educational interventions for people experiencing mental health difficulties or educational interventions developed in partnership with users and family members, which is the focus of the EOLAS study. Hence, the importance of this evaluation, as a sound evidence-base is required to inform future development of shared approaches to care.

CHAPTER 2

Background & development of the EOLAS Information Programme

INTRODUCTION

In order to set the evaluation of EOLAS in context, this chapter describes the aims of the programme, governance structure, strategies and processes used to develop and deliver the education programme. In addition, some of the challenges encountered during the development phase are highlighted.

Background and aims

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia, bipolar disorder and related 'illnesses') for users of services and family members in the HSE Kildare and West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users of services and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

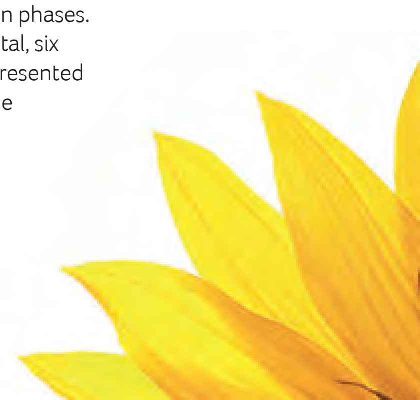
The project was a localised venture between the HSE Kildare/West Wicklow Mental Health Service, Shine, the Irish Advocacy Network and Kildare Youth Services. It was funded by the Genio Trust and designed to be a collaborative venture between practitioners working in mental health services, users of services and family members. The guiding values were captured in the mission statement of the EOLAS Project using the acronym SUPPORT: shared, understanding, partnership, participation, openness, respect and trust.

Governance structures

In keeping with the values of partnership and participation, the overall project was managed by a steering group that included clinicians from a range of disciplines (medicine, nursing, social work and psychology), users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team Trinity College Dublin. Two project workers, with responsibility for various aspects of project development, design, recruitment and roll out, were employed part-time to support the steering group. In addition, two researchers, including a researcher with experience of using mental health services, were employed as part of the research team. To assist with the day-to-day aspects of the project, a number of sub-committees were also formed. These reported to and received feedback from the main steering committee. The timeframe for the total project was less than 12 months due to the nature of the funding. The design, development and roll out of the programme occurred between January and August 2011, with the evaluation phase, including write-up and modifications to the original programme being complete by December 2011. An overview of the EOLAS process is presented in Figure 1.

Generating collaboration and commitment within the mental health teams

Generating commitment and 'buy in' from the mental health teams within the HSE Kildare/ West Wicklow area was considered critical to the success of the programme, as both the participants and the facilitators would have be to recruited from within those services. To achieve this, both the project workers and members of the research team met with a number of clinical teams to explain the aims of the project, and the processes and strategies to be used in the design, recruitment, roll out and evaluation phases. During these meetings, time was set aside to answer questions and to elicit feedback and suggestions. In total, six clinical, multidisciplinary and community mental health teams in the Kildare and West Wicklow area were presented with information and asked to assist. In addition to the meetings with clinical staff, the project workers made presentations to some community and voluntary sector providers and informed people about the project through posters. A website with information about the programme was also designed by a member of the steering group: **www.theEOLASproject.com**



From the outset, it was agreed that the information programme would be delivered to people who had a diagnosis of schizophrenia or bipolar disorder. This decision was based on a belief that the main information needs would be similar for both diagnostic groups and that a combined group would be an efficient use of resources. In general, the idea of the EOLAS Project was well received by the clinical teams, who were of the view that it would address key information deficits and the needs of users and families.

While the teams welcomed the fact that the programme would be delivered in both urban and more rural venues, teams within the more rural areas highlighted issues such as transport, cost and travel time. Other concerns expressed by some members of the clinical teams included the appropriateness of having users of services with different diagnosis within the same group, as well as some concern around ownership and facilitation of the programme. Following discussion and clarification, the clinical team members agreed to become involved in the recruitment phase of the project, which required them to circulate information and refer both users of services and family members to the initial consultation groups and the programme, once it was developed. Some members of teams, at this stage, also volunteered to be clinical co-facilitators.

Maintaining high ethical standards and support

Engaging in research in the area of mental health can be fraught with challenges, ranging from difficulties in recruitment to a view that mental health users of services and family members are too 'vulnerable' to participate fully in research. For this reason, from the start priority was given to maintaining the highest standards of information giving, protection and support of participants. Ethical approval to conduct both the information programme and the subsequent evaluation was given by the ethics committee within the service and the ethics committee of the university where the evaluation team worked.

At the outset, it was decided that the most appropriate way to recruit users was through clinical referral by the various mental health teams. It was thought that this referral process would go some way to ensuring that only those people who were 'well enough' would become involved. The involvement of the mental health teams also ensured that if members of the project group were concerned about any participant, they had immediate access to support for the person. In addition, potential participants (users of services, family members and clinicians) were informed from the outset in advertising literature and verbally by the project workers that the programme was being evaluated by an independent external group from Trinity College Dublin. Participants were also informed that they could participate in the EOLAS Project without obligation to participate in the evaluation. To ensure that the project workers were adequately supported, a system of peer debriefing and debriefing with their manager was implemented.

Designing the education programme: Eliciting multiple perspectives

Historically, people with mental health problems and family members have lacked a voice and have been excluded from decision-making in areas ranging from service development to their own care (Department of Health and Children 2006; McDaid 2006; World Health Organization 2010). Consequently, one of the core objectives of the EOLAS Project was to develop an information programme that was pertinent to the needs and wants of all the participants, that was developed collaboratively and where users of services' and family members' voices would take centre stage. In order to achieve this goal, a series of focus groups were held with users, family members and clinicians. During the focus groups, the participants were facilitated to identify and discuss the issues that were important to them and to identify what they would like to see included in the programme.

In total, 15 focus groups, facilitated by the project workers, were conducted in seven different locations throughout County Kildare (Athy, Celbridge, Newbridge, Maynooth, Johnstown Bridge, Naas, Kildare). Participants for the focus group were recruited through clinical referrals and posters that were displayed throughout the services.

Initially, recruitment to the focus groups was slow with a poor turnout at some venues. However, once this issue was brought to the attention of the steering committee, they made further contact with clinicians requesting assistance in recruitment. This strategy proved useful as more participants came forward. In total, 58 people participated in the focus groups. Table 1 provides a more detailed breakdown of participant numbers.

TABLE 1. NUMBER OF FOCUS GROUPS BY TYPE AND NUMBER OF PARTICIPANTS IN EACH

GROUP	NUMBER OF FOCUS GROUPS	TOTAL NUMBER OF PARTICIPANTS
Users of services	7	30
Family	7	21
Clinicians	1	7

The focus group discussion was guided by a topic guide developed by the project workers in conjunction with the clinical sub-group and addressed issues around recovery, staying well and information needs. To facilitate clinicians who were unable to attend the focus group an e-version questionnaire based on the topic guide was also distributed.

Key outcomes of users of services and family focus groups as perceived by the project workers

Overall, participants engaged proactively in the focus group discussions. The project workers reported that the user and family member groups were characterised by accounts of loss, grief, trauma and frustration. Both family member and user participants reported that there were few outlets where they could discuss their emotions and deal with their problems. Counselling was either too difficult to access, too expensive or had a long waiting list. As a result, the project workers heard some distressing stories and reported the overriding emotion in both groups as one of grief. This grief manifested itself in terms of a sense of loss, anger and powerlessness. The project workers responded to the outpouring of emotions by allowing participants to express their emotions for a period of time and then gently and sensitively re-focusing the person to the aims of the focus group. In addition to this strategy, the project workers also invited each person, at the end of the discussion to write how they felt the group went. In situations where the project workers had concerns about a participant, they informed the clinical team.

The grief expressed by the users of services appeared to be associated with their 'illness' and diagnosis. They spoke of experiencing shame and regret over their 'illness', and grieved the negative impact that their mental health problem had on their life and relationships. Users of services were frustrated with the perceived over-emphasis on medication within services and the absence of information on other forms of therapies. In addition, they expressed frustration at the lack of consultation and involvement in their medication regime.

Despite the distressing stories recounted by the users of services, the project workers found that they *"were remarkably measured in their responses, even in relation to their grievances with the mental health services"*. They found that participants were reconciled with their experiences, forward looking, very motivated towards recovery and wanting to move on with their lives. They requested information on how to manage their mental health problem or 'condition'. Specifically, they wanted information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with 'symptoms', 'medication side-effects', low self-esteem, negative attitudes from others and the shame they experienced as a result of having had a psychotic episode. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment, or as in the words of one project worker, they wanted to *"get on with things and lead their life."*

In contrast, the project workers reported that family focus groups were characterised by the expression of far greater amounts of anger, grief, trauma and loss. The family members were grieving the loss of their relative who they felt had, metaphorically, 'died'. Family members were stressed about their caring role and felt angry with the lack of support from the mental health services. Family members felt *"stuck, caught, lost"* and *"left out"* by the mental health system. They were angry with a system that did not consult them around decisions made about the care of their family member or provide them with information that might help them in their caring role. This lack of consultation and information further compounded their distress and added to their confusion, anger and disempowerment. The following two quotes were indicative of what the project workers heard:

> *"No one seems to take the time to explain, 'This is how the system operates. This is what we do. This is how we do it.'"*
>
> *"It's really a case of having to stand your ground, having literally to bang on the table and say, 'I'm not going from here until I get what I want.'"*

Family members, therefore, wanted to meet with a psychiatrist and to be given more information on their family member's 'illness', treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.

Detailed analysis of the focus groups indicated common themes across both the user and family groups; however, each had a very different emphasis and focus. Consequently, it was decided that the needs and wants of users of services and family members were so diverse that two separate programmes needed to be developed and delivered. Findings from the users groups also confirmed the previous decision to combine people with different diagnosis (schizophrenia and bipolar disorder). The overall themes identified from each group focus group are summarised in Table 2.

TABLE 2. THEMES IDENTIFIED IN USERS OF SERVICES AND FAMILY MEMBER FOCUS GROUPS

USERS OF SERVICES GROUP	FAMILY MEMBERS
Medication, its positive benefits and its side effects	Coming to terms with family member 'illness'
Diagnosis	How to deal with anger and anguish
Rights and advocacy	Understanding how the mental health service works
Asking questions of clinicians	Skills to ask questions of clinicians
Staying well and recovery	Opportunity to speak to doctors about diagnosis and medication
Community integration	Opportunity to discuss experiences
Sharing stories	

Key outcomes of clinician focus group and e-survey as perceived by the project workers

One clinician focus group was held with members of mental health teams located in the HSE Kildare and West Wicklow area with the aim of exploring their views on the content and structure of the programme. Participants in this group strongly supported the development of the programme as they were of the view that communication with family members was lacking across all teams. They also felt that in addition to giving information to users and family members, the education programme should support participants to gain the confidence to ask questions of practitioners.

As an outcome of the focus group and e-survey, a number of ideas for the development of information handouts were identified, such as information handouts on common clinical terms, questions to ask about 'illness' or medication and descriptions of the role of each team member. Participants were of the view that information on these issues might help to *"demystify the language and process"* for users and family members and encourage participants to be proactive about empowering themselves into the future.

Designing the education programme: Core philosophy

Although the programme was designed to be primarily focused on disseminating information and, consequently, was to be instructional in nature, special emphasis was to be placed on the ethos of adult learning principles (Knowles 1970). Knowles is credited with devising the basic model of Andragogy [1] in the 1970s, which is generally considered to be both a philosophy and a practice of adult learning. Its logic rests on the assumptions that as a person matures: (1) they become more self-directing in their learning; (2) their wealth of personal experience needs to be acknowledged as a resource for learning; (3) their learning is oriented toward performing roles and tasks; (4) they have an increased need to apply their learning to immediate real life situations and, accordingly; (5) the person's orientation toward learning is problem centred (Knowles 1970; Knowles et al. 2005). Thus, emphasis within the programme was to be placed on creating a mutually co-operative learning environment by adhering to the values of voluntary participation, mutual respect, a collaborative spirit, action, critical reflection and self-direction (Brookfield 1988). It was hoped that this approach would enable participants to feel more empowered in their subsequent dealings with the mental health services.

Designing the education programme: Content, format and teaching strategies

The content to be included in the information programme were based on the thematic analysis of the information from the focus groups. The analysis and development of the information programme was overseen by the clinical subgroup. Deciding on the depth and breadth of each topic required consideration of how best to reflect the participants' needs with due considerations of the time constraints and resources available. This aspect of the project was particularly challenging for the project workers and clinical subgroup as the timeframe for completion was extremely short (less than 2 months).

Each session was designed to be 90 minutes in duration, and consisted of input from the facilitators, learning activities, opportunity for questions and answers and some personal sharing and reflection. The learning activities were to be done in groups, pairs and individually, with the facilitators moving through the groups supporting participants as they worked through each activity. Thus, each session was to include elements of self-directed learning and some peer learning with an emphasis on the application to one's own life experience. At the end of each session, participants were requested to do a piece of work for the next session. This strategy was included in the hope that participants would be encouraged to become more proactive in sourcing information and interacting with practitioners.

In addition, participants were given detailed written handouts with information on the topic addressed during the session. It was hoped that at the end of the programme participants would have a personal resource manual that they could revisit or share with their family members and friends. The written handouts were voluntarily submitted by members of the team including a psychiatrist, pharmacist, solicitor and advocate. In keeping with the principles of adult learning, the concepts of empowerment, recovery and advocacy were to underpin each session.

In addition to input from the clinical and peer facilitators, a number of other people were to attend the information sessions and provide input. It was clear from the users and family member focus groups that they would like to meet with 'experts'. To access experts to speak to eight different groups in four different locations was a challenge. A number of psychiatric consultants volunteered to speak on diagnosis, treatment and medication. Inputs were also to be given by Community Welfare Officers, occupational therapists, social worker and psychologists. These speakers were drawn from the local mental health service in the hope of increasing the chance that the participants would identify with them and, subsequently, have less difficulty approaching them.

The user programme ran over eight weeks and addressed information on mental health service provision, diagnosis, treatment, medication and care, strategies to maintain relapse prevention, advice on pro-active engagement with mental health services, sources of self-help information, support groups and agencies, personal stories, statutory rights and entitlements, and the Mental Health Act.

The family programme ran over seven weeks and the main topics included were strategies to attain and maintain a good quality of life for family members, information on mental health service provision, diagnosis, consultations, medication, treatment and care, reliable sources of information, communication and engagement with services, advocacy, coming to terms with living with mental health difficulties, legal and statutory rights, and positive stories.

As stated at the outset, the timeframe for developing and rolling out the programme was approximately eight months. This timeframe resulted in the project workers developing and writing aspects of the programme (information handouts and activities) as it was being rolled out. Consequently, facilitators had little time to familiarise themselves with some aspects of the content and may have only received the information on the day of that particular session. In view of this and to ease the delivery of the programme, the project workers did develop guidelines for the facilitators. The guidelines were to provide direction to the facilitators on how to introduce, facilitate and close each session. In addition, direction was given on the duration of time to be spent on each activity.

Recruiting and training the facilitators

Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users or family members). Clinicians brought their clinical expertise, while users and family members brought a wealth of personal knowledge and experience.

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[1] Andragogy is a term frequently used to denote adult learning.

Due to the previously noted time pressure, there was no formal application or interview process to select suitable facilitators; it was more a case of who was available and willing to volunteer. The majority of family member and user facilitators were recruited through their participation in the focus groups, with some having been approached and recruited by members of mental health teams. The clinical facilitators were recruited from the clinical teams within the services.

Educating the facilitators was considered to be crucial to the success of the programme. However, due to time constraints and clinical pressures, it was only possible for facilitators to receive a two day training programme. The first day of training centred on facilitation skills and was delivered by a private organisation that was skilled in delivering facilitation programmes. The second day focused on helping the facilitators to familiarise themselves with the facilitator handbook and the content of the programme materials developed (see Table 3). In total, 13 clinicians and 10 peer facilitators attended the training.

TABLE 3. TOPICS FOR FACILITATOR TRAINING

DAY 1	DAY 2
Agreeing principles and values	Information on aim, objectives and content of each module
Stages of group development	Demonstration of one module by the project workers
Responding to process challenges	Practice demonstration by clinician and peer facilitator
Listening and clarifying skills	
Working with a co-facilitator	

Rolling out the programmes

A separate programme for family members and users of services was delivered in four centres in the Kildare and West Wicklow Mental Health Services area (Kildare, Athy, Maynooth and Naas) throughout the months of July and August 2011.[2] Programmes were run in venues independent of the health services, which included hotels and community centres. Throughout the programme, the facilitators were supported by the project workers, along with the Assistant Director of Nursing. This level of support was necessary to ensure that practicalities, such as an absence of facilitators, transport for participants, organising guest speakers and photocopying, could be responded to in a timely and efficient manner. In addition, the Assistant Director of Nursing acted as a point of clinical contact, advice and liaison with the mental health teams if the facilitators became concerned about any participant.

A number of strategies were used to recruit user and family member participants for the information programme. Users were recruited by the clinical teams, by posters within the mental health services and through a presentation to EVE mental health support services in county Kildare. Family members were also recruited through clinical teams and by posters within the mental health services.

Summary

- The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental difficulties (medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members in the HSE Kildare and West Wicklow area.
- The project was managed by a steering group that included clinicians, users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team. Two project workers were also employed.
- Collaborative principles guided all stages of the project. To generate support for the project, presentations on the aims and objectives of the project were made to members of the clinical team, the community and voluntary sector. In addition, focus groups (n = 15) were conducted with users of services, family members and clinicians to identify the information needs of users of services and family members.
- Users of services expressed a desire for information on how to manage their mental health or 'condition', as well as information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with 'symptoms', 'medication side-effects', low self-esteem, and negative attitudes from others. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment.
- Family members wanted to meet with a psychiatrist and to be given more information on their family member's 'illness', treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.
- Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres in the Kildare and West Wicklow Mental Health Services area (Kildare, Athy, Maynooth and Naas) throughout the months of July and August 2011.
- Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users ofservices or family members), who attended a two day training programme.

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[2] Due to low attendance rates, the family member course at one location was discontinued.

CHAPTER 3

Research methodology

INTRODUCTION

In this chapter the study aims, objectives, study design, methods and ethical procedures are described.

Aims and objectives of evaluation

The aims of the evaluation were to explore participants' experience of their involvement in a collaborative user and clinician led information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia, bipolar disorder or related 'illness') and to evaluate the impact of the EOLAS Project on participants' perceived knowledge, attitudes and well-being.

Specifically, the objectives of this evaluation were:

- to investigate the impact attending the information programme had on users of services, and family members' perceived knowledge, attitudes towards recovery, hope, support, advocacy and well-being;
- to explore participants' experience of being involved in the information programme;
- to explore the experiences of both the clinician and peer facilitators in the delivery phase; and
- to determine ways of improving and developing the EOLAS information programme.

Design

This evaluation used a sequential mixed method design involving the collection of both quantitative and qualitative data. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the programme of participants, facilitators and project workers.

Data collection methods

Data were collected using a combination of questionnaires and interviews. Data on the impact of the EOLAS Project were collected using pre and post programme questionnaires. Questionnaires were completed by participants prior to starting the information programme (pre-programme), at the end of each information session and immediately after completion (post-programme).

A post-programme semi-structured interview was used to explore the participants', facilitators' and project workers' experiences and opinions of the EOLAS Project, including their suggestions for improving the programme.

Questionnaire design

The surveys examined the possible outcomes of participating in the programme, such as increased hopefulness, increased knowledge of mental health issues and improved attitudes towards recovery. The post-programme questionnaires also explored the participants' satisfaction with the EOLAS Project, including content and process of delivery. There were two versions of the questionnaire developed: one version for users of services and the other for the family member EOLAS participants.

Pre-programme questionnaire

The pre-programme user questionnaire consisted of seven sections. Demographic data were gathered in sections A and G, including information on age, gender, civic status, living circumstances, employment status, level of education and daily living activities. The medical diagnosis for the participant's mental health difficulty was asked about in section A.

Section B consisted of a 15-item scale on which participants rated their level of perceived knowledge of mental health issues including symptoms, coping skills, relapse triggers and roles within the community mental health team. The questions in this section were scored using a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree).

Section C comprised the Recovery Attitudes Questionnaire 7 (RAQ-7), which consisted of a 7-item scale developed by Borkin et al. (2000). The RAQ-7 has been used and tested with people with self-experience of mental health issuse, carers, their families and mental health practitioners. The scale had a Cronbach's alpha of 0.70 and a test-retest reliability coefficient of 0.67 in a sample of 844 (Borkin et al. 2000). It is deemed to be appropriate to assess attitudes toward recovery and to differentiate between those who are familiar with and positive towards the idea of recovery from those who are not (Borkin et al. 2000). Based on discussions by the members of the EOLAS research sub-committee, three additional items were added to this section. These items examined perceptions of how interpersonal relationships impact on recovery. The questions in this section were 5-point Likert scale questions ranging from 1 (strongly agree) to 5 (strongly disagree).

Section D (views on hope in your life) used the Herth Hope Index (HHIndex). This instrument measures the respondent's level of hopefulness for the future. The response format of the HHIndex is a 4-point scale from 1 (strongly agree) to 4 (strongly disagree). Herth (1992) initially tested the HHIndex in a convenience sample of 172 adults (70 acutely ill, 71 chronically ill and 31 terminally ill patients). Internal consistency was estimated by a Cronbach's alpha of 0.97, with a 2-week test-retest reliability of 0.91 (Herth 1992). Concurrent criterion-related validity was supported by demonstrating moderate to high correlations between the HHIndex and the original HHScale (r = .92), the Existential Well-being Scale (r = .84) and the Nowotny Hope Scale (r = .81).

Section E (self-advocacy) asked participants to rate their views on being able to advocate for themselves in relation to their mental health issue. The 10 items were scored on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). These 10 items were taken from the 12 item Brashers et al.'s (1999) Patient Self-Advocacy Scale (PSAS). These items were selected by the EOLAS research sub-committee and reworded for the Irish context (e.g. physician was changed to mental health team/worker). The PSAS has demonstrated good reliability (Cronbach's alpha = 0.78) and validity (criterion and construct) in two samples, one of 174 adults from an HIV-AIDS population and 218 adults from a general population (Brashers et al. 1999).

Section F (drug attitudes) included five items taken from the 10-item Drug Attitude Inventory (DAI-10) (Hogan et al. 1983). The purpose of this section was to examine the participant's attitudes towards medication for mental health difficulties. The original inventory included a true/false response format. The research team and the EOLAS research sub-committee decided that a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree) would be more appropriate to measure attitudes in this study. The DAI-10 has consistently demonstrated good internal consistency and high test-retest reliability (e.g. Cronbach's alpha 0.83 in a sample of 157 by Yoon et al. 2005).

The pre-programme family member questionnaire consisted of eight sections. This version of the pre-programme survey used the same scales as the users version in sections A (background information), B (knowledge of mental health issues), C (recovery attitudes), D (self-advocacy), F (views on hope in your life), and H (additional background information). The only difference being that the items were reworded to link the questions to their family member's experience of their relative's mental health difficulty. It was emphasised throughout the survey that the questions refer to the respondent's own views and attitudes and not that of their relative who uses the mental health services.

Additional scales that were included in the family member the questionnaire included section E (social network of support) and section G (your general health). The Social Network of Support scale was created by the members of the EOLAS research sub-committee and refined by the research team for the purposes of this study. This six item scale examines the family member's or friend's perceptions of the social support that is available to them to help them cope with their caregiving responsibilities, as well as to deal with their own needs. The social networks that were specified in these items included other members of their own family, friends, other families and members of the mental health team. The six items were scored on a 5-point Likert scale ranging from strongly agree (1) to strongly disagree (5).

Section G featured the 12 item version of the General Health Questionnaire (GHQ-12). The GHQ-12 is an extensively used self-report instrument for the detection of mental health issues in the community and non-psychiatric clinical settings (e.g. primary care). It refers to the severity of psychological complaints relative to the person's normal situation. Reliability and validity of this instrument has been consistently demonstrated. Schmitz et al. (1999) demonstrated a Cronbach's alpha of 0.91 in a sample of 408 randomly selected sample adult outpatients from 18 primary care centres in Dusseldorf, Germany; furthermore, evidence of concurrent and criterion validity has also been reported (Schmitz et al. 1999).

Post-programme questionnaires

For comparative reasons, the post-programme questionnaires (both for users and family members) repeated all the questions included in their respective pre-programme questionnaires without alteration. The post-programme questionnaires (both users and family member) contained an additional section towards the end of the survey. This section (satisfaction with EOLAS Project) was designed to evaluate the programme in terms of participants' perceptions of the operation of the programme, learning tools and teaching methods. The section consisted of a number of new 5-point Likert questions, ranging from 1 (strongly agree) to 5 (strongly disagree). Two 5-point Likert scale items were also added to this section to elicit participants' overall satisfaction and enjoyment of the programme scored from 1 (extremely low) to 5 (extremely high). Participants were also given an opportunity to write free responses to a question asking for any other comment they would like to make about the EOLAS Project.

Pilot of questionnaires

Data collection tools were developed after several refinements and iterations in conjunction with the EOLAS research sub-committee. The surveys were also piloted with a group of users and family members. The feedback from the pilot indicated that the questionnaires were user-friendly and could be completed within the suggested timeslot of 20 minutes. The participants in the pilot study made several recommendations for some minor rewording and formatting alterations. The survey instruments were subsequently adjusted on foot of this feedback.

End of session feedback forms

Data were also collected using individual feedback forms that facilitators asked participants to complete at the end of each EOLAS session. The feedback forms asked about their likes and dislikes in relation to the session attended and were used to supplement the data generated in the questionnaires and interviews.

Interviews

Post-programme semi-structured interviews were used to elicit the participants' and facilitators' views of and experiences of the EOLAS Project. A series of interviews were also undertaken with the project workers at various intervals during the span of the project in order to learn about their experiences and views.

Separate interview topic guides were developed for each of the four cohorts of interviewees (users, family member, facilitators and project workers), as each cohort had a different focus for the interviews. The interview guide for the users of services focused on the impact of the programme on their daily living, well-being and the experience of being in a group of peers with similar mental health difficulties. The interview topic guide for the family members concentrated on the impact of the programme on their ability to deal with their caregiving responsibilities, their own distress and the experience of being in a group with other family members caring for someone who has experienced a mental health difficulty. The interview guide for the facilitators closely examined their experiences of being a co-facilitator, their preparation for the role and what helped or hindered them in this role. Finally, the interview guide for the project workers examined their experiences of developing the project, rationale for decision making, challenges encountered and strategies for overcoming them, and strengths and limitations of the programme.

Participant recruitment strategies

Participants for the EOLAS Project were recruited by the mental health service funding the project. This occurred independent of the researchers. During the recruitment process, potential participants were informed from the outset in advertising literature and by the programme organisers that the programme was being evaluated by an independent external group from Trinity College Dublin. At this time, the participants were given an information brochure prepared by the researchers. The information brochure informed potential participants of the details of the study including its purpose, process, potential benefits and harms, data collection procedures, time commitment, voluntary participation, the right to withdraw without prejudice, assurance of confidentiality (including in study publications), the lead researcher's contact details and an offer to answer any questions. Participants were also informed that they could participate in the EOLAS Project without obligation to participate in the evaluation.

EOLAS participants had at least a week to read the information before the start of the programme. On the first day of the programme, participants were given a pre-programme questionnaire in an envelope along with a research information sheet. They were requested to complete the questionnaire if they wished to be involved and return it in the envelope provided. Participants were informed not to write their names or any other personal information on the questionnaires. Participants who did not wish to complete the questionnaire were also advised that they could return the questionnaire without completing it. In this way, people who did not wish to participate could do so without feeling pressured by their peers.

The pre-programme pack that was distributed in the first session of the programme also included an opt-in form for the post programme semi-structured interviews. With this form, participants could indicate their willingness to be part of an interview. Each form had an accompanying stamped envelope addressed to the researchers. Those who chose to be interviewed were contacted by a member of the research team who answered any questions they had.

The post-programme questionnaires were distributed by the researchers at the end of the final EOLAS session. Interview opt-in forms were again included in these survey packs so as to maximise the numbers of interviewees.

The facilitators (user and clinical) were recruited at the facilitator training programme. A member of the research team gave a presentation on the rationale behind the EOLAS evaluation, as well as detailing the methodological tools that would be used and the underlying ethical principles to which they would adhere. In particular, the voluntary nature of engaging in the research aspect of the EOLAS Project was stressed by the researchers. During the facilitator training programme, each facilitator was given an information pack containing a research information sheet and a post-programme interview opt-in form with accompanying stamped envelope addressed to the TCD research team.

Sample

In total, 30 users of services attended the first session of the EOLAS Programme across the four project areas. Of these, 28 users of services completed the pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Twelve users of services completed both questionnaires. Response rates of 93% and 40%, respectively, can be estimated for service user questionnaires pre and post course. In total, 25 family members attended the first session of the EOLAS Programme across the four project areas. Of these, 25 family members completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. Of these, eight completed both questionnaires. Response rates of 100% and 72%, respectively, can be estimated for family member questionnaires pre and post course.

In total, 34 people participated in interviews. The interviews lasted between 20 and 90 minutes. They were conducted at a place of convenience for the interviewee.

Pre-survey sample

Users of services

In total, 28 users of services completed the pre-survey. Of the 25 participants who provided information, 72% (n = 18) had not attended the EOLAS focus group. Their demographic information and diagnoses are presented in Table 4. Nearly three-quarters were male and participants ranged in age from 23 to 80. Nearly half were single and 30% were either married or had a partner. Approximately equal percentages had completed third level, upper secondary level or lower secondary level. The majority of the sample reported that they had received a diagnosis for their mental health issue. Of these participants, approximately half had been diagnosed with schizophrenia and an additional 28% with bipolar disorder. Eight percent of participants had been diagnosed with schizoaffective disorder and the remaining 8% with depression or severe depression.[3]

TABLE 4. DEMOGRAPHIC AND CLINICAL PROFILE OF PRE-PROGRAMME SURVEY SAMPLE: USERS OF SERVICES

VARIABLE	N (%)
Gender	
Male	20 (74%)
Female	7 (26%)
Civic status	
Single	13 (48%)
Married	5 (19%)
Separated	3 (11%)
Divorced	2 (7%)
Widowed	1 (4%)
Partner	3 (11%)
Level of schooling completed	
Primary	3 (12%)
Lower secondary	8 (32%)
Upper secondary	7 (28%)
Third level	7 (28%)
Received a medical diagnosis for mental health problem	
Yes	24 (92%)
No	2 (8%)
Diagnosis received	
Bipolar	7 (28%)
Schizophrenia	14 (56%)
Schizoaffective	2 (8%)
Depression	2 (8%)

Information on the domestic details and daily activities of the pre-programme users of services is presented in Table 5. Of the 26 who provided information about their living situation, just over 60% were living with family members. About one-quarter lived alone. The greatest proportions lived either in a home either they or their family owned or were paying the mortgage for. Approximately one-quarter of the participants were renting either from local authority or privately. Participants were involved in a wide variety of daily activities.

TABLE 5. DOMESTIC DETAILS AND DAILY ACTIVITIES OF USERS OF SERVICES

VARIABLE	N (%)
Current living arrangements	
Alone	6 (23%)
Family members	16 (62%)
Non-family members	4 (15%)
Type of housing	
Home that is owned/paying mortgage for	9 (36%)
Home that family member owns/paying mortgage for	7 (28%)
Renting from local authority	4 (16%)
Renting from private landlord	2 (8%)
Living in community housing/hostel	3 (12%)
Typically spend the day	
Meeting friends & family	11 (42%)

(Continued on next page...)

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[3] This is a self-reported diagnosis. Participants' records may have recorded other diagnoses but this was not checked. In addition, participants had the option of ticking more than one diagnosis.

(...Table 5 continued)

Involved in other hobbies/interests	10 (39%)
Reading books/magazines	10 (39%)
Looking after home/family	9 (35%)
Watching T.V.	15 (58%)
Attending day programme	6 (23%)
Working for payment (full/part-time)	6 (23%)
Attending school/college	2 (8%)
Other	
– Horses	1 (4%)
– Internet	1 (4%)
– Listen to radio	1 (4%)
– Rehabilitating	1 (4%)
– Sleeping/avoiding contact	1 (4%)

Family

In total, 25 family members completed the pre-survey. One-third had attended the EOLAS focus groups and over half heard about the EOLAS programme from a mental health care worker. Of those who provided information about their gender, 75% were female. Participants ranged in age from 31 to 70. Approximately three-quarters of the sample were married. In terms of education, just under half had completed third level education. Of those who described their relationship to the person they were caring for, the majority were parents (40%), partners (30%) or siblings (25%). The majority of the sample reported that their family member had received a diagnosis and the most commonly reported diagnosis for their family member was schizophrenia. Further details are presented in Table 6.

TABLE 6. DEMOGRAPHIC PROFILE OF PRE-PROGRAMME SURVEY SAMPLE OF FAMILY

VARIABLE	N (%)
Gender	
Male	6 (25%)
Female	18 (75%)
Civic status	
Single	3 (12%)
Married	18 (72%)
Separated	3 (12%)
Divorced	-
Widowed	-
Partner	1 (4%)
Level of schooling completed	
Primary	6 (24%)
Lower secondary	5 (20%)
Upper secondary	3 (12%)
Third level	11 (44%)
Relationship to users of services	
Parent	10 (42%)
Spouse/partner	7 (29%)
Sibling	6 (25%)
Other family relationship	2 (7%)
Received a medical diagnosis for family member's mental health problem	
Yes	22 (92%)
No	2 (8%)
Diagnosis received for family member	
Bipolar	2 (9%)

(Continued on next page...)

(...Table 6 continued)

Schizophrenia	8 (36%)
Schizoaffective	2 (9%)
Other	10 (46%)
– Morbid jealousy	3 (33%)
– Psychosis/delusional disorder	3 (33%)
– Yes and No- diagnosis varies by doctor	1 (11%)
– Depression	1 (11%)
– PTSD/generalised anxiety disorder	1 (11%)
Attend pre EOLAS focus group	
Yes	8 (33%)
No	16 (67%)
Where EOLAS was heard about from:	
Mental health care worker	13 (54%)
Family member/friend with mental health problem	5 (21%)
Other	6 (25%)
– Care worker	1 (17%)
– District nurse	1 (17%)
– From support	1 (17%)
– Medical team of parent	1 (17%)
– Support group in Naas	1 (17%)
– Wife	1 (17%)

Post-survey sample

Users of services

In total, 12 users of services completed the post-programme survey. Of those who provided information about their gender, the respondents were evenly split between males (50%; n = 5) and females (50%; n = 5). The age range was between 30 and 63 years. All of these respondents attended over six EOLAS sessions: 30% (n = 3) attended six, 20% (n = 2) attended seven and 50% (n = 5) attended eight.

Family

In total, there were 18 family members who completed the post programme survey. Of those who provided information about their gender, 76% (n = 13) were female and 24% (n = 4) were male. All were between 31 and 68 years of age. All respondents had attended four or more EOLAS sessions: 11% (n = 2) attended four, 33% (n = 6) attended five, 33% (n = 6) attended six and 22% (n = 4) attended seven.

Interview sample

In total, 32 people (19 programme participants, 11 facilitators and 2 project workers) participated in 34 interviews (19 programme participants, 11 facilitators and 4 project workers).

Programme participant sample

In total, 19 programme participants were interviewed. Of these programme participants, 11 were family members. The family member programme participants were approximately evenly split between females (n = 6) and males (n = 5) and all were between the ages of 22 and 66 years. These participants were mostly parents (n = 7), split approximately evenly between mothers and fathers. There were also two siblings, one husband and one wife of user participants. There were eight users of services who participated in the interviews, four males and four females.

Programme facilitator sample

In total, 11 facilitators participated in interviews: seven clinicians, two users of services and two family members. Of the seven clinicians, there were roughly half males (n = 3) and half females (n = 4), all between the ages of 25 to 45 years. Of the users of services, one was a 35-year old female and the other was a 27-year old male. The two family facilitators were both females in their fifties and mothers of users of services.

Data analyses

All participants were given a numeric code to assist in the matching of questionnaires. Quantitative data were entered into the Statistical Package for the Social Sciences version 18 (SPSS) for analysis. Both descriptive and inferential statistics were generated. Categorical data are summarised in terms of percentages and continuous data were summarised using means and, where appropriate, medians. Ranges and standard deviations provided an index of variability within the data. To examine changes over time, Wilcoxon signed rank tests were conducted on continuous data due to the small number of participants completing both pre and post EOLAS measures. In addition, as the GHQ scores can be categorised into clinical cases, a McNemar test examined change in categorisation over the programme of the EOLAS Project. Questionnaires that could not be matched were excluded from these analyses. For all inferential analyses, statistical significance was set at .05. Where percentages in the findings chapters are presented, unless stated otherwise, these percentages have been calculated out of the total N, including both users of services and family members.

All interviews were audio recorded and transcribed verbatim for analysis using a thematic approach. The qualitative data were entered into the data management software package NVivo version 8. The transcripts were checked for accuracy and cleared of any identifying information. The analytical process involved listening to the audio recordings, while systematically coding the written transcripts for emerging themes and ideas. Codes were compared for similarity and differences and merged into higher themes. The overall analytic approach was guided by the constant comparative process (Glaser and Strauss 1967). To enhance the rigour of the analysis, data were analysed by more than one researcher and findings compared. All interview participants were given codes to protect confidentiality. The codes include SU for user of services and SU F for user of services facilitator; F for family member and FF for family member facilitator; and CF for clinical facilitator.

Ethics and privacy

Ethical approval to conduct the study was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin and the ethics committee associated with the service where the information programme was developed and delivered. The rights and dignity of participants were respected throughout by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality and withdrawal without prejudice.

Consent was viewed as an ongoing process, which required negotiation throughout all aspects of the study. Return of the completed questionnaires was taken as consent. All participants were asked to sign a written consent form prior to interview, consenting to be interviewed and tape-recorded.

Participants were reassured that information that may identify them would not be used in any presentation or publication resulting from the study. They were also reassured that their non-participation in the evaluation would not jeopardise in any way their involvement in this, or subsequent programmes, should they become available.

Summary

- The evaluation used sequential mixed method design involving both quantitative and qualitative approaches. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the EOLAS Project of participants, facilitators and project workers.
- Ethical approval to conduct the study was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin.
- In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Of these, twelve completed both questionnaires. In addition, 25 family completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. Of these, eight completed both questionnaires.
- In total, 34 interviews were conducted. Of these, 19 were with programme participants, 11 were with facilitators and four interviews were conducted with the two project workers.
- Quantitative data were entered into the Statistical Package for the Social Sciences version 18 (SPSS) for analysis. Both descriptive and inferential statistics were generated. To examine changes over time, Wilcoxon signed rank tests were conducted on continuous data due to the small number of participants completing both pre- and post EOLAS measures.
- All interviews were audio recorded and transcribed verbatim. The qualitative data were entered into the data management software package NVivo version 8 and analysed using a thematic approach.

CHAPTER 4

Findings – Overall satisfaction and impact of the programme

INTRODUCTION

This section reports the findings on participants' overall satisfaction with the EOLAS Project and discusses the findings of the pre and post questionnaires in relation to impact on perceived knowledge, support, advocacy, recovery attitudes and hopefulness. In addition, qualitative data from the interviews are included to support or challenge the quantitative findings.

Overall satisfaction and enjoyment with the programme

A very positive result of the survey is that all of the post-programme participants (n = 26), including users and family members, reported that they would recommend the programme to others. This positive outcome was also reflected in the interviews:

> *"I found it very helpful. I couldn't find anything negative about it at all." (F 2)*

> *"I thought it was a very good course. It served its purpose." (SU 4)*

Supporting these positive results, the vast majority of participants who completed the survey found EOLAS very enjoyable and were highly satisfied with it. Nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) as high or extremely high (see Table 7). Only small proportions rated their satisfaction and enjoyment of the programme as low or neutral, with the majority of neutral and low ratings in the family member sample.

TABLE 7. OVERALL SATISFACTION AND ENJOYMENT OF THE EOLAS PROJECT

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	High or extremely high	Neither high nor low	Low or extremely low	High or extremely high	Neither high nor low	Low or extremely low
Overall satisfaction (N = 29; n = 11, 18)	100% (11)	0% (0)	0% (0)	84% (15)	11% (2)	6% (1)
Overall enjoyment (N = 29; n = 11, 18)	91% (10)	9% (1)	0% (0)	94% (17)	0% (0)	6% (1)

Impact of the programme on perceived knowledge of mental health issues

Findings from the qualitative interviews suggested that both the users and family participants perceived that the majority of the information they received was very helpful and informative. Both groups spoke of gaining a *'better understanding'* of either their own or another's mental health problem. The sessions on medication, stress and relaxation techniques and the role of team members in the multidisciplinary team were highlighted as particularly informative:

> *"The one on medication was good...and I suppose the one the stress, you know the definitions of stress and how to recognise it, that type of stuff was good." (SU 2)*

> *"It was also useful to know about all the different services that are out there, you know, which a lot of people wouldn't have been aware of." (F 3)*

> *"Clients definitely gained more understanding of what their illness is, what the teams do." (CF 2)*

> *"Now I understand why I have a diagnosis. I have now decided to start my own road to recovery I am now going to do something about it myself" (SU survey)*

A number of guest speakers attended various sessions throughout the EOLAS Project. The majority of family and user participants found the session with the psychiatrist guest speaker to be extremely informative and helpful. The benefits of this session were strongly described as relating to the fact that participants were given an opportunity to ask questions about diagnosis and medication and receive answers. The quotes from the end of session feedback sheets also mirrored this interview feedback.

> *"The day the psychiatrist came to discuss was an absolute, oh, it was like doors being opened or something. That was the one that we just said, 'If only we could have even spoken to a psychologist or whatever in the beginning,' and that was fantastic and he discussed medications and discussed [other] things...so that night was the best." (F 6)*

> *"The information was useful, especially about diagnosis and symptoms...It was the type of thing that was always fuzzy in my mind...I felt I picked up a lot from that...sort of put it all together." (SU 6)*

> *"Consultant's discussion excellent, gained great information, got answers from questions I didn't know who to ask...simplified complicated things with good examples." (SU feedback sheet)*

Some user participants spoke very positively about the relapse prevention session facilitated by the psychologist and felt they benefited from discussion on 'triggers' and 'early warning signs'. While recognising that learning relaxations techniques took time, the emphasis on strategies other than medication was viewed as positive.

> *"They tell you to relax and don't be worrying about, you know just focus on what you have to do, don't be over doing it and running a mile...This is the way it is, if you think that you are going to be as high as a kite, kind of do your breathing exercises... and take it easy and if you have any problems talk to your doctor...It helped me to understand myself better because I'd be really hard on myself." (SU 2)*

> *"It was the type of thing you could walk away with and when I'm sitting on a train or bus, I could practice myself, which was great...I found that it isn't all about medication. It's not about mental health. It is actually about your day-to-day, how you go about things and how you think certain things...I suppose that before we would have talked about medication as a fix up, whereas medication is a tool. There's more tools used than just medication." (SU 6)*

The findings from knowledge section of the questionnaire supported the interviews, with family data showing a statistically significant change in overall perceived levels of knowledge post EOLAS (Wicoxon z (7) = 2.39, $p < .05$). Of note, in relation to the knowledge items, family participants rated that they had a better understanding of their relative's legal rights in the mental health services (Wilcoxon z (12) = 2.57, $p < .01$), they knew how to help their relative deal with voices (Wilcoxon z (11) = 2.23, $p < .05$) and that they were more familiar with strategies for helping their relative get involved in the local community (Wilcoxon z (12) = 2.00, $p < .05$) (more details are included Appendix II). Although it was not possible to examine changes in total perceived knowledge for users of services as only two participants provided complete data, the interview findings discussed indicate that users of services learned knowledge, skills and techniques from the EOLAS Project.

One of the hoped for outcomes of the EOLAS Project was that it would improve the health and well-being of the participants. While the General Health Questionnaire (GHQ-12) showed no statistically significant overall change (Wilcoxon z (4) = -1.81, p = NS) for family members, findings from the users interviews indicate that the lifestyles of some participants had been enhanced as a result of attendance at the programme. For example, one user reported that he was made aware through the programme that he was *'isolating himself from others'* and has since taken *'steps to connect'* (SU 5) and engage with other people. In another case, the person stated that:

> *"I think it not only makes you feel empowered...I think it affects your behaviour in a way that improves your mental health and makes it kind of an opportunity where it [relaxation] will be more consistent." (SU 6)*

The value of the programme as a source of information was also reiterated by the clinical facilitators who viewed the programme as filling a major gap within the services.

> *"We were providing something that's largely been absent. It's [education] not been available for relatives. It may or may not have been available to service users in a less formal sense, but certainly for the family members I think it was well-received because it was filling a vacuum." (CF 4)*

Impact of the programme on self-advocacy

Issues of empowerment and self-advocacy are at the heart of the drive towards equal involvement of users of services and carers within the mental health services (McDaid 2006). Findings from the user interviews did suggest that following the programme they had greater confidence in approaching and asking questions of practitioners. They spoke of feeling more empowered to question practitioners about their medication, request a reduction in the dosage and talk about relapse triggers.

> *"Well at least now I know that I have the right to ask certain questions." (SU 6)*

> *"I didn't know much about it kind of, but now it's kind of, yeah, you don't mind asking questions or reading through the thing." (SU 1)*

> *"You feel empowered in a couple of ways. One is to talk about your medication and another is to be a bit more open about what your thought process is, that's causing the episodes...the triggers that causes it is very similar in each of my cases. I do feel that I can talk to the psychiatrist or the doctor about that [medication and triggers] now and him to have an input on that." (SU 8)*

Although participants spoke of enhanced self-advocacy, there were no statistically significant changes on the Self-Advocacy Scale for either family members (Wilcoxon z (8) = 1.71, p = NS) or users of services (Wilcoxon z (8) = 0.70, p = NS).

Impact of the programme on family members feelings of support

It was clear from the interviews that family participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Although there were no statistically significant overall changes on the Social Network of Support Scale for family members (Wilcoxon z (7) = .034, p = NS), family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.

> *"It was great that everybody could come together and you know learn from each other, you know that was useful." (F 1)*
>
> *"I think that's all people want...they want information and they want to meet other people who are in similar boat. I think people feel very isolated." (F 2)*

Many family member participants described how hearing other family's stories 'normalised' and validated their own experiences.

> *"It makes you realise, as well, no matter how bad your problems are, if you throw all the problems everybody in the room had into the middle of the room, you'd take back your own. You know if you live with your own you can deal with your own but you always think, 'God how do they cope?' and they look at you and they go, 'How do you cope?' and it's amazing isn't it? And it kind of gives you, builds you up and makes you feel a bit stronger as well. You get acknowledged. You know it's acknowledged that you're putting up with or what you're dealing with and that's a big thing." (F 6)*
>
> *"So I think there's that kind of, a bit of a sigh of relief...There's other people out there like us. So you know we're all in the same boat. So I think in that sense it was good. . We got information from them [facilitators] and we equally met other people but it was the other people gave us the strength." (F 9)*

Some of the family members interviewed had little previous opportunity to talk about their experiences in an open and honest manner. Family participants spoke of the difficulty in talking to people both within their own family and outside because of feelings of betrayal and the stigma associated with a mental health problem, while others were of the view that people did not have an understanding of mental illness.

> *"I suppose families of people with mental health issues live in a kind of world of their own. You certainly can't talk to the other person's family, in my case anyway. You can't really talk to your own family because every move you make is being scrutinised as to who you're telling what to...So it [EOLAS] was the one outlet..." (F 7)*
>
> *"You were able to talk about things that you couldn't really talk to anyone else about because they don't really understand it like, you know, none of my friends have brothers with mental illness." (F 8)*

Similar to family members in many other studies (Mental Health Commission 2005; Kartalova-O'Doherty et al. 2008), the family members in this study were quite angry and frustrated at their marginalisation by the mental health system. They spoke of lack of information, involvement and support when family members were in crisis. They lacked direction on how to cope or respond to their family member and, at times, considered that they were abandoned by the services. The following were just some of the frustrations expressed:

> *"He had done harm in his house, he'd broke chairs and a few things and all this when three doctors were after telling me that I couldn't sign him in. It was frustrating...But what I'm saying is doctors and people like that don't seem to take any notice of relatives a lot of the time and we are closer to what's happening, you know? We have knowledge of the actual, what's happening on the ground." (F 2)*
>
> *"So we were having a psychotic young man in the house [family member goes on to describe the young man's behaviour] and we weren't allowed be involved in his treatment. We had to pay for everything for him, his clothes, his food and everything and he was conspiring to kill us, that was his mental thing at the time. He was totally, totally paranoid and in his head he had to kill his parents and the only thing we were told to do was call the guards and that was the answer from the health people and we couldn't do that because he was ill, he wasn't a criminal." (F6)*

Some family members faced major stress when their family member was about to be discharged home because they not been prepared for the future.

> *"I begged the hospital)...'Please hold him for tonight...Whatever you do don't let him out tonight.' They did [keep him for the night] but they let him out at seven o'clock the next morning and when our other son went up, he was wandering the car park with his clothes in his hands...and when I rang the hospital they told me I had two choices: take him home or there was an old man's hostel that opened at five o'clock." (F 8)*

Consequently, for the vast majority of family members the EOLAS Project provided a well-needed 'safe space' where they could vent their strong emotions and give voice to their feelings of grief, frustration and anger. It was also a place where they reported not feeling guilty about 'complaining'.

> *"To go and be able to talk about it with somebody else knowing like it's private and you know that what you say in the room… stays there…It was like you were able to open up and dig in there and get them feelings out, that you harbour for a long time. So I think that's what the other people got out of it as well." (F 1)*

> *"I mean you always feel bad about complaining about your loved one or your family member but I mean you just have to get it off your chest sometimes…But as I say you do feel like, do feel a bit as if you're betraying somebody when you're moaning about them but you know you just have to." (F 5)*

However, in contrast some participants felt that they were betraying their family member by talking about their issues in a group context.

> *"There was also within the group and possibly it's the reason for the group, a bit of a bitching session about spouses and a bit of kind of, yeah, a bit of a bitching session, bit of kind of telling tall tales out of school and things like that. Now I know the whole thing was confidential, people need to get things off their chest and things like that but it just kind of didn't sit well." (F 7)*

Sibitz et al.'s (2007) study emphasised the value and benefits of exchanging information with peers during a psychoeducational programme. Their study reported that peer interaction enhanced self-esteem, social interaction skills and improved participants' social networks. Although the primary focus of EOLAS was on providing information, user participants also spoke of the support they received from meeting other people with similar experiences.

> *"The group sharing was good…and say you had a break for your coffee and the whole lot and it was quite nice…We could share whatever and somebody would say, 'Oh yes I know, that happened to me, I do this or I do that', like there was a lot of communication." (SU 2)*

> *"It was fabulous to have that experience, especially from someone who had been there and done that, been down the same road you've been down and found tools…And that had helped them, so it wasn't just pie in the sky things, these things have actually, other people had found [them] useful." (SU 6)*

> *"Knowing you're not the only one out there with this problem." (End of session feedback sheet)*

The quantitative data also strongly supported the view that hearing other people's stories was helpful (see Table 8). A clear majority of participants agreed that that hearing other service user/family member stories was supportive (93%; n = 28) and an effective way of learning (93%; n = 27).

TABLE 8. HEARING OTHERS' STORIES

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Hearing other service users' / family members' stories was supportive (N = 30; n = 12, 18)	92% (11)	8% (1)	0% (0)	94% (17)	6% (1)	0% (0)
Hearing other ' / family members' stories was an effective way of learning (N = 29; n = 11, 18)	91% (10)	9% (1)	0% (0)	94% (17)	6% (1)	0% (0)

Impact of the programme on recovery attitudes and hopefulness

The concept of hope is emerging within the recovery literature with a number of researchers viewing hope as central to people's recovery journey. Higgins and McBennett (2007) identify the common themes underpinning the writings of people who have described their own individual recovery journey. Universal in all the writings is the issue of hope and optimism (Higgins and McBennett 2007). Discussions on the concept of hope and hopefulness about the future emerged within the interviews. Some family members spoke of leaving the sessions more hopeful about their and their family member's future as a result of listening to the facilitators and other participants. For example, this family member described how through the programme she was reassured about her concerns and given hope that her relative could someday have a job and a family.

> *"Oh they [facilitators] were very, very good and certainly very uplifting…like if you came in feeling really shite and not knowing that there was any hope, they'd certainly bring you back up…and sort you out, definitely. I thought they were very good like that. So coming in as a newcomer, I would say they would be brilliant at giving hope. Like I mean at one stage I thought, I mean, there is no cure for schizophrenia and at one stage I thought terrible thoughts, 'You'll [referring to child] never be married, never have kids. I'll never be a grandmother and all this kind of stuff,' and I was put right back in my place and said, 'Don't ever say there's no hope'…I was told there are people who go out and get jobs and do this and do that and I said, 'Oh yeah, well yeah, so I have to sort of stop that'…But it was all done in, you know, a good uplifting sort of, 'Come on. Cop on' and 'It's not like that at all.'"(F 6)*

In contrast to these statements, other family members appeared to leave having absorbed a narrative of despair or hopelessness. The subliminal message received appears to be centred around *'no happy ending'* and *'life time of medication'* for their family member. The source of this narrative of hopelessness appears to have been certain clinical facilitators and guest speakers rather than the actual EOLAS manual. In addition, the session on medication did not appear to present an option for users to 'come off' medication. The following are indicative of some of the comments made:

> *F: "We had great hopes that eventually [names user of service] would be able to get off the medication and stuff like that but now we've come to accept that he's not, he's like this for the rest of his life, you know."*
>
> *I: "Based on the EOLAS Project or just based on your own...?"*
>
> *F: "Well [name of psychiatrist guest speaker] came to talk to us about...and he gave a very interesting lecture and it was kind of starting to sink in with me then that, you know, because we were able to ask questions and things like that, kind of asking you know questions like, I was thinking from [name of service user]'s point of view, will he ever be able to come off the medication and I thought maybe someday they'd be able to take him off it, but now I see that that's not going to be the case. [Name of service user] is going to be on this medication forever and a day." (F 3)*
>
> *"There was a few things in that now that was a bit scary, you know, about the medication, and more or less that you hoped they would be able to come off the medication at some stage, whereas [EOLAS Project] left little light at the tunnel for that, you know." (F 1)*
>
> *"I left the first session with very, very mixed feelings about the whole thing...I remember at one stage we were just talking about various things and the nurse [clinical facilitator] came up and said, 'You almost have to mourn the fact that you never have a proper relationship with your spouse,' which obviously caught me by surprise and something very unsettling...So that really kind of, I suppose I kind of accepted that fact, anyway, but hearing it out and out in the open wasn't that easy. So I was kind of, I spent the rest of the week kind of wondering would I go back or wouldn't I?" (F 7)*

In the questionnaires, the Recovery Attitude Questionnaire (RAQ-7) was used to measure attitudes towards recovery and the Hearth Hope Index (HHIndex) was used to measure any increase in hopefulness. There were no statistically significant changes on RAQ-7 for family members or users and no statistically significant changes on the HHIndex for family members or users. The interview findings perhaps shed light on why these findings were not significant, with participants reporting receiving mixed messages around hope and recovery from facilitators.

Impact of the programme on drug attitudes of users of services

There was no statistically significant overall change on the Drug Attitude Inventory (DAI-10) for users. However, as discussed, they did suggest within the interviews that they were more knowledgeable on the medication prescribed for them and more willing to ask questions about their medication.

Summary

- All participants would recommend the programme and nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) of the programme as high or extremely high.
- In terms of perceived knowledge, family members reported significantly higher levels of knowledge post EOLAS. Although it was not possible to examine changes in total knowledge for users of services, findings from the qualitative interviews suggested that both the users of services and family participants perceived that the majority of the information they received was very helpful and informative.
- While the General Health Questionnaire (GHQ-12) showed no statistically significant overall change for family members, findings from the users of services interviews indicate that the lifestyles of some participants had been enhanced as a result of attendance at the programme.
- There were no statistically significant overall changes on the Social Network of Support Scale for family members. However, it was clear from the interviews that family participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.
- A clear majority of participants felt that that hearing other users / family member stories was supportive (93%; n = 28) and an effective way of learning (93%; n = 27).
- There were no statistically significant changes on Recovery Attitude Questionnaire (RAQ-7) for family members or users of services. Similarly, there was no statistically significant overall change on the Drug Attitude Inventory (DAI-10) for users of services.
- There were no statistically significant changes on the Hearth Hope Index (HHIndex) for family members or users of services. While some family members spoke of leaving the sessions more hopeful about their and their family member's future, other family members appeared to leave having absorbed a narrative of despair or hopelessness.

CHAPTER 5

Findings – Facilitation and teaching strategies

INTRODUCTION

The design, presentation and delivery of the programme were to be based on the principles of adult education. To achieve this, a number of different teaching and facilitation strategies were employed. This chapter focuses on these strategies, as well as the successes and challenges encountered.

Creating an atmosphere of trust: Being respected and valued

Interview data suggest that the group rules about behaviour, attitudes and engagement that were drawn up by participants at the first session contributed to the constructive and respectful atmosphere that was created within the group. The ground rules related to confidentiality, respecting others' opinions and allowing others to voice their views. These ground rules enabled the development of an atmosphere of trust, confidentiality and openness, as described by these participants:

> *"They [ground rules] were all sound like...You felt, you know, comfortable there." (SU 5)*

> *"Like if you didn't want to say anything, you didn't have to, you know, and it was nice..." (SU 2)*

Supporting these qualitative findings, survey participants were asked whether they felt their views and opinions, as well as their knowledge, were respected throughout the programme. The vast majority of participants (97%; n = 29) felt that their views and opinions were respected, with 87% (n = 26) of participants reporting that their knowledge was respected. Further details are presented in Table 9.

TABLE 9. FEELING RESPECTED

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Participants' views and opinions were respected (N = 30, n = 12, 18)	100% (12)	0% (0)	0% (0)	94% (17)	6% (1)	0% (0)
Participants' knowledge was respected (N = 30, n = 12, 18)	92% (11)	8% (1)	0% (0)	83% (15)	17% (3)	0% (0)

Satisfaction with programme content and objectives

Participants were asked how much they agreed or disagreed with two statements about the programme objectives and content (see Table 10). The results were very positive as nearly all of the participants (97%; n = 29) agreed that the objectives of the programme were clear and more than 90% (n = 27) felt that the content of the programme was clearly presented.
One service user described, *"I think the course did exactly what it said on the tin, you know?" (SUF 2)*

TABLE 10. PROGRAMME OBJECTIVES AND CONTENT

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The objectives of the programme were clear (N = 30; n = 12, 18)	100% (12)	0% (0)	0% (0)	94% (17)	6% (1)	0% (0)
The content was clearly presented (N = 29; n = 12, 17)	100% (12)	0% (0)	0% (0)	88% (15)	6% (1)	6% (1)

While participants were of the view that the content was clear, a number of family members, especially those who had years of experience with the mental health care system, perceived the content of the programme to be the idealised theory as opposed to the reality of how the system operates. For some, this led to feelings of irritation and anger as they did not feel the programme content reflected their experiences of feeling marginalised and excluded within the system. This is exemplified in the following comment:

> *"Sometimes you felt it was just an exercise...You were doing A, B, C, D and E. We're here to tell you A, B, C, D and E. I suppose the hard part for anybody, even within the group, would have been that, as I said to you Monday to Friday [there are no services], nothing, after 4 o'clock and if I hear recession and if I hear cut backs and there's no funding, that would annoy you...I suppose the people we met were excellent. The information you got was good to a degree and then again there was always the negative, the negative always kept coming out, no funding, no money, no help...That was something they [the programme facilitators] kept saying, 'You need your own space,' and, 'You need to have time for yourself,' and, 'You need this.' How are you supposed to get that? Who is giving us the support? There is no respite." (F 9)*

Satisfaction with depth of programme content

Interview participants spoke of needing more information on a number of issues. One of the family participants suggested that including a solicitor with expertise in family law as a guest speaker would be particularly useful:

> *"We did say it would have been good to have a night where a solicitor would be involved...because the psychiatrist was brilliant but an evening with a solicitor maybe to find out what are your legal, 'What do you do to legally get somebody committed? Can you not...? Are you legally allowed to do...?' What ifs." (F 6)*

Written feedback included comments such as:

> *"Suggest a further visit by consultant/doctor" (End of session feedback sheet)*

> *"Would like to have more time allowed with the Doctor – maybe could come back for full session." (End of session feedback sheet)*

In line with these comments, approximately one in five participants felt the programme content was insufficient (20%; n = 6) and repetitive (23%; n = 7). Further details are presented in Table 11.

TABLE 11. PROGRAMME DEPTH AND REPETITION

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The depth of the content on the programme was sufficient (N = 30; n = 12, 18)	84% (10)	8% (1)	8% (1)	67% (12)	6% (1)	28% (5)
The content of the programme was repetitive (N = 30; n = 12, 18)	25% (3)	8% (1)	67% (8)	22% (4)	11% (2)	67% (12)

Group work

Participants were also asked how effective they found group work as a way of learning. A clear majority of participants agreed that group work was an effective way of learning (87%; n = 26) (see Table 12). While some participants felt neutrally about these statements, just 3% (n = 1) disagreed with this statements.

TABLE 12. GROUP WORK

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Group work was an effective way of learning (N = 30; n = 12, 18)	92% (11)	8% (1)	0% (0)	83% (15)	11% (2)	6% (1)

In relation to group process, participants found that the group sharing experience was sometimes dominated by one personality, which diminished their enjoyment and contribution. Despite the efforts of the facilitators to refocus the group to the topics under discussion and prevent some participants from 'over-speaking' and dominating the discussions, their strategies did not always work.

> *"In some cases, one or two individuals just took the floor and held the floor …I'm sure it can be difficult for a psychiatric nurse to referee in a situation like that because you know you want to give this individual their time and it's probably quite difficult to kind of cut them off and hand over to somebody else." (F 7)*

> *"I think what actually happened was, this [person] would go on and on, but you'd have, not a word was kind of said [by facilitator]...[person] had a domineering opinion." (SU 3)*

> *"Some people going on too long and not considering other people" (End of session feedback sheet)*

Facilitators also identified this issue as a challenge.

> *"It was an information providing service, not a therapy service, and that was a bit difficult at the start because people were there and wanted to vent their anger and frustration at the services." (CF 2)*

Written learning materials and information handouts

As stated all participants were given written information handouts, which meant that over the duration of the programme, participants could build up a resource pack on the different topics discussed. The user participants found the information handouts very helpful as they could refer back to them after the programme was complete.

> *"You could go back and have a look and say, 'Well that's me or that's not me'...so it was quite good." (SU 1)*

> *"You'd sort of forget what you had done so it's nice to have it [handouts] there that you can look back again." (SU 7)*

Although the family members found the information handouts beneficial, they did express annoyance that they had to attend the programme to access written information. They were of the view that this information should be available to everybody once they attended the service.

> *"The idea of it [information handout] is good. It should be available much more widely. There should certainly be an information booklet and the basic information for everybody...for a family of somebody who has a mental illness there should be an information booklet...I have found over the years that doctors are very reluctant even to explain." (F 4)*

Survey participants were also asked to comment on the written learning materials in relation to usefulness and ease of navigation (see Table 13). More than 80% (n = 23) of the sample felt that the planning sheets and learning materials used were easy to navigate. Whilst all of the users of services agreed the learning materials were easy to navigate, some of the family members and friends felt neutrally about this and one disagreed. While 79% (n = 22) of the sample felt that the planning sheets and learning materials were an effective way of learning, 21% (n = 6) felt neutrally about this. Again, a greater proportion of family members and friends reported feeling neutrally.

TABLE 13. WRITTEN LEARNING MATERIALS

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The planning sheets / learning materials were easy to navigate (N = 28; n = 10, 18)	100% (10)	0% (0)	0% (0)	72% (13)	22% (4)	6% (1)
The planning sheets / learning materials were an effective way of learning (N = 28; n = 10, 18)	90% (9)	10% (1)	0% (0)	72% (13)	28% (5)	0% (0)

Surprisingly, although their ease of navigation was rated highly in the survey, during the interviews it emerged that family members felt that some of the programme materials were inaccessible, being too text heavy and using language that was overly technical.

> *"Certainly either pare down the materials or just bring it down to kind of bullet point, PowerPoint kind of stuff, you know, as opposed to just reams upon reams of paragraphs. I would say the handouts need to be shortened." (F 7)*

Participants suggested that the manner in which the written information was used during the programme could also be improved. It was felt that the amount of paperwork and reading may have intimidated and undermined the confidence of some participants, especially if they had literacy issues. In some cases 'public reading' in which each group member took turns reading sections of the text out loud was used. This was a consequence of time delays in delivering session materials, nevertheless it was viewed as an unappealing and uninteresting way to present information. It could also be viewed as an inappropriate method, especially given the underlying adult education philosophy of the programme, with many participants reporting that reading out loud felt like *'being back at school'* and felt the time spent reading affected the time available for group discussions. The following are reflective of comments made.

> *"We all kind of went around in a circle and read a paragraph and just went around and around and around...it was basically like English class on a few occasions. It was more reading a handout as opposed to discussing and having an interactive dynamic...I think maybe one or two of them...might have been a bit of literacy problem there." (F7)*

> *"It's something that's very dry, just sitting down and reading." (SU 6)*

Occasionally, it appeared that some facilitators used their own initiative to introduce exercises to increase participant engagement and understanding. These initiatives were very much appreciated by the participants, as this family member described:

> *"I know one of the days she [facilitator] talked about people hearing voices and she had us going to groups and one of us had to talk down to someone there while having a conversation. So that was a good idea really because it just gives you an idea, just a little exercise, what it can be like and, of programme, some well known people have written about their experiences, [but] it's hard to imagine it if you've never had it I suppose." (F 5)*

Application of EOLAS programme to own life

Of the 28 participants to respond, three quarters (75%; n = 21) felt that they were encouraged to apply the content of the programme to their own circumstances (see Table 14). However, a greater proportion of family members was neutral or disagreed with the statement.

TABLE 14. I WAS ENCOURAGED TO APPLY THE CONTENT OF THE EOLAS PROGRAMME TO MY OWN CIRCUMSTANCES

USERS OF SERVICES (N = 10)			FAMILY MEMBERS AND FRIENDS (N = 18)		
Agree	Neutral	Disagree	Agree	Neutral	Disagree
80% (8)	20% (2)	0% (0)	72% (13)	17% (3)	11% (2)

In addition to applying the programme information to one's own life, it appeared from the interviews that the content of the programme and the learning materials supplied were also used as information resources within the community. Participants, particularly family members, described how they passed on the information to other members of the family to heighten awareness and understanding:

> *"Oh yeah, [the materials are] very good because we were able to read through afterwards and go through everything afterwards because we got to take them home with us. So we've a full binder full of literature, and as well as that, if anybody else ever asks questions, I can say, 'Here, have a read through that.'" (F 6)*

Summary

- The vast majority of participants (97%; n = 29) felt that their views and opinions were respected, with 87% (n = 26) of participants reporting that their knowledge was respected.
- Nearly all of the participants (97%; n = 29) agreed that the objectives of the programme were clear and more than 90% (n = 27) felt that the content of the programme was clearly presented. A number of family members, especially those who had years of experience with the mental health care system, perceived the content of the programme to be the idealised theory as opposed to the reality of how the system operates.
- Whilst the majority of the sample felt that the depth of the programme content was sufficient (73%; n = 22) and not repetitive (67%; n = 20), approximately one in five participants felt the programme content was insufficient (20%; n = 6) and repetitive (23%; n = 7).
- Although a clear majority of participants agreed that group work was an effective way of learning (87%; n = 26), some found the discussion was sometimes dominated by one personality, which diminished their enjoyment and contribution.
- While 79% (n = 22) of the sample felt that the planning sheets and learning materials were an effective way of learning and found the written information handouts very helpful, family members found some of the programme materials inaccessible, being too text heavy and using language that was overly technical. They also expressed annoyance that they had to attend the programme to access written information and were of the view that this information should be available to everybody once they attended the service.

CHAPTER 6

Findings – Structural issues

INTRODUCTION

In this third chapter of findings, structural issues of the EOLAS Programme are discussed. They are discussed under six headings: timing of the EOLAS Programme, open nature of the group, duration of sessions, number of participants, venues and evaluation process.

Timing of EOLAS information

There was a sense from both family members and user participants that the information in the EOLAS Programme would be most beneficial to 'newcomers' in the mental health system. The majority of the family members had been involved with the mental health services for several years and had developed their own ways of negotiating the system and sourcing information *'the hard way'*. Consequently, although they found the programme beneficial, they were of the view that the EOLAS Programme was more suitable for people who are new to the system.

> *"We found it helpful to a point but I think it would be great for people who are beginning in the mental health system. It would be great if there was more information within the group, the EOLAS, that there was more information to hand out to say newcomers because when you're starting off, pre-diagnoses, you're floundering and you don't know what's going on, you don't know where to turn…We just had to throw tantrums, scream to be heard and it was a total nightmare. There was absolutely no help anywhere, nothing, and it's only in hindsight, in the EOLAS group we kept saying, 'Well this would have been great if [given earlier]…We had to go through the hard way and find out everything the hard way." (F 6)*

Similarly, users of services also supported the idea of rolling the programme out nationally, but, again, they emphasised the need to provide the information earlier to more recently diagnosed users of mental health services. In their view, people who were attending the service for a long time had information about symptoms and treatment from their previous engagement with services.

> *"The earlier the better…this is just stuff that you need to know." (SU 7)*

Open nature of group

The open nature of the group in allowing participants to join in on any of the sessions was perceived to be problematic by the clinical facilitators as in their views it disrupted the group dynamics.

> *"People were coming in and out of the group, people who were there initially were not there in the next group and some of them joined in later on." (CF 2)*

In addition to the open nature of the group, due to it being the holiday period when the programme was rolled out and absences among facilitators, some groups experienced different facilitators delivering the programme. This *'chopping and changing'* (F 4) of facilitators was viewed negatively by participants as they felt that it did not lend itself to consistency and relationship building within the group.

> *"Ok, it was July, August. It was holiday time. She [clinical facilitator] was perfectly entitled to take her leave but I think it kind of upset the flow because we were kind of getting used to somebody new and then she was back I think for the last two sessions." (F 7)*

Insufficient time to address issues

The lack of time and time constraints were a recurring theme within all of the interviews and were also evident in the end of session feedback sheets. One of the main benefits of the programme was the opportunity to explore the session topics and share experiences. However, participants were of the view that there was insufficient time to address all of the content associated with each session and, consequently, sessions felt rushed, with inadequate time for in-depth discussion or for participants to share their views and experiences. In many cases, the session ran over the allotted 90 minutes. This was particularly the case when there were guest speakers, with many participants complaining that that these sessions were too short.

> *"Just like you know if you're having a bad day, you know you could talk a small bit about it but not enough time…" (SU 5)*

> *"The time thing definitely wasn't enough. There was an hour and a half per session. It's definitely not enough." (CF 2)*

> *“Ran overtime…Not finishing on time…Some left early because of time over run…Time constraints – doesn’t really allow for an in-depth discussion on the topic.” (End of session feedback sheet)*

The lack of time was also evident in the fact that conversations continued between participants in the car parks after the end of sessions.

> *“We all parked in the car park and the discussions kept on going on for 20 minutes, half an hour afterwards. I think purely because…there simply wasn’t enough time within it [the programme].” (F 7)*

The dissatisfaction with the time available was also reflected in the survey data. While half of the survey participants (n = 15) felt there was adequate time for discussion, 43% (n = 13) disagreed. As can be seen in the table, a greater proportion of family members did not feel there was adequate time for discussion (see Table 15).

TABLE 15. THERE WAS ADEQUATE TIME FOR DISCUSSION

USERS OF SERVICES (N = 12)			FAMILY MEMBERS AND FRIENDS (N = 18)		
Agree	Neutral	Disagree	Agree	Neutral	Disagree
59% (7)	8% (1)	33% (4)	44% (8)	6% (1)	50% (9)

Referral system: Low numbers on EOLAS programme

The referral system was considered disappointing in so far as the numbers enlisted to some of the programmes were low. The project workers found that recruitment depended on the enthusiasm of the mental health teams about the purpose and aim of the programme and, in many situations, referrals rested on the shoulders of already over-stretched and under-resourced nurses. Some participants were of the view that the low numbers negatively impacted on the group dynamics and was a reflection of inadequate advertising and limited referral or enrolment routes.

> *“I’m sure the people running it would be disappointed that the attendance fell off…It’s a bit of a waste of resources…Like I got nothing about it, I just got a phone call and then the nurse came out and got me to fill in a form with her…like you’re either interested or you’re not.” (F 4)*

> *“I just thought there wasn’t very many there, I just thought that was a shame you know…Even if it had been in the local paper or even on the local parish newsletter…say, ‘This is coming up,’ and ‘It’s confidential,’ and this kind of thing, you know?”(F 5)*

Venues

It was felt that some of the venues worked well, while others were perceived as being too small to accommodate the group.

> *“Like that it was a lovely venue…It was comfortable…It was lovely you know. It just made you feel very relaxed.” (Interviewee identifier removed as it compromises participant’s anonymity)*

> *“The size of the room was way too small…a huge amount of clutter… there was lot of kind of just general clutter…It got very, very warm at times.” (Interviewee identifier removed as it compromises participant’s anonymity)*

Evaluation process

The distribution of the pre and post programme questionnaires, as well as the end of session feedback sheets, was viewed negatively by programme participants. Participants were of the view that there were too many questions and questionnaires to be completed, which interfered with the ‘flow’ of the programme or may have been challenging for people who had literacy issues.

> *“I don’t like these questionnaires where you have to tick where you ‘strongly agree’ and all this kind of thing, hate them.” (F 5)*

> *“I think it was necessary…I know we were asked first, there was a questionnaire, our likes and dislikes…One of the fellas for dislikes wrote, ‘dislike filling in forms’…So I think there is a feeling that too much paper work.” (SU 8)*

A sense of urgency: Unrealistic timeframe

As highlighted, the timeframe to complete the project was very ambitious. Project workers spoke of feeling under immense pressure to meet the various timelines. Clinicians were under pressure to include recruiting of participants and facilitators as another role to their over-stretched agendas. This sense of time urgency was also apparent on the EOLAS steering group committee. While the following comment by a member of the steering committee is very complimentary, it does highlight the degree of pressure experienced due to the severe time constraints.

> *“From my part, it was a pleasure working with all the people on the EOLAS committee and it’s good to see people at that level and immersed in their profession and that they push themselves to work outside their normal working hours to get jobs done.” (SU representative)*

Summary

- There was a sense from both family members and user of services participants that the information in the EOLAS Programme should be delivered immediately to 'newcomers' in the mental health system.
- The low numbers on the programme in some areas and the open nature of the group in allowing participants to join in on any of the sessions were perceived to be problematic as they were felt to be disruptive to the group dynamics. In addition, the *'chopping and changing'* among facilitators in some programmes was viewed negatively as participants felt that it did not lend itself to consistency and relationship building within the group.
- While half of the survey participants (n = 15) felt there was adequate time for discussion, 43% (n = 13) disagreed. Interview participants also commented on the lack of time available to fully address the content associated with each session or to allow for in-depth discussion and sharing of views and experiences.
- Participants were of the view that there were too many evaluation questionnaires to be completed, which interfered with the 'flow' of the programme or may have been challenging for people who had literacy issues.

CHAPTER 7

Findings – Peer and clinician involvement

INTRODUCTION

One of the main objectives of the EOLAS Project was the implementation of the information programme using peers and clinicians as co-facilitators. Numerous writers highlight the various challenges and road blocks to the successful involvement of user and family members as equal partners within the mental health services (McDaid 2006; McEvoy et al. 2008). This section focuses on the strengths of having a joint approach, as well as the challenges encountered with peer and clinician involvement.

Recognition of value of peer and clinician involvement

The peer aspect of the programme was described positively by both family members and users of services within the interviews. Both groups were full of praise for the peer facilitators, as they felt that not only was the peer facilitator someone who could understand and empathise with them, but also someone from whom they could take inspiration and hope.

> *"He [user facilitator] talked at your own level, you know? He talked to you as a service user when he was talking about the illness. You'd go, 'Well, I had that as well...You sort of think to yourself, 'Well if they can do it and handle their illness like that, so can I.' So you identify with that fact that they have actually taken that step to be able to come in to a meeting like that and say, 'Yes, I suffer from schizophrenia or from a mental health illness and now I'm coordinating this programme.'" (SU 8)*

> *"She [user facilitator] was so confident and then she identifies with us because she suffered like us...You know, she'd say, 'Oh I know, yeah, that's what happens.'" (SU 2)*

> *"There was a girl [family facilitator] there from [name of town]...her [names relative] has schizophrenia, as well, and she was great, you know? Outgoing and, you know, just nice to have her there because she'd a bit of experience as well...Someone who actually knows what it's like to live with it, you know what I mean?" (F 5)*

The involvement of peers also appeared to foster new understandings as people started to appreciate the person *'on the other side of the fence'*. Clinical facilitators were of the view that working with the peer facilitators promoted empathy and enabled them to relate at a more 'human' level than they felt was possible within the traditional professional role divisions. One clinical facilitator described this change in the following way:

> *"I found that [working with peer facilitators] interesting...I found that really, really interesting, even those two days [of training], you know, because you weren't like specifically talking about mental illness, you were talking about other things, like on a kind of...a more human level." (CF 7)*

Similarly, some peer facilitators referred to how being part of the steering group enabled them to understand the intensive workload that clinicians work under.

> *"Like I can see now that I've been involved in that [steering committee], I can see now why it's so difficult to get speaking to him [member of the clinical team], sure, he hasn't a minute. He was at that meeting and his phone was hopping...I can understand it now but when you're actually in that situation, on the other side of it, you don't see that, you don't really understand that. So just, yeah, different insight isn't it?" (FF 2)*

Some participants also felt that the clinicians learned a substantial amount about the experiences and situations of family members from participating in the facilitation.

> *"I think that the people [clinical facilitators] delivering the course...were maybe learning more from it than (laughs) than the carers...I'm not saying they were stunned but they were taken a bit aback because it was maybe a first time that they would have maybe heard what carers had to say." (F 4)*

Although the user participants were of the view that the clinician facilitators were *'about the cold hard facts of the illness'*, they described them as *"lovely"*, *"wonderful"* and *"brilliant"* and were of the view that having the clinician in the programme brought balance and would help in future relationships.

> *"You do need a balance in the room of both...You can identify with the clinician as well as the peer facilitator...[It] helps in future relationships." (SU 8)*

Co-facilitation challenges

From the interviews and surveys, although it was clear that the presence of a peer facilitator was seen as a valuable aspect of the programme, many also described how traditional power dynamics prevailed. For instance, one peer facilitator described how the clinical facilitator consistently referred to the participants as *'patients'* and often referred to the service where she worked and where some of the participants were clients. It was felt that these references reinforced the power dynamic of the clinician as the authority and the participant as the subordinate. Consequently, this person was of the view that future programmes should not have a clinician, a person of "authority", from the same service that participants attended. While she generally described her working relationship with the clinical facilitator as *'brilliant'* and *'very good'*, she perceived this power differential through the symbolism of the clinician holding the keys to the EOLAS venue:

> *"She [clinical facilitator] always had the keys (laughs). I actually laugh at these bundles of keys, you know, that people take around with them. It's a sign of power." (SUF 1)*

Although the feedback from participants suggested that the peer facilitators had high credibility and were perceived as role models for hope, similar to the users of services in McDaid's (2006) study, the peer facilitators tended to reflect the wider social norms of over-valuing clinical expertise and professional training and devaluing their own experiential knowledge. Participants spoke of lacking what they perceived as resources for participation in facilitation, such as knowledge of 'illness', pharmacology, and treatments; consequently, they tended to defer to the 'medical expertise' of the clinicians.

> *"I had my humanity and I had the experience of doing it [caring] but I didn't have the medical background and that's what I was lacking, more knowledge of that...He had medical background , I just ...gave him the space to do it...As a facilitator I didn't have much to do. So in that sense, the lay people weren't involved. You need...you have to have clinicians. If you're going to do it in the same way, you'd have to have clinicians on board all the time to deliver the information." (FF 1)*

> *"I remember there was one part and I said, 'Oh...I can't do that,' because if they ask me a question on that I wouldn't really know how to answer it because I wasn't a professional clinician basically. So she did that and she was asked questions on that. I'm glad I didn't do that bit." (FF 2)*

The lack of true involvement by some of the peer facilitators was also commented on by the participants. They suggested that the peer facilitator's own personality and confidence seemed to impact greatly on how they engaged in the co-facilitation process, with those who valued their self-knowledge on par with clinical knowledge and who had greater confidence being more likely to share their experiences and engage with the participants on the programme. Others did not relate any of their own experiences and were seen as more hesitant in their engagement, leading to their sessions being mainly clinician led.

> *"The family facilitator never even spoke. She was quiet. Maybe she was very nervous...She was a kid. She was a lovely girl. A bit shy I suppose reading in front of people..." (F 10)*

> *"She [service user facilitator] used to read out things and you know she didn't talk too much [service user facilitator]." (SU 5)*

> *"She did a lot of reading... didn't do so much talking really...Some days the [peer] facilitator just read through stuff." (SU 7)*

In their interviews, the clinician facilitators also revealed that they were aware of these issues but were at a loss on how to change the dynamics. They appeared to lack the facilitation skills necessary to enable co-facilitators to participate on an equal basis.

> *"It was difficult at times when the difficult questions were there and she [peer facilitator] was just looking across at me...You felt you were on your own because the [peer facilitator] didn't really have the confidence or didn't have the knowledge or didn't have, not the ability but just, you know, 'What will I do next?' Like I mean it was new for everybody but you pushed on or referred to the lesson plan and, 'This is what we're doing next', because it was supposed to be, 'I do part A. You do part B. I do part C. You do part D,' and I found myself kind of like, 'Well ok, I better push on." (CF 2)*

In their interviews, clinical facilitators described the time constraints and pressure they felt during their training that seemed to create a sense of urgency around the EOLAS Project. Many felt that the working aspects of co-facilitation had not been given sufficient thought and discussion during the training days and, consequently, there was a lack of clarity about the role of the peer facilitator.

> *"I don't think we fully thought through or it [role of the peer facilitator] hadn't been made fully explicit or maybe we didn't know, the co-facilitators didn't know where to put themselves in the delivery of the group." (CF 4)*

> *"I found that there was frequently a lack of clarity about the role of the co-facilitator... And it led to them kind of taking a step back and deferring almost to the staff member which is fine but then it led to the group in some cases being solely led by me and the co-facilitator not really having an input beyond welcoming people...the co-facilitators didn't know where to put themselves in." (CF 6)*

Developing the skills of co-facilitation requires time, reflection and, above all, an opportunity for the co-facilitators to meet up and to get to know each other, engage in discussion about the process and to plan on how to conduct and facilitate each session. The participants in this study commented on the lack of time to meet up with their co-facilitator prior to the programme and how it impacted negatively on their ability to clarify their roles and to make plans on how to work together in a cohesive manner.

> *"It was left till very late to organise who is going where and who is doing what…if you know who you're facilitating, co-facilitating with, you could in practice meet up with them beforehand and try and get to know them and come up with a plan on how you're going to conduct the group and how you're going to facilitate the group on the day. So definitely that should be looked at…so that you can prepare better." (CF 1)*
>
> *"We weren't really given enough time between the facilitation training and when the actual thing was starting." (CF 5)*

As a consequence of lack of facilitation skills, confidence and minimal time spent together prior to the programme, peer facilitators appeared to have been responsible for more task-oriented roles, such as welcoming participants and making tea, rather than leading the programme.

> *"The peer facilitator, her job boiled down to kind of making tea, giving out the handouts, reading paragraphs every now and then. She was very much a halfway house between the family member side of the house and the nurse or the health care professional side of it. I think the group would have worked every bit as well had she not been there and that's no slur on the individual herself but in that incidence." (F 7)*
>
> *"I don't think they [participants] really looked at me as a facilitator; they looked to me as a parent who was just helping [name of clinical facilitator], if you know what I mean, which was lovely, because it took the pressure off me altogether." (FF 2)*

Another issue that may have contributed to placing the clinical facilitator as 'expert,' which family members experienced, was the challenge of positioning their individual identities within the new role of co-facilitator. Some spoke of the difficulty they had of separating and reconciling their usual role (family carer) from and with their new co-facilitator role. This difficulty appeared to arise due to the fact that in many cases family co-facilitators were hearing and learning the information themselves for the first time.

> *"I found it a little bit strange really because in one sense I was a facilitator and in the other sense I was a parent…Where I was sitting down listening to maybe [name of clinical facilitator], who I was doing it with, who was brilliant, and listening to her, and then I'd listen to maybe a guest speaker. I was the parent then in that room. Do you know what I mean?" (FF 2)*

The responses from survey participants appear to reflect the findings of the qualitative interviews. While survey participants generally agreed that having a peer as a facilitator on the programme was a positive experience (79% n = 23), the remaining 21% (n = 6) felt neutrally about having a peer facilitator on the programme (see Table 16).

TABLE 16. PEER FACILITATORS

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Having a service user / family member facilitator on the programme was a positive experience (N = 29, n = 12, 17)	92% (11)	8% (1)	0% (0)	70% (12)	30% (5)	0% (0)

Summary

- Survey participants generally agreed that having a user of services or family member as a facilitator on the programme was a positive experience (79% n = 23). However, the remaining 21% (n = 6) participants felt neutrally about having a peer facilitator on the programme.
- Both groups felt the peer facilitators were people who understood and empathised with them but also people from whom they took inspiration and hope. The involvement of peers also appeared to foster new understandings as people started to appreciate the person *'on the other side of the fence'*.
- Many participants also described how traditional power dynamics prevailed, which positioned the clinicians as the leaders, with their clinical expertise and knowledge predominating resulting in the self-experience of peer facilitators not being equally valued. In some groups, the peer facilitators appeared to be responsible for more task-oriented jobs.
- Time constraints were an underlying challenge for the facilitators as it was felt that due to lack of time, the co-facilitators were not able to thoroughly discuss and prepare for how they would share their facilitating duties.

CHAPTER 8

Summary and recommendations

INTRODUCTION

This is the first study in Ireland that evaluated a peer and clinician led mental health information programme for people experiencing mental health difficulties (schizophrenia and bipolar disorder). Overall, it can be said that the EOLAS Project was an ambitious venture given the complexity of the objectives and the short timeframe available for its completion (less than one year).

Aim and objectives of project

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members in the HSE Kildare and West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

Development of information programme

Collaborative principles guided all stages of the project. The project was managed by a steering group that included clinicians, users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team. Two project workers and two researchers, including a researcher with experience of using the mental health services were also employed. To identify the information needs of users of services and family members a number of focus group interviews were conducted with the users of services, family members and clinicians.

Users of services expressed a desire for information on how to manage their mental health or ‘condition’, as well as information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with ‘symptoms’, ‘medication side-effects’, low self-esteem and negative attitudes from others. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment.

Family members, in contrast, wanted to meet with a psychiatrist and to be given more information on their family member’s ‘illness’, treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.

Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres. Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users of services or family members), who were recruited from within the service and attended a two day training programme.

Evaluation methodology

The evaluation component used a sequential mixed method design involving both quantitative and qualitative approaches. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the programme of participants, facilitators and project workers. In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Of these, twelve completed both questionnaires. In addition, 25 family members completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. In total, 34 interviews were conducted. Of these, 19 were with programme participants, 11 were with facilitators and 4 were with the 2 project workers. Both descriptive and inferential statistics were generated. All interviews were audio recorded and transcribed verbatim. The qualitative data were entered into the data management software package NVivo version 8 and analysed using a thematic approach. Ethical approval to conduct the evaluation was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin and the ethics committee for the service.

Discussion of findings

Overall, it can be said that the EOLAS Project was a success and achieved its key objectives. While a number of the survey instruments did not show a statistically significant change, findings from the interviews suggest that the programme had a number of positive outcomes, including increases in perceived knowledge, empowerment and support. Both groups of participants spoke of leaving the programme with a 'better understanding' of either their own or another's mental health problem. In addition, users of services, in particular, spoke of feeling more empowered to question practitioners about their care and treatment. The sessions on medication, stress and relaxation techniques, and the role of team members in the multidisciplinary team were highlighted as particularly informative. Participants also highlighted the value of having the opportunity to ask a psychiatrist questions about diagnosis and medication. However, despite the satisfaction of the participants with the information received, both family members and user participants were of the view that the EOLAS Programme should be available to everybody immediately when they attend the mental health service, as part of an everyday quality service.

A number of studies have highlighted the supportive nature of peer groups (Rappaport 2000; Finn et al. 2007; Sibitz et al. 2007; Barber et al. 2008; Resnick and Rosenheck 2008) and findings from this evaluation were no different. Although EOLAS was primarily an information programme, the supportive space created appeared to fill a significant need for emotional support. Participants valued the opportunity to meet people in similar circumstances, share their experiences, learn from each other and provide mutual support. Both family members and users had experienced a lot of grief, shame, anger and loss. Family members spoke of lacking support networks both within and outside the mental health services and consequently valued a 'safe' place to vent their frustrations and concerns, and gain support. Indeed, a recent report by the Inspector of the Mental Health Commission Ireland (2010) on talking therapies identified poor availability of psychological therapies throughout the mental health services, with a waiting time of up to 2 years for therapy. In this context, it is not surprising that the level of family distress and emotion expressed within the group was high, and that they expressed a desire to increase the duration of sessions to facilitate a more in-depth discussion. In addition, given the short timeframe available to prepare facilitators for their role, it is equally unsurprising that some facilitators found it challenging to facilitate discussion in a supportive manner and manage the group dynamic, while simultaneously maintaining the focus on information sharing.

Principles of adult learning underpinned the development of the EOLAS Project. In other words, facilitators would seek to enable mutual co-operation with adult learners by adhering to the values of voluntary participation, mutual respect, a collaborative spirit, action and reflection and self-direction (Brookfield 1988). Findings indicate that participants valued the various teaching strategies used, including discussion groups, activities and information sheets. Hearing other people's stories was also considered a helpful learning strategy. However, some participants were of the view that they lacked time within sessions to address the content in-depth or to allow for discussion and sharing of views and experiences. Other issues that appeared to impact negatively on learning and group dynamics were the low numbers on some of the programmes, the open nature of the group, the changing of facilitators and the manner in which some of the learning materials were used. All of these issues require consideration for subsequent programmes.

As highlighted, time was a crucial factor in the programme. The brevity of time available to complete the project impacted negatively of the quality of the written information materials. Some participants found the written materials inaccessible, too text heavy and using language that was overly technical. However, since the initial EOLAS pilot programme and following some preliminary feedback from the research team, a second edition of the information handouts and facilitator's manual have been developed and evaluated by users and family members. Findings from these focus group discussions revealed that participants welcomed and were very enthusiastic about the revised information materials. They spoke of finding the language, content and layout to be more user-friendly, readable and informative. The revised facilitator handbook provides clearer guidelines on literacy issues, supporting participants in carrying out activities, and using the written information handouts as prompts for discussion as opposed to 'public reading'.

Findings from this study support previous Irish research that indicates there is minimal information given to users and family members as part of routine practice within mental health care (Mental Health Commission, 2005; Brosnan, 2006). Although benefiting from the EOLAS programmes, both groups of participants (users and family) indicated their desire to receive the information much sooner in their journey through the services and were adamant that the programme should be provided to people, as a matter of routine practice, once they attend the service.

Recruiting users and family members to the programme was carried out by clinicians from the various mental health teams. It was thought that this process would 'screen out' any user that might be too 'vulnerable' to attend. It could be said that this is an overly paternalistic attitude and has the potential to negate the right of users to be considered as full adult citizens capable of making their own decisions (Bracken and Thomas 2005). It also takes away any means of spontaneity and diminishes the voluntary participative aspect so inherent to adult learning. Rather than being considered as people first and foremost with a mental health problem, they are considered to be primarily a 'patient' whose mental health difficulties impacts negatively on their decision-making ability and, consequently, the inherent power imbalance that currently exists within mental health services is maintained. Furthermore, if the only mechanism for users to be referred onto the programme is through their clinicians, there is a risk that user participants perceive the programme to be a clinical-focused programme rather than a collaborative effort between peers and clinicians.

User and carer involvement is frequently introduced into practice as intrinsically worthwhile. Involvement is thought to lead to empowerment, increased access to social contacts, and reduce inequalities between users and practitioners, thus improving relationships with service providers (Simpson and House 2003; McEvoy et al. 2008; McDaid 2009). In many cases this was true for the current study, as many peers and participants (users and family) spoke of the positive outcomes of having been involved. However, one of the core differences between the EOLAS Programme and other programmes evaluated in the literature is the dual nature of the facilitation as it incorporated both peer and clinician facilitation. Overall, participants were positive about the dual nature of the facilitation and valued the role of each facilitator for different reasons. In their view, peers had credibility by virtue of self-experience and provided hope and inspiration. In contrast, the clinicians came with 'clinical expertise' that they also valued. Having said this, findings indicate that due to a variety of reasons including insufficient preparation of facilitators around power dynamics, the value of self experience over clinical expertise, and strategies for co-facilitation, on occasion, traditional power dynamics prevailed within the group. Consequently, the clinical facilitators were positioned as the 'leaders', with clinical knowledge becoming more valuable than the voice of self-experience. As McDaid (2006: 58) points out "simple equality of presence…will not ensure equal participation"; thus, the over-referencing of professional expertise and the delegation of 'trivial tasks' to peers are issues that requires urgent attention in subsequent facilitator training programmes. McDaid (2006, 2009) advocates for greater capacity building among users of services and practitioners by retraining professionals to value experiential knowledge and rebalancing power relations through assigning users of services authority. Without this, there is a danger that participants leave the programme with a message that reinforces the lack of power of users and their family members to influence and effect change within the mental health services. It may also deter other users and family members from becoming involved as facilitators in other projects for fear of tokenism.

Previous published studies appear to confine the delivery of programmes to people who had received a very specific diagnosis, with a reluctance to combine people from different diagnostic groups (Rummel et al. 2005). Indeed in the early phase of the EOLAS Project there were some concerns among practitioners around mixing people with different diagnoses. Practitioners were concerned that the 'stigma' attached to a diagnosis of schizophrenia may inhibit people who had a diagnosis of bipolar disorder attending, and that their information needs would differ. This study demonstrates that combining people with different 'diagnoses' offers a promising approach, especially when there may not be enough potential participants to make organising diagnosis-specific groups a feasible option. Findings from this study would also support Rabovsky and Stoppe's (2006) view that there are many aspects of information needs common to users of services with a variety of diagnoses, including their desire for information on medication, diagnosis, service provision, advocacy, warning signs, family relationships and recovery.

In addition, previous studies reviewed tended to use highly structured methodologies for their evaluations, which were dominated by quantitative tools. By adopting a more mixed methods approach within this evaluation and through integrating more qualitative approaches, this study enabled a different perspective on the programme to emerge, complementing the existing literature. The flexibility of the interview shed light on unexplored or previously unexamined perspectives, such as co-facilitation challenges.

Overall, the EOLAS Project embodied the nature and principles of collaboration. The complete project was developed in conjunction with users, family members and clinicians. Its success in meeting its objectives and producing a high quality information programme was due in no small way to people's commitment to the principles of collaboration. The team produced clear manuals that can be accessed and used by other services. Indeed, services can be confident that the content of the manuals is based on the voice of users and family members, as opposed to the 'expertise' of practitioners, which has characterised the vast majority of the programmes documented in the literature. The EOLAS Project clearly demonstrates and reinforces the importance of engaging with all stakeholders, and hearing the voice of users and families if changes in mental health services are to be achieved and sustained.

In addition to producing a set of manuals, feedback from all stakeholders also indicates that the EOLAS Project was a positive initiative within the service as it commenced a dialogue on the importance of user and family involvement. The project design, governance, delivery and evaluation strategies as described in the report offers a blueprint for future developments that are collaborative in nature and provides a framework by which other services can work towards achieving a number of the quality standards as laid down by the Mental Health Commission (2007); namely standards 3.3, 3.4, and 6.1. Standard 3.3 states that "peer support/ advocacy is available to service users of services"; standard 3.4 indicates that "a clear accessible mechanism for participation in the delivery of mental health services is available to service users"; and standard 6.1 states "families, parents and carers are empowered as team members receiving information, advice and support as appropriate" (32-40). Despite the limitations of the project and the need for further capacity building among facilitators, there is no doubt that the EOLAS Project is a step in the right direction towards making users and their families equal partners within the mental health services.

Limitations

As stated, overall the results of the evaluation are quite positive; however, they need to be interpreted in light of the following issues:

- Participants volunteered to take part in the information programme and this may have attracted people who were more interested and positive about this form of development. In addition, participants volunteered for the evaluation interviews and this may have biased the data toward people with more positive experiences or participants who wished to present the service in a favourable light. Therefore, it cannot be assumed that they represent the general population of users, family members or clinicians.
- The overall numbers of participants who completed the programme and completed both the pre and post questionnaires were smaller than anticipated, thus minimising the likelihood of finding any statistical difference in the pre and post measures. Due to the small sample size, caution should be taken when interpreting any statistical findings.
- A key limitation of the present study relates to the relationship between some of the measures and the content of the intervention. Some measures reflect quite general psychological constructs (e.g. recovery, hope and self-advocacy) and the item content of the measures may not have reflected the specific content of the intervention. The measures were selected on the basis of assessing a clinically relevant construct and having established use in the research literature. In selecting such measures it was hoped to demonstrate the effectiveness of the intervention and to be able to benchmark such changes with other studies in the literature; however, the items from such scales may not have been that sensitive to change as the intervention sessions may not have addressed issues pertinent to the items. Similarly, it is possible that some measures (e.g. GHQ) were inappropriate given the content of the intervention.
- The study did not include a control group for comparison and long term outcomes were not evaluated.

Recommendations

Bearing in mind that the written materials (information leaflets and facilitator manual) for the programme have been revised and subsequently evaluated by a cohort of users and family members, the researchers make recommendations under a number of key areas:

- The revised programme should be offered to users and family members both within and outside the Kildare and West Wicklow services to cater for those who did not get the opportunity to attend.
- Subsequent programme delivered should give consideration to:
    - Expanding recruitment strategies to include extensive advertising in community, user and advocacy organisations.
    - Extending the duration of each session to two hours to enable participants to engage in more in-depth discussion about people's personal and individual experiences.
    - Including a solicitor with expertise in family and mental health law as a guest speaker and potentially including sessions on self-advocacy.
    - Including in future programmes a session on how to set up a support group and list those organisations that may be able to assist and provide advice should family members wish to proceed with this initiative.
    - Providing time for each co-facilitation pair to meet and discuss strategies that would facilitate the smooth roll out of the programme.
    - Minimising the number of facilitators who facilitate on any one programme.
    - Exploring the creative use of learning strategies, such as video, PowerPoint and case studies.
    - Sending new editions of written information handouts to NALA who, for a fee, will screen the literature and assess for user-friendliness.
- Future training programmes of facilitators should:
    - Incorporate in-depth discussion and reflection on the inherent power differentials between clinicians and peer facilitators and explore strategies of how to minimise such issues.
    - Incorporate awareness raising exercises that would emphasise the unique and valuable contribution peer facilitators bring to programme delivery.
    - Include skills training on how to manage group dynamics and respond to individuals who may dominate group discussion, perhaps through employing more role play training within the programme.
    - Explicitly encourage facilitators to deploy an ethos of hope and recovery into programme delivery.
    - Provide opportunities for participants to practice peer facilitation and receive feedback in a learning context.
    - Encourage guest speakers to attend the complete facilitation training or at least the session that provides an overview of the programme so that they might gain a holistic understanding of the programme structure and ethos.
- The revised facilitators training programme should be given recognition by an appropriate accrediting and training body.
- In view of the unique need of the users of the services, consideration should be given to:
    - Providing all users of services with relevant written information based on the EOLAS Project handouts.
- In view of the unique needs of family members identified in the study, consideration should be given to:
    - Providing all family members on their first encounter with mental health services relevant written information based on the EOLAS Project handouts.
    - Providing family members with information on support groups and free and accessible counselling services within their region as a matter of course once they attend the mental health services.
    - Appointing a key worker who would act as a 'mediator' between families, users of services and mental health services.
- The revised programme be further evaluated and consideration be given to:
    - Using a larger cohort of users of services and family members and evaluating within a greater number of services to ensure that statistical findings are robust.
    - Further testing and examining the quantitative measures to identify those that would be most suitable in evaluating the efficacy of the EOLAS. For example, the qualitative interviews noted the value of enhanced social support, which was not assessed in the battery of questionnaires used. Similarly, coping strategies and goal setting were not assessed, which may have proved more sensitive to what the intervention could achieve.
    - Evaluating the impact and effect of different modes of delivery of the information programme, such as face-to-face peer and clinician led versus online delivery.
    - Including outcomes, such as knowledge, self-advocacy, hope, sense of support, help seeking behaviour and perspective on willingness to engage and collaborate with service providers.
    - Evaluating the long-term benefits of these interventions using longitudinal study designs.
    - Devising evaluation strategies that require shorter self-completion questionnaires.
    - Securing funding in order to enable the roll out and further evaluation to occur at a national level.

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Appendix I: Studies identified for review

NAME	POPULATION	DURATION OF INTERVENTION	CURRICULUM CONTENT	TEACHING METHODS	THEORETICAL PERSPECTIVE	OUTCOMES MEASURES	OUTCOMES OF INTERVENTIONS	MAIN FINDINGS
Dixon et al (2004)	Family-to-family. 95 family members of those with severe mental illness from 15 different class groups across the state of Maryland U.S.A.	12 weeks of 2-3 hour sessions	Info on mental illnesses, treatments, medication & rehabilitation. Learn about self-care, mutual assistance & communication skills, problem-solving strategies, advocacy & emotional insight.	Trained family volunteers. Highly structured, scripted manual.	Based on theories of stress and coping, trauma recovery, adaptation and support. Family well-being primary concern.	Structured telephone interviews at 4 time intervals (waitlist, pre, post and 6 months post). Family Experience interview schedule: Family Impact Survey and Family Empowerment Scale. Data collectors had family members who had mental illness.	FFEP associated with reduced subjective burden reduce worry, increase knowledge of mental illness, mental health system & self-care.	Family-to-Family peer taught psychoeducation programs improve well-being of family members and increase their understanding of mental health. No significant reduction in these effects 6 months after the programme
Pickett-Schenk et al (2008)	Family-led intervention.231 intervention group. 231 waiting list. Family members of adults with mental illness in Louisiana, U.S.A. 3 intervention sites. Randomized control trial	8 weeks. 2hr sessions. Taught in non-clinical settings. Free to all participants. Class sizes 10-15.	Biological causes & standard treatment of various mental illnesses. Problem-solving skills. Coping strategies. Normative reactions to mental illness. Self-care. Community treatment progs & consumer recovery.	Trained volunteers who have adult family member with mental health difficulty. Team of two instructors. Manual-led.	Programme appears to be mostly recovery-oriented.	In person structured interviews at 3 time intervals (1month before intervention (baseline control), post-programme (3 months post-baseline control), 6 months post-programme (8months post-baseline control). Family knowledge scale. Family information needs scale	Intervention group – greater knowledge increases. Information need decreases. These gains were maintained after 6 months	Family- led education interventions provide families with the info they need to better cope with relative's mental health problem
Druss et al (2010)	80 participants to both intervention & waiting list groups from Urban community mental health centre in southern states USA	6 sessions	Self-management of disease. Medications, upcoming appointments, dietary intake, physical activity, connection b/n mind & body	Team of two peer educators Manualised intervention	Bio-medical model appears to predominate. Focus on medication management. HARP is an adaptation of Chronic Disease Self-Management Program	Baseline and 6 months post. Physical health related quality of life (HRQOL).Patient Activation Measure. Behavioural risk factor surveillance system.	Intervention group greater improvement in patient activation, medication adherence & physical activity	HARP (health & recovery peer program) improves a range of outcomes, esp. those with chronic medical co-morbidity
Rummel et al (2005)	2 peer moderators. 58 patients. 4 outpatients & 54 inpatients of open psychiatric ward of university psychiatric hospital, Munich, Germany.	7 groups of 8 sessions. 2 sessions per week. 1 hour each.	Symptoms/diagnosis/causes of schiz. Medication effects & side effects. Psychosocial therapy. Warning signs & contingency plan. Dealing with schiz & influence of family & friends.	Two peer co-moderators, with physician present at beginning of training	Biomedical model Feasibility study of pilot programme	Baseline and endpoint questionnaire to group participants. Knowledge of Illness about schizophrenia and disease concept scales. Subjective feedback sheet on moderators' knowledge, empathy, pedagogical abilities, practical experience)	Knowledge & concept issues improve. Trust in doctor and medication increased. Positive subjective assessment of peer moderators	Peer-to-peer psychoeducation in schizophrenia is feasible. Peers are credible role models

Appendix I: Studies identified for review (Continued)

NAME	POPULATION	DURATION OF INTERVENTION	CURRICULUM CONTENT	TEACHING METHODS	THEORETICAL PERSPECTIVE	OUTCOMES MEASURES	OUTCOMES OF INTERVENTIONS	MAIN FINDINGS
Resnick & Rosenheck (2008)	Vet-to-Vet (War veterans with mental health difficulties, many homeless) 3 cohorts. 1 standard care (N=78). 2 intervention (N=218). 3 attended more than 10 sessions (N=102).	Runs 5 days a wk. attendance voluntary	Read & discuss format for established curriculum of recovery oriented publications	Peer provided Read and discuss format	Explicitly collaborative / partnership model between users of services and clinicians Recovery approach	3 cohorts. 1 standard care. 2 interventions. 3 attended more than 10 sessions. Follow up interviews at 1, 3 and 9 months by experienced, independent rater. Measures of recovery orientation, confidence & empowerment Recovery attitudes Questionnaire: mental health confidence scale, making decisions scale, empowerment over illness scale, activities of daily living, global assessment of functioning. Addiction severity index, brief psychiatric rating scale etc	Cohort 2 and 3 superior outcomes on all outcomes, especially among cohort 3 who attended most regularly.	Participation in peer-led psychoeducation enhances well being – in both recovery and traditional clinical measures
Barber et al 2008	1, 847 anonymous surveys from 38 various Vet-to-Vet programmes in U.S.	Runs 5 days a week. attendance voluntary	Read and discuss format for established curriculum of recovery oriented publications	Peer provided Read and discuss format	Explicitly collaborative / partnership model between users of services and clinicians Recovery approach	Level of participation on programme and any facilitation. Satisfaction with programme. Veteran recovery attitudes. Spirituality. Engagement in meaningful personal activities.	Programme positive experience. High satisfaction with programme linked to stronger sense of recovery and engagement. Payment of facilitators.	Paper demonstrates a monitoring system of peer support on Vet-to-Vet
Pickett et al (2010)	160 participants in Building Recovery of Individual Dreams & Goals (BRIDGES) ed prog. U.S.A.	8 week programme	Recovery focused	Trained instructors who publically disclose that they are in recovery from mental illness	Recovery-focused	Structured interviews (pre and 1 month post-programme). Symptoms, hopefulness, social support, self-advocacy, empowerment, adaptive coping	Post-BRIDGES fewer psychiatric symptoms, decrease maladaptive coping, increased hopefulness, self-advocacy, empowerment and recovery.	Peer-led education interventions valuable resource. More research into long-term benefits required.
Pickett-Schenk et al (2006)	Family-led education intervention – Journey of Hope 462 participants (relatives of those with mental illness) Chicago, U.S. A.	3 months programme	Carer coping strategies, Stress management, Recovery, relationships, hopefulness	Trained family carers	Recovery-focused	Randomly assigned control (waitlist) and treatment group followed for 9 months. Pre, post and post-6 months. Caregiving satisfaction scale. Family information needs scale – problem management and social functioning subscales.	Treatment group showed a marked improvement in caregiving satisfaction & info needs after programme & continuously 6 months after.	Education and support from other family members in structured programme is effective in meeting caregiving needs
Cook et al (2010)	381 WRAP participants from Vermont & Minnesota	7 day programme	Self-management of mental illness to people in mental health Recovery	Trained peers	Recovery-focused	Pre and post programme surveys. 3 dimensions of self-management: attitudes, knowledge and skills.	Significant increases in hopefulness, awareness of warning signs & symptom triggers, use of wellness tools, crisis plan, soc support & take responsibility for wellness	This study contributes to the evidence base for peer-led programmes

Appendix II: Detailed statistical findings

Users of services

SUMMARY STATISTICS FOR MEASURES OVER TIME

	PRE EOLAS MEAN (SD)[MEDIAN]	POST EOLAS MEAN (SD)[MEDIAN]
Knowledge (n=2)	44.13 (3.83)[44]	67.5 (10.61)[67.5]
Recovery Attitude Questionnaire (n=8)	40.81 (4.06)[39]	44.75 (5.00)[46]
Patient Self-Advocacy Scale (n=8)	32.63 (7.08)[32.5]	34.63 (5.62)[34.5]
Drug Attitude Inventory (n=8)	18.25 (2.55)[17.5]	18.13 (3.09)[17.5]
Hearth Hope Index (n=7)	30.86 (5.45) [30]	33.29 (4.07)[34]

KNOWLEDGE

	PRE EOLAS (N = 25, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I understand why I am on medication.	12 (48%)	10 (40%)	1 (4%)	2 (8%)	-	7 (58%)	4 (33%)	1 (8%)	-	-
I know about stress management techniques for myself.	5 (20%)	12 (48%)	3 (12%)	4 (16%)	1 (4%)	3 (25%)	6 (50%)	3 (25%)	-	-
I understand what my relapse triggers are. (Pre n=22)	5 (23%)	10 (46%)	4 (18%)	2 (9%)	1 (5%)	2 (17%)	8 (67%)	1 (8%)	1 (8%)	-
I know how to access mental health services for myself (Pre n=23)	8 (35%)	12 (52%)	3 (13%)	-	-	6 (50%)	6 (50%)	-	-	-
I know what the role of each member of the multi-disciplinary team is (e.g. nurse, etc).	7 (28%)	10 (40%)	7 (28%)	1 (4%)	-	5 (42%)	6 (50%)	-	1 (8%)	-
I know how to ask questions of the multi-disciplinary team members. (Pre n=23)	6 (26%)	8 (35%)	5 (22%)	3 (13%)	1 (4%)	4 (33%)	6 (50%)	2 (17%)	-	-
I understand my legal rights in the mental health services.	4 (16%)	5 (20%)	10 (40%)	5 (20%)	1 (4%)	5 (42%)	6 (50%)	-	1 (8%)	-
I know how to deal with voices (if appropriate). (Pre n=15; Post n =10)	5 (33%)	7 (47%)	2 (13%)	1 (7%)	-	3 (30%)	2 (20%)	4 (40%)	1 (10%)	-
I know how to deal with strange thoughts (if appropriate). (Pre n=20; Post n = 11)	5 (25%)	8 (40%)	1 (5%)	4 (20%)	2 (10%)	3 (27%)	4 (36%)	4 (36%)	-	-
I know how to deal with family conflict/ interactions. (Pre n=23; Post n =10)	4 (17%)	9 (39%)	4 (17%)	4 (17%)	2 (9%)	3 (30%)	4 (40%)	1 (10%)	2 (20%)	-
I know how to cope with the side effects of my medication. (n=24)	5 (21%)	9 (38%)	6 (25%)	3 (13%)	1 (4%)	3 (25%)	5 (42%)	4 (33%)	-	-
I know how to cope with changes in my mood.	4 (16%)	9 (36%)	5 (20%)	5 (20%)	2 (8%)	2 (17%)	8 (67%)	2 (17%)	-	-
I am familiar with strategies for seeking employment.(Pre n=21; Post n =11)	6 (29%)	3 (14%)	8 (38%)	2 (10%)	2 (10%)	3 (27%)	4 (36%)	4 (36%)	-	-
I am familiar with strategies for getting involved in the local community (Post n =11)	5 (20%)	6 (24%)	6 (24%)	6 (24%)	2 (8%)	3 (27%)	5 (46%)	2 (18%)	1 (9%)	-
I am familiar with strategies for establishing friendships/relationships.	4 (16%)	8 (32%)	8 (32%)	4 (16%)	1 (4%)	2 (17%)	7 (58%)	3 (25%)	-	-

RECOVERY ATTITUDE QUESTIONNAIRE

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
People in recovery sometimes have set backs.	15 (58%)	11 (42%)	-	-	-	8 (67%)	4 (33%)	-	-	-
To recover requires belief that I can recover.	15 (58%)	10 (39%)	1 (4%)	-	-	8 (67%)	4 (33%)	-	-	-
Stigma associated with mental health problems can slow down the recovery process. (n=24)	11 (46%)	9 (38%)	2 (8%)	2 (8%)	-	6 (50%)	5 (42%)	-	-	1 (8%)
Recovery can occur even if symptoms of mental health problems are present. (n=25)	10 (40%)	8 (32%)	4 (16%)	2 (8%)	1 (4%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)	-
Recovering from mental health problems is possible no matter what you think may cause it.	8 (31%)	14 (54%)	4 (15%)	-	-	5 (42%)	5 (42%)	2 (17%)	-	-
All people with serious mental health problems can strive for recovery.	11 (42%)	15 (58%)-	-	-	-	7 (58%)	4 (33%)	-	1 (8%)	-
People differ in the way they recover from a mental health problem.	10 (39%)	16 (62%)	-	-	-	7 (58%)	5 (42%)	-	-	-
My relationship with the mental health team contributes to recovery.	12 (46%)	14 (54%)	-	-	-	7 (58%)	5 (42%)	-	-	-
I am responsible for my own recovery.	10 (39%)	10 (39%)	5 (19%)	1 (4%)	-	6 (50%)	6 (50%)	-	-	-
My relationship with my family contributes to my recovery.	12 (46%)	9 (35%)	4 (15%)	1 (4%)	-	6 (50%)	6 (50%)	-	-	-

HEARTH HOPE INDEX

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)				POST EOLAS (N = 12, UNLESS OTHERWISE STATED)			
	SA	A	D	SD	SA	A	D	SD
I have a positive outlook toward life. (Pre n=27)	4 (15%)	16 (59%)	6 (22%)	1 (4%)	4 (33%)	6 (60%)	2 (17%)	-
I have short and/or long-range goals.	5 (19%)	16 (62%)	3 (12%)	2 (8%)	4 (33%)	7 (58%)	-	1 (8%)
I feel all alone.(Pre n=25)	5 (20%)	5 (20%)	12 (48%)	3 (12%)	1 (8%)	2 (17%)	8 (67%)	1 (8%)
I can see possibilities in the midst of difficulties.	7 (27%)	14 (54%)	5 (19%)	-	6 (50%)	6 (50%)	-	-
I have a faith that gives me comfort.(Pre n=25)	10 (40%)	10 (40%)	2 (8%)	3 (12%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)
I feel scared about my future. (Pre n=25)	6 (24%)	12 (48%)	5 (20%)	2 (8%)	4 (33%)	4 (33%)	4 (33%)	-
I can recall happy/joyful times.(Pre n=27)	11 (41%)	12 (44%)	4 (15%)	-	6 (50%)	6 (50%)	-	-
I have deep inner strength.	8 (31%)	14 (54%)	2 (8%)	2 (8%)	6 (50%)	5 (42%)	1 (8%)	-
I am able to give and receive caring/love.(Pre n=27)	10 (37%)	13 (48%)	4 (15%)	-	6 (50%)	4 (33%)	2 (17%)	-
I have a sense of direction	8 (31%)	12 (46%)	5 (19%)	1 (4%)	4 (33%)	6 (50%)	1 (8%)	1 (8%)

PATIENT SELF-ADVOCACY SCALE

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I believe it is important for people with psychosis to learn as much as they can about their mental health problems and treatments. (Pre n=27)	18 (67%)	8 (30%)	1 (4%)	-	-	7 (58%)	5 (42%)	-	-	-
I actively seek out information on my mental health problem	9 (35%)	10 (39%)	3 (12%)	2 (8%)	2 (8%)	3 (25%)	6 50%)	3 (25%)	-	-
I don't get what I need from my mental health team because I am not assertive enough. (Pre n=27)	4 (15%)	8 (30%)	8 (30%)	6 (22%)	1 (4%)	1 (8%)	2 (17%)	3 (25%)	5 (42%)	1 (8%)
I am more assertive about my mental health care needs than most Irish citizens.(Pre n=25; Post n =11)	2 (8%)	6 (24%)	12 (48%)	5 (20%)	-	1 (8%)	5 (46%)	5 (46%)	-	-
I frequently make suggestions to my mental health team about my mental health care needs.	5 (19%)	10 (39%)	5 (19%)	6 (23%)	-	2 (17%)	7 (58%)	2 (17%)	1 (8%)	-
If my mental health team prescribes something I don't understand or agree with, I question it. (Pre n=27)	12 (44%)	10 (37%)	2 (7%)	2 (7%)	1 (4%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)	-
Sometimes there are good reasons not to follow the advice of a mental health team.	1 (4%)	6 (23%)	9 (35%)	6 (23%)	4 (15%)	1 (8%)	2 (17%)	3 (25%)	5 (42%)	1 (8%)
Sometimes I think I have a better grasp of what I need medically than my mental health team does.	5 (19%)	6 (23%)	5 (19%)	7 (27%)	3 (12%)	2 (17%)	3 (25%)	1 (8%)	5 (42%)	1 (8%)
If I am given a treatment by my mental health team that I don't agree with, I am likely to not take it.	5 (19%)	6 (23%)	3 (12%)	11 (42%)	1 (4%)	1 (8%)	1 (8%)	2 (17%)	6 (50%)	2 (17%)
I don't always do what my health care worker has asked me to do.	4 (15%)	5 (19%)	5 (19%)	11 (42%)	1 (4%)	1 (8%)	4 (33%)	1 (8%)	5 (42%)	1 (8%)

DRUG ATTITUDE INVENTORY

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
For me, the good things about medication outweigh the bad. (n=27)	11 (41%)	10 (37%)	4 (15%)	1 (4%)	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-	-
I take medications of my own free choice.	12 (46%)	9 (35%)	3 (12%)	2 (8%)	-	5 (42%)	5 (42%)	1 (8%)	1 (8%)	-
I take medication only when I feel ill.	1 (4%)	2 (8%)	3 (12%)	15 (58%)	5 (19%)	2 (17%)	-	1 (8%)	7 (58%)	2 (17%)
Taking medication will prevent me from having a breakdown/becoming unwell.	17 (66%)	5 (19%)	4 (15%)	-	-	5 (42%)	7 (58%)	-	-	-
It is unnatural for my mind and body to be controlled by medications.	6 (23%)	4 (15%)	6 (23%)	9 (35%)	1 (4%)	1 (8%)	3 (25%)	3 (33%)	2 (17%)	3 (25%)

Family and friends

SUMMARY STATISTICS FOR MEASURES OVER TIME

	PRE EOLAS MEAN (SD) [MEDIAN]	POST EOLAS MEAN (SD) [MEDIAN]
Knowledge	45.14 (7.27) [45]	55 (8.22) [51]
Recovery Attitude Questionnaire	40.81 (4.06) [39]	43 (3.61) [44]
Patient Self-Advocacy Scale	34.75 (3.28) [33.5]	37.75 (2.49) [38.5]
Social Network of Support Scale	19.14 (4.02) [20]	19.42 (3.05) [20]
Hearth Hope Index	37.71 (3.59) [38]	40.14 (4.06) [4]
General Health Questionnaire	11.25 (5.19) [9]	9.5 (5.68) [7]

KNOWLEDGE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I understand why my relative/friend is on medication (Pre n =25)	12 (48%)	12 (48%)	1 (4%)	-	-	12 (67%)	6 (33%)	-	-	-
I know about stress management techniques for myself	4 (17%)	8 (33%)	6 (25%)	3 (13%)	3 (13%)	4 (22%)	5 (28%)	6 (33%)	3 (17%)	-
I understand what my relative/friend's relapse triggers are (Pre n =25; Post n =17)	6 (24%)	9 (36%)	4 (16%)	5 (20%)	1 (4%)	4 (24%)	6 (35%)	3 (18%)	4 (24%)	-
I know how to access mental health services for my relative/friend (Pre n =23)	3 (13%)	11 (48%)	3 (13%)	2 (9%)	4 (17%)	7 (39%)	8 (44%)	-	1 (6%)	2 (11%)
I know what the role of each member of the multi-disciplinary team is (e.g. nurse, social worker, psychiatrist, psychologist)	2 (8%)	6 (25%)	9 (38%)	2 (8%)	5 (21%)	6 (33%)	6 (33%)	1 (6%)	3 (17%)	2 (11%)
I know how to ask questions of the multi-disciplinary team members	4 (17%)	2 (8%)	12 (50%)	3 (13%)	3 (13%)	4 (22%)	5 (28%)	7 (39%)	1 (6%)	1 (6%)
I understand my relative/friend's legal rights in the mental health services	3 (13%)	2 (8%)	7 (29%)	4 (17%)	8 (33%)	7 (39%)	6 (33%)	2 (11)	3 (17%)	-
I know how to help my relative/friend deal with voices (if appropriate) (Pre n =22; Post n=17)	1 (5%)	2 (9%)	9 (41%)	4 (18%)	6 (27%)	4 (24%)	4 (24%)	8 (47%)	1 (6%)	-
I know how to help my relative/friend deal with strange thoughts (if appropriate)	1 (4%)	10 (42%)	5 (21%)	5 (21%)	3 (13%)	3 (17%)	8 (44%)	4 (22%)	3 (17%)	-
I know how to deal with family conflict/ interactions	2 (8%)	7 (29%)	6 (25%)	6 (25%)	3 (13%)	4 (22%)	7 (39%)	3 (17%)	3 (17%)	1 (6%)
I know how to help my relative/friend cope with the side effects of their medication (n=25)	1 (4%)	4 (16%)	10 (40%)	7 (28%)	3 (12%)	-	11 (61%)	4 (22%)	2 (11%)	1 (6%)
I know how to cope with changes in my relative/ friend's mood	2 (8%)	5 (21%)	8 (33%)	5 (21%)	4 (17%)	2 (11%)	8 (44%)	5 (28%)	1 (6%)	2 (11%)
I am familiar with strategies for helping my relative/friend seek employment (Pre n=21; Post n =17)	-	2 (10%)	6 (29%)	5 (24%)	8 (38%)	1 (6%)	2 (12%)	7 (41%)	4 (24%)	3 (18%)
I am familiar with strategies for helping my relative/friend get involved in the local community	-	3 (13%)	8 (33%)	5 (21%)	8 (33%)	-	6 (33%)	5 (28%)	4 (22%)	3 (17%)
I am familiar with strategies for helping my relative/friend establish friendships/relationships (Pre n =25)	2 (8%)	4 (16%)	9 (36%)	4 (16%)	6 (24%)	1 (6%)	5 (28%)	5 (28%)	6 (33%)	1 (6%)

– Items with significant changes are in bold.

RECOVERY ATTITUDE QUESTIONNAIRE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
People in recovery sometimes have set backs	12 (50%)	10 (42%)	1 (4%)	-	1 (4%)	10 (56%)	8 (44%)	-	-	-
To recover requires service users to believe themselves that they can recover	12 (50%)	11 (46%)	1 (4%)	-	-	9 (50%)	9 (50%)	-	-	-
Stigma associated with mental health problems can slow down the recovery process	10 (42%)	11 (46%)	2 (8%)	-	1 (4%)	5 (28%)	8 (44%)	4 (22%)	1 (6%)	-
Recovery can occur even if symptoms of mental health problems are present	6 (25%)	11 (46%)	4 (17%)	2 (8%)	1 (4%)	5 (28%)	10 (56%)	2 (11%)	1 (6%)	-
Recovering from mental health problems is possible no matter what you think may cause it (Pre n =23)	7 (30%)	6 (26%)	7 (30%)	2 (9%)	1 (4%)	3 (17%)	11 (61%)	3 (17%)	1 (6%)	-
All people with serious mental health problems can strive for recovery	5 (21%)	15 (63%)-	3 (13%)	-	1 (4%)	6 (33%)	8 (44%)	4 (22%)	-	-
People differ in the way they recover from a mental health problem	9 (38%)	13 (54%)	2 (8%)	-	-	8 (44%)	10 (56%)	-	-	-
A service user's relationship with the mental health team contributes to their recovery	11 (46%)	11 (46%)	2 (8%)	-	-	10 (56%)	6 (33%)	-	1 (6%)	1 (6%)
The service user is responsible for their own recovery (Pre n =23)	3 (13%)	6 (26%)	9 (39%)	4 (17%)	1 (4%)	5 (28%)	5 (28%)	3 (17%)	3 (17%)	2 (11%)
The service user's relationship with their family contributes to their recovery	9 (38%)	13 (54%)	2 (8%)	-	-	11 (61%)	7 (39%)	-	-	-

HEARTH HOPE INDEX

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)				POST EOLAS (N = 12, UNLESS OTHERWISE STATED)			
	SA	A	D	SD	SA	A	D	SD
I have a positive outlook toward life. (Pre n=25)	7 (28%)	17 (68%)	1 (4%)	-	7 (58%)	5 (42%)	-	-
I have short and/or long-range goals.	3 (13%)	19 (79%)	2 (8%)	-	4 (33%)	7 (58%)	-	1 (8%)
I feel all alone.	5 (21%)	5 (21%)	13 (54%)	1 (4%)	1 (8%)	3 (25%)	7 (58%)	1 (8%)
I can see possibilities in the midst of difficulties.	4 (17%)	19 (79%)	1 (4%)	-	3 (25%)	9 (75%)	-	-
I have a faith that gives me comfort.	3 (13%)	14 (58%)	4 (17%)	3 (13%)	4 (33%)	6 (50%)	2 (17%)	-
I feel scared about my future. (Pre n=23; Post n =11)	6 (26%)	10 (44%)	6 (26%)	1 (4%)	1 (9%)	1 (9%)	9 (82%)	-
I can recall happy/joyful times. (Post n =12)	9 (38%)	14 (58%)	-	1 (4%)	6 (50%)	6 (50%)	-	-
I have deep inner strength. (Post n =12)	10 (42%)	13 (54%)	-	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-
I am able to give and receive caring/love.(Post n =12)	11 (46%)	12 (50%)	1 (4%)	-	7 (58%)	5 (42%)	-	-
I have a sense of direction (Post n =12)	4 (17%)	16 (67%)	3 (13%)	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-
I believe that each day has potential. (Pre n =23)	4 (17%)	18 (78%)	1 (4%)	-	5 (42%)	7 (58%)	-	-
I feel my life has value and worth.	13 (54%)	10 (42%)	1 (4%)	-	6 (50%)	6 (50%)	-	-

– Items with significant changes are in bold.

PATIENT SELF-ADVOCACY SCALE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I believe it is important for people with psychosis to learn as much as they can about their mental health problems and treatments.(Pre n =25)	14 (56%)	10 (40%)	1 (4%)	-	-	12 (67%)	5 (28%)	1 (6%)	-	-
I actively seek out information on my family member/friend's mental health problem	8 (33%)	10 (42%)	4 (17%)	2 (8%)	-	7 (39%)	9 (50%)	2 (11%)	-	-
I don't get what I need from my family member/ friend's mental health team because I am not assertive enough.(Pre n =23)	5 (22%)	1 (4%)	11 (48%)	4 (17%)	2 (9%)	1 (6%)	3 (17%)	9 (50%)	4 (22%)	1 (6%)
I am more assertive about my family member/ friend's mental health care needs than most Irish citizens.	3 (13%)	5 (21%)	13 (54%)	2 (8%)	1 (4%)	3 (17%)	9 (50%)	4 (22%)	2 (11%)	-
I frequently make suggestions to the mental health team about my family member/friend's mental health care needs. (Pre n =23)	3 (13%)	4 (17%)	7 (30%)	8 (35%)	1 (4%)	1 (6%)	7 (39%)	6 (33%)	3 (17%)	1 (6%)
If the mental health team prescribes something for my family member/friend that I don't understand or agree with, I question it. (Pre n =25)	9 (36%)	11 (44%)	4 (16%)	1 (4%)	-	3 (17%)	10 (56%)	5 (28%)	-	-
Sometimes there are good reasons not to follow the advice of a mental health team.(Pre n =23)	2 (9%)	8 (35%)	8 (35%)	3 (13%)	2 (9%)	2 (11%)	-	10 (56%)	5 (28%)	1 (6%)
Sometimes I think I have a better grasp of what family member/friend needs medically than their mental health team does.(Pre n=25)	6 (24%)	5 (20%)	8 (32%)	6 (24%)	-	2 (11%)	4 (22%)	6 (33%)	5 (28%)	1 (6%)
If my family member/friend is given a treatment by their mental health team that I don't agree with, I encourage them not to take it.	-	1 (4%)	6 (25%)	12 (50%)	5 (21%)	-	2 (11%)	4 (22%)	9 (50%)	3 (17%)
I don't always do what my family member/ friend's mental health care worker has asked me to do.(Pre n=22)	1 (5%)	3 (14%)	4 (18%)	11 (50%)	3 (14%)	-	2 (11%)	3 (17%)	10 (56%)	3 (17%)
I ask questions about my family member mental health problems from the mental health team (Pre n =22; Post n =13)	7 (32%)	9 (41%)	6 (27%)	-	-	6 (46%)	5 (39%)	2 (15%)	-	-

– Items with significant changes are in bold.

SOCIAL NETWORK OF SUPPORT SCALE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 11)				
	SA	A	N	D	SD	SA	A	N	D	SD
I feel supported by the mental health team in relation to my family member's mental health problem.	3 (13%)	5 (21%)	5 (21%)	6 (25%)	5 (21%)	2 (18%)	3 (27%)	2 (18%)	3 (27%)	1 (9%)
I feel supported by other families in relation to my family member's mental health problem.	3 (13%)	3 (13%)	11 (46%)	3 (13%)	4 (17%)	2 (18%)	3 (27%)	2 (18%)	4 (36%)	-
I feel supported by my own family/friends in relation to my family member's mental health problem. (Pre n =23)	5 (22%)	9 (39%)	5 (22%)	-	4 (17%)	3 (27%)	5 (46%)	-	3 (27%)	-
I feel supported by the mental health team in meeting my own needs	2 (8%)	-	10 (42%)	6 (25%)	6 (25%)	1 (9%)	2 (18%)	2 (18%)	5 (46%)	1 (9%)
I feel supported by other families in meeting my own needs	4 (17%)	4 (17%)	9 (38%)	3 (13%)	4 (17%)	1 (9%)	1 (9%)	4 (36%)	5 (46%)	-
I feel supported by my own family/friends in meeting my own needs	5 (22%)	8 (35%)	6 (26%)	1 (4%)	3 (13%)	1 (9%)	4 (36%)	3 (27%)	3 (27%)	-

GENERAL HEALTH QUESTIONNAIRE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)				POST EOLAS (N = 11, UNLESS OTHERWISE STATED)			
Been unable to concentrate on whatever you are doing? (pre n =23)	Better than usual 1 (4%)	Same as usual 16 (70%)	Less than usual 3 (13%)	Much less than usual 3 (13%)	Better than usual 1 (9%)	Same as usual 7 (64%)	Less than usual 2 (18%)	Much less than usual 1 (9%)
Lost much sleep over worry?	Not at all 6 (25%)	No more than usual 8 (33%)	Rather more than usual 6 (25%)	Much more than usual 4 (17%)	Not at all 3 (27%)	No more than usual 7 (64%)	Rather more than usual 1 (9%)	Much more than usual -
Felt that you are playing a useful part in things? (post n =9)	More so than usual 6 (25%)	Same as usual 12 (50%)	Less so than usual 5 (21%)	Much less than usual 1 (4%)	More so than usual -	Same as usual 7 (78%)	Less so than usual 1 (11%)	Much less than usual 1 (11%)
Felt capable of making decisions about things? (Pre n =25)	More so than usual 5 (20%)	Same as usual 19 (76%)	Less so than usual 1 (4%)	Much less than usual -	More so than usual -	Same as usual 8 (73%)	Less so than usual 3 (27%)	Much less than usual -
Felt constantly under strain?	Not at all 3 (13%)	No more than usual 12 (50%)	Rather more than usual 4 (17%)	Much more than usual 5 (21%)	Not at all 1 (9%)	No more than usual 5 (46%)	Rather more than usual 4 (36%)	Much more than usual 1 (9%)
Felt you couldn't overcome your difficulties?	Not at all 6 (25%)	No more than usual 11 (46%)	Rather more than usual 6 (25%)	Much more than usual 1 (4%)	Not at all 2 (18%)	No more than usual 6 (55%)	Rather more than usual 3 (27%)	Much more than usual -
Been able to enjoy your normal day-to-day activities? (Pre n =23)	*More so than usual 2 (9%)*	*Same as usual 13 (57%)*	*Less so than usual 7 (30%)*	*Much less than usual 1 (4%)*	*More so than usual 1 (9%)*	*Same as usual 7 (64%)*	*Less so than usual 2 (18%)*	*Much less than usual 1 (9%)*
Been able to face up to your problems?	*More so than usual 6 (25%)*	*Same as usual 13 (54%)*	*Less so than usual 5 (21%)*	*Much less than usual -*	*More so than usual -*	*Same as usual 8 (73%)*	*Less so than usual 3 (27%)*	*Much less than usual -*
Been feeling unhappy and depressed?	*Not at all 5 (21%)*	*No more than usual 12 (50%)*	*Rather more than usual 5 (21%)*	*Much more than usual 2 (8%)*	*Not at all 4 (36%)*	*No more than usual 5 (46%)*	*Rather more than usual 2 (18%)*	*Much more than usual -*
Been losing confidence in yourself? (Pre n =23)	*Not at all 10 (44%)*	*No more than usual 8 (35%)*	*Rather more than usual 2 (9%)*	*Much more than usual 3 (13%)*	*Not at all 5 (46%)*	*No more than usual 3 (27%)*	*Rather more than usual 3 (27%)*	*Much more than usual -*
Been thinking of yourself as a worthless person?	*Not at all 14 (58%)*	*No more than usual 6 (25%)*	*Rather more than usual 4 (17%)*	*Much more than usual -*	*Not at all 7 (64%)*	*No more than usual 2 (18%)*	*Rather more than usual 2 (18%)*	*Much more than usual -*
Been feeling reasonably happy, all things considered?	*More so than usual 3 (13%)*	*Same as usual 12 (50%)*	*Less so than usual 9 (38%)*	*Much less than usual -*	*More so than usual 2 (18%)*	*Same as usual 6 (55%)*	*Less so than usual 3 (27%)*	*Much less than usual -*

EXECUTIVE SUMMARY

The current emphasis within Irish mental health service policy is on promoting a partnership approach between users of services, families and practitioners within an ethos of recovery. One strategy to promote this philosophy is the development of peer led educational interventions for both users and family members. The literature suggests that peer led programmes can have positive outcomes in terms of enhanced knowledge, empowerment and support. To date, the majority of programmes evaluated tended to be developed by practitioners and delivered either through the use of a clinician or peer model. In addition, there is a dearth of studies evaluating collaborative peer and clinician led educational interventions for people experiencing mental health difficulties or educational interventions developed in partnership with users and family members, which is the focus of the EOLAS project.

Aim of the evaluation

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (schizophrenia and bipolar disorder) for users of services and family members in the HSE Kildare/ West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

Methods

Collaborative principles guided all stages of the project. To identify the information needs of users of services and family members, a number of focus group interviews were conducted with the users of services, family members and clinicians. Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres. Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users of services or family members), who were recruited from within the service and attended a two day training programme.

This evaluation used a sequential mixed method design, involving the collection of both quantitative and qualitative data. Data were collected using pre and post course questionnaires followed by an integrated qualitative component to explore participants', facilitators' and project workers' experiences and views of the programme. In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. In addition, 25 family/friends completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. In total, 34 interviews were conducted with users of services, family members, facilitators and project workers.

Key findings

- Overall, it can be said that the EOLAS Project was a success and achieved its key objectives. All participants would recommend the programme and nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) of the programme as high or extremely high.
- While a number of the survey instruments did not show statistically significant changes, findings from the interviews suggest that the programme had a number of positive outcomes, including increases in perceived knowledge, empowerment and support. Both group of participants spoke of leaving the programme with a 'better understanding' of either their own or another's mental health problem. In addition, users of services, in particular, spoke of feeling more empowered to question practitioners about their care and treatment.
- It was clear from the interviews that participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.
- Findings indicate that participants valued the various teaching strategies used, including discussion groups, activities and information sheets. Hearing other people's stories was also considered a helpful learning strategy. However, some participants were of the view that they lacked time within sessions to address the content in-depth or to allow for discussion and sharing of views and experiences. Other issues that appeared to impact negatively on learning and group dynamics were the low numbers on some of the programmes, the open nature of the group, the changing of facilitators and the manner in which some of the learning materials were used.
- Both family members and user participants were of the view that the EOLAS Programme should be available to everybody immediately when they attend the mental health service, as part of an everyday quality service.
- One of the core differences between the EOLAS Programme and other programmes evaluated in the literature was the dual nature of the facilitation as it incorporated both peer and clinician facilitation. Survey participants generally agreed that having a user of services/family member as a facilitator on the programme was a positive experience (79%; n = 23). Interview

participants valued the role of each facilitator for different reasons. In their view, peers had credibility by virtue of self-experience and provided hope and inspiration. In contrast, the clinicians came with 'clinical expertise' that they also valued.

- Although the involvement of peers appeared to foster new understandings as people started to appreciate the person 'on the other side of the fence', findings also indicate that due to a variety of reasons, including insufficient preparation of facilitators around power dynamics, the valuing of clinical expertise over self-experience, and insufficient strategies for co-facilitation, on occasion, traditional power dynamics prevailed within the group. Consequently, the clinical facilitators were positioned as the 'leaders', with clinical knowledge being seen as more valuable than the voice of self-experience.
- Previous published studies appear to confine the delivery of programmes to people who had received a very specific diagnosis, with a reluctance to combine people from different diagnostic groups. This study demonstrates that combining people with different 'diagnoses' offers a promising approach, especially when there may not be enough potential participants to make organising diagnosis-specific groups a feasible option.

Recommendations

Bearing in mind that the written materials (information leaflets and facilitator manual) for the programme have been revised and subsequently evaluated by a cohort of users of services and family members, the researchers make recommendations under a number of key areas:

- The revised programme should be offered to users and family members both within and outside the Kildare/Wicklow services to cater for those who did not get the opportunity to attend and consideration should be given to providing all users of services and family members with relevant written information based on the EOLAS Project handouts immediately when they attend the mental health service as part of an everyday quality service.
- Subsequent programmes delivered should give consideration to expanding recruitment strategies, extending the duration of sessions and using additional creative teaching strategies.
- Future training programmes of facilitators should provide opportunities for in-depth discussion and reflection on the inherent power differentials between clinicians and peer facilitators and explore strategies of how to minimise such issues. In addition, future training programmes need to incorporate awareness raising exercises that would emphasise the unique and valuable contribution peer facilitators bring to programme delivery.
- The revised facilitators training programme should be given recognition by an appropriate accrediting and training body.
- In view of the unique needs of family members, consideration should be given to providing family members with information on support groups and accessible counselling services, and appointing a key worker who would act as a 'mediator' between families, users of services and mental health services.
- The revised programme should be further evaluated using a larger cohort of participants to ensure that statistical findings are robust. Further testing of the quantitative measures to identify those that would be most suitable in evaluating the efficacy of the EOLAS Programme is required. In addition, there is a need to evaluate the long-term benefits of EOLAS and to test the effect of different modes of delivery of the information programme, such as peer and clinician led face-to-face delivery versus online delivery.

CHAPTER 1

BACKGROUND LITERATURE

INTRODUCTION

In order to give a context to the EOLAS Project, the subject of the report, this chapter will review some relevant policy and research literature. The aim of the EOLAS Project was to develop, deliver and evaluate a peer and clinician led information programme on recovery from the experience of mental health difficulties (people with a medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members. The chapter begins with some policy background to user and family involvement in mental health care, as well as some background literature on the informational needs of both groups. This is followed by a section on recent trends in psychoeducational programmes, including the new, emerging area of peer-to-peer educational interventions for people experiencing mental health difficulties.

Users of services and family involvement: A partnership approach

Both national and international mental health services are moving to incorporate a more recovery-oriented philosophy into service provision. One of the core principles underpinning recovery is a shift in the paradigm of care and the relationships between practitioners, users of services and family members (Mental Health Commission 2006; Higgins et al. 2010). Indeed, various international and national health and social care policy documents have articulated a need for increased user and family involvement in the development, delivery and evaluation of mental health services (Department of Health and Children et al. 2008; World Health Organization 2010). The policy document *A Vision for Change* also reflects this collaborative perspective on service provision and recommends user and carer involvement in every aspect of service delivery with a view to enabling the recovery process (Department of Health and Children 2006). In addition, organisations, such as the National Institute for Clinical Excellence (2009) and the Mental Health Commission Ireland (2005), as well as Irish researchers (Brosnan 2006; Crowe 2006; Dunne 2006; Higgins 2008), strongly endorse partnership between users of services, family and practitioners, and consider that the ideals of a shared service approach will have positive outcomes for all.

Involvement of users of service has been linked to improved quality of health care, higher levels of satisfaction with services, increase in users' willingness to engage in treatment and improved health outcomes (Repper and Perkins 2003; Department of Health and Children et al. 2008; Higgins 2008). Similarly, there is a growing body of international evidence that recognises the importance of involving family members within the mental health services and the pivotal role played by family members and friends in supporting people with mental health issues in their recovery journey (Maurin and Boyd 1990; Rose 1996).

In addition to involving users and family members, there is an increased recognition that having access to peer support and peer groups is an important part of the recovery process for users (Mental Health Commission 2005; McDaid 2006; Higgins 2008; Slade 2009), and equally an important source of emotional support for family members (Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008; Jonsson et al. 2011). Peers, whether users of the service or family members, are considered to have greater credibility than practitioners and provide friendship, support, hope and direction, as well as encouraging development of coping skills (Resnick et al. 2004; Barber et al. 2008; Resnick and Rosenheck 2008). However, peer-to-peer approaches, although well developed and successful in other health contexts, have been underdeveloped in mental health care in general (Sibitz et al. 2007), including within Ireland.

Users of services informational needs

Despite the recognition of the rights of people who use the mental health service to have the most up-to-date information in both written and verbal format (Mental Health Commission 2005; Higgins 2008; World Health Organization 2010), the reality of every day Irish practice suggests that many services are behind in meeting the Mental Health Commission's standards on information giving (Mental Health Commission, 2005). Some of the quality standards identified include reference to users of services being "facilitated to be actively involved in their own care and treatment through the provision of information" (Mental Health Commission 2005: 30) and the importance of ensuring that information is "communicated in a way that is easily understood and made available both in verbal and written form" (Mental Health Commission 2005). Numerous studies carried out by Irish user groups and their representative organisations on users' experience of mental health service provision have highlighted a number of concerns. These include: poor communication with clinicians; lack of information relating to rights, diagnosis and treatment options, lack of choice and lack of access to alternative treatments (Western Health Board and Schizophrenia Ireland 2002; Brosnan 2006; Crowe 2006; Dunne 2006; National Service User Executive 2011).

Family member informational needs

Similarly, there is a growing body of international evidence that recognises the pivotal role that family members and friends play in supporting people with mental health issues (Maurin and Boyd 1990; Rose 1996). Gamble and Brennan (2006) identify that historically families have been as much burdened by the mental health system as by the person's mental health problem. Family members have often been (and often are still) perceived as part of the problem, if not the cause, of serious mental health issues. The reality, according to these authors, is that the treatment and recovery from serious mental health problems would not be possible without the participation of families and informal carers as they represent a major resource and support network for users (Gamble and Brennan 2006). However, to enable families to support their relatives, researchers have been identifying the importance of giving families information about their relative's mental health problem as far back as the 1970s (Hatfield 1978; Lefley 2001). In the Irish context, one of the recommendations of *A Vision for Change* is the "need to provide families and carers with support, information, and easily accessible help when needed" (Department of Health and Children 2006: 106). Furthermore, a recent report from the Mental Health Commission underlined family carers' needs for more understanding, information, empathy and respect from mental health service providers (Mental Health Commission 2005). However, Kartalova-O'Doherty et al.'s (2008) qualitative study involving 38 family carers of people who experience mental health problems highlights the short comings within the Irish mental health services. Participants within the study outlined the lack of services and support for family carers and reported receiving limited information from service providers about their relative's illness, treatment and prognosis. The participants also reported experiencing a clash between practitioners' desire to maintain the person's rights to confidentiality around diagnosis and treatment, and the families need to understand how they best can support and help their relative. Some key recommendations of this report were the need to introduce a key worker who would act as a 'mediator' between families, users of services and mental health services, and the need to provide families with information about diagnosis and other aspects of care.

Recent trends in information and psychoeducational programmes

Psychoeducational interventions are structured information programmes that focus on enhancing the emotional, social and behavioural well-being and the recovery journey of the individual who has experienced mental health problems. Psychoeducational approaches have been developed with a view to increasing knowledge and understanding of illness and treatment. It is supposed that increased knowledge has positive effects on quality of life and well-being, and enables people to cope more effectively. To date, clinician led interventions have dominated the field. Five Cochrane systematic reviews of psychoeducation and other psychosocial interventions indicate that the positive outcomes of psychoeducation, include reduction in relapse and readmission rates and improved psychosocial functioning (Pekkala and Merinder 2002; Cleary et al. 2008; Tungpunkom and Nicol 2008; Pharoah et al. 2010; Xia et al. 2011). For instance, Pekkala and Merinder's (2002) Cochrane review of 10 didactic psychoeducation programmes for people diagnosed with schizophrenia spectrum disorders reported that around 12 relapses can be avoided, or at least postponed for a year, if 100 users of services receive psychoeducation. Psychoeducation may also enhance adherence to medication, but the extent of improvement remains unclear (Pekkala and Merinder 2002). Research indicates that brief (eight to ten sessions) psychoeducational programmes produce significant reductions in relapse and rehospitalisation rates compared to treatment as usual at two year follow up (Buchkremer et al. 1997), five year follow up (Hornung et al. 1999) and seven year follow up (Bauml et al. 2007). Small effect sizes have been reported for knowledge gain (Pekkala and Merinder 2002; Rummel et al. 2005; Lincoln et al. 2007). The results for more immediate outcomes such as compliance with medication, improved mental state and psychosocial functioning are inconsistent, with differing methodologies providing different results (Cleary et al. 2008; Tungpunkom and Nicol 2008; Pharoah et al. 2010; Xia et al. 2011). In addition, the reviews do not draw any firm conclusions on the impact of psychoeducation on outcomes such as insight, medication-related attitudes or overall satisfaction with services. No standardised approach has been taken in relation to the duration of psychoeducational interventions, with programmes ranging from 1 to 24 sessions reported in the literature. The majority of previous psychoeducation evaluation studies have been conducted with users of services with durations of illness varying from 6.3 years to 14 years.

As stated, the vast majority of studies included in these reviews focus on professional developed and professional led interventions (Rummel-Kluge and Kissling 2008). In recent years, there have been some international studies examining peer led educational interventions. This section explores the existing, albeit scant, international literature on peer-to-peer and collaborative peer and clinician led educational programmes for people who experience mental health difficulties. The absence of a centralised data base makes it impossible to determine the number of professional or peer led information programme offered to users and family members within Ireland.

In total, nine relevant international studies on peer led educational interventions were located (Appendix I includes further details). Six studies were located that evaluated user led psychoeducational programmes (Rummel et al. 2005; Barber et al. 2008; Resnick and Rosenheck 2008; Cook et al. 2010; Druss et al. 2010; Pickett et al. 2010) and three studies evaluated family led psychoeducational programmes (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). There did not appear to be any studies of programmes, which were designed for both families and users of services or that were collaboratively facilitated by both family members and users of services.

Resnick et al. (2004), Resnick and Rohenheck (2008) and Barber et al. (2008) evaluated the 'Vet-to-Vet' programme, the peer-to-peer intervention for U.S. war veterans, across different settings and employing varying methods. Rummell et al. (2005) conducted an evaluation of a user led eight session programme in an open psychiatric ward of a university psychiatric hospital in Munich, Germany. In contrast to the bio-medical model underlying the Rummel et al. (2005) intervention, Cook et al. (2010) examined a recovery-oriented seven day Wellness Recovery Action Plan (WRAP) programme among 381 participants from two states in the USA. In a similar vein, Pickett et al. (2010) evaluated the eight week Building Recovery of Individual Dreams and Goals (BRIDGES) programme among 160 participants across the USA. Within the literature on family-focused programmes, Pickett-Schenk

et al. (2006; 2008) evaluated the family led educational intervention 'Journey of Hope', albeit in different contexts using different methods and populations. Dixon et al. (2004) examined a 12 week 'Family-to-Family Education Programme' based in Maryland, USA.

Findings from the evaluations suggest that peer user led psychoeducation enhances well-being, as measured by both recovery and traditional clinical tools. It was reported that these programmes result in significant improvements in hopefulness (Pickett et al. 2010), awareness of warning signs and symptom triggers (Druss et al. 2010), improved use of wellness tools, crisis planning, social support, and in taking responsibility for wellness (Cook et al. 2010). In addition, findings have also shown fewer psychiatric symptoms (Rummel et al. 2005), decrease in maladaptive coping (Druss et al. 2010), and improved self-advocacy, empowerment and recovery (Barber et al. 2008; Resnick and Rosenheck 2008). Furthermore, peer family member led education for family members resulted in a marked improvement in caregiving satisfaction and increased knowledge of mental illness, the mental health system and self-care (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). The evidence, thus, indicates that peer-taught programmes, whether user or family member led, are feasible and that peer facilitators serve as credible and positive role models.

The programmes reviewed were largely designed by practitioners and had little or no user input in their development. Thus, users of services or family members who attended the programmes were positioned as 'receivers' of expert, pre-packaged knowledge. The content of the programmes generally addressed areas such as symptoms of schizophrenia, causes, pharmacological and psychosocial treatment strategies, relapse prevention and the role of family support. The duration of the programmes tended to be one to two hour sessions and were typically conducted for eight weeks. Most of the programmes reviewed were highly structured and highly scripted manual-based programmes (Dixon et al. 2004; Pickett-Schenk et al. 2008; Druss et al. 2010).

The majority of the studies did not detail the specifics of the teaching methods employed on the programme, with the exception of the Vet-to-Vet programme (Resnick et al. 2004; Barber et al. 2008; Resnick and Rosenheck 2008), which used a non-prescriptive, discussion format. The focus of each session involved the reading and discussion of an established curriculum of recovery-oriented publications. The Vet-to-Vet programme appeared to be the only intervention in the literature that explicitly employs service-user involvement at a partnership level in both the development of the programme and the learning tools used on the programme (Resnick et al. 2004; Resnick and Rosenheck 2008).

There appeared to be a trend of co-facilitating involving two facilitators across the various educational interventions (Rummel et al. 2005; Pickett-Schenk et al. 2008; Druss et al. 2010). In all cases, both facilitators appeared to be either two family members or two users of services. The educational interventions delivered to both users and family members tended to be delivered more to people with a diagnosis of schizophrenia spectrum disorders, rather than bi-polar (Rummel et al. 2005; Barber et al. 2008; Resnick and Rosenheck 2008; Cook et al. 2010; Druss et al. 2010; Pickett et al. 2010). There also appeared to be a tendency to provide programmes that were disorder-specific and which did not 'mix' people with different diagnoses.

Many of the studies simply stated that the facilitators were trained without detailing the training procedures that were undertaken (Dixon et al. 2004; Pickett-Schenk et al. 2006; Pickett-Schenk et al. 2008). The exception to this was Rummel et al. (2005) who employed a five step training programme to train two users of services co-facilitators, with a physician present at the beginning of training. The first step involved the trainee facilitators attending the psychoeducation group as participants for a complete programme, while observing and noting the facilitators' skills. The second step involved the trainees attending four training workshops over a two month period. The next step involved the two trainees facilitating several sessions together while being observed by a physician. Following this, the two trainees moved onto facilitating several sessions without being supervised by a clinician. The final stage in the training programme was the recruitment of new facilitators from cohorts of participants who had completed the psychoeducational group. The presence of a physician during the training of the facilitators may have been due to the fact that the majority of the participants on the programme evaluated by Rummel et al. (2005) were still in-patients in an 'open psychiatric ward'.

Summary

The current emphasis within Irish mental health service policy is on promoting a partnership approach between users, families and practitioners within an ethos of recovery. One strategy to promote this philosophy is the development of peer led educational interventions for both users and family members. The literature suggests that peer led programmes can have positive outcomes in terms of enhanced knowledge, empowerment and support. To date, the majority of programmes evaluated tended to be developed by practitioners and delivered either through the use of a clinician or peer model. Due to the differences in methodologies, participant profiles and programme content, it is not possible to compare the differential effects and outcomes of the clinician led with the peer-led approach to psycheoeducation. In addition, there is a dearth of studies evaluating collaborative peer and clinician led educational interventions for people experiencing mental health difficulties or educational interventions developed in partnership with users and family members, which is the focus of the EOLAS study. Hence, the importance of this evaluation, as a sound evidence-base is required to inform future development of shared approaches to care.

CHAPTER 2

Background & development of the EOLAS Information Programme

INTRODUCTION

In order to set the evaluation of EOLAS in context, this chapter describes the aims of the programme, governance structure, strategies and processes used to develop and deliver the education programme. In addition, some of the challenges encountered during the development phase are highlighted.

Background and aims

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia, bipolar disorder and related ‘illnesses’) for users of services and family members in the HSE Kildare and West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users of services and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

The project was a localised venture between the HSE Kildare/West Wicklow Mental Health Service, Shine, the Irish Advocacy Network and Kildare Youth Services. It was funded by the Genio Trust and designed to be a collaborative venture between practitioners working in mental health services, users of services and family members. The guiding values were captured in the mission statement of the EOLAS Project using the acronym SUPPORT: shared, understanding, partnership, participation, openness, respect and trust.

Governance structures

In keeping with the values of partnership and participation, the overall project was managed by a steering group that included clinicians from a range of disciplines (medicine, nursing, social work and psychology), users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team Trinity College Dublin. Two project workers, with responsibility for various aspects of project development, design, recruitment and roll out, were employed part-time to support the steering group. In addition, two researchers, including a researcher with experience of using mental health services, were employed as part of the research team. To assist with the day-to-day aspects of the project, a number of sub-committees were also formed. These reported to and received feedback from the main steering committee. The timeframe for the total project was less than 12 months due to the nature of the funding. The design, development and roll out of the programme occurred between January and August 2011, with the evaluation phase, including write-up and modifications to the original programme being complete by December 2011. An overview of the EOLAS process is presented in Figure 1.

Generating collaboration and commitment within the mental health teams

Generating commitment and ‘buy in’ from the mental health teams within the HSE Kildare/ West Wicklow area was considered critical to the success of the programme, as both the participants and the facilitators would have be to recruited from within those services. To achieve this, both the project workers and members of the research team met with a number of clinical teams to explain the aims of the project, and the processes and strategies to be used in the design, recruitment, roll out and evaluation phases. During these meetings, time was set aside to answer questions and to elicit feedback and suggestions. In total, six clinical, multidisciplinary and community mental health teams in the Kildare and West Wicklow area were presented with information and asked to assist. In addition to the meetings with clinical staff, the project workers made presentations to some community and voluntary sector providers and informed people about the project through posters. A website with information about the programme was also designed by a member of the steering group: **www.theEOLASproject.com**

From the outset, it was agreed that the information programme would be delivered to people who had a diagnosis of schizophrenia or bipolar disorder. This decision was based on a belief that the main information needs would be similar for both diagnostic groups and that a combined group would be an efficient use of resources. In general, the idea of the EOLAS Project was well received by the clinical teams, who were of the view that it would address key information deficits and the needs of users and families.

While the teams welcomed the fact that the programme would be delivered in both urban and more rural venues, teams within the more rural areas highlighted issues such as transport, cost and travel time. Other concerns expressed by some members of the clinical teams included the appropriateness of having users of services with different diagnosis within the same group, as well as some concern around ownership and facilitation of the programme. Following discussion and clarification, the clinical team members agreed to become involved in the recruitment phase of the project, which required them to circulate information and refer both users of services and family members to the initial consultation groups and the programme, once it was developed. Some members of teams, at this stage, also volunteered to be clinical co-facilitators.

Maintaining high ethical standards and support

Engaging in research in the area of mental health can be fraught with challenges, ranging from difficulties in recruitment to a view that mental health users of services and family members are too 'vulnerable' to participate fully in research. For this reason, from the start priority was given to maintaining the highest standards of information giving, protection and support of participants. Ethical approval to conduct both the information programme and the subsequent evaluation was given by the ethics committee within the service and the ethics committee of the university where the evaluation team worked.

At the outset, it was decided that the most appropriate way to recruit users was through clinical referral by the various mental health teams. It was thought that this referral process would go some way to ensuring that only those people who were 'well enough' would become involved. The involvement of the mental health teams also ensured that if members of the project group were concerned about any participant, they had immediate access to support for the person. In addition, potential participants (users of services, family members and clinicians) were informed from the outset in advertising literature and verbally by the project workers that the programme was being evaluated by an independent external group from Trinity College Dublin. Participants were also informed that they could participate in the EOLAS Project without obligation to participate in the evaluation. To ensure that the project workers were adequately supported, a system of peer debriefing and debriefing with their manager was implemented.

Designing the education programme: Eliciting multiple perspectives

Historically, people with mental health problems and family members have lacked a voice and have been excluded from decision-making in areas ranging from service development to their own care (Department of Health and Children 2006; McDaid 2006; World Health Organization 2010). Consequently, one of the core objectives of the EOLAS Project was to develop an information programme that was pertinent to the needs and wants of all the participants, that was developed collaboratively and where users of services' and family members' voices would take centre stage. In order to achieve this goal, a series of focus groups were held with users, family members and clinicians. During the focus groups, the participants were facilitated to identify and discuss the issues that were important to them and to identify what they would like to see included in the programme.

In total, 15 focus groups, facilitated by the project workers, were conducted in seven different locations throughout County Kildare (Athy, Celbridge, Newbridge, Maynooth, Johnstown Bridge, Naas, Kildare). Participants for the focus group were recruited through clinical referrals and posters that were displayed throughout the services.

Initially, recruitment to the focus groups was slow with a poor turnout at some venues. However, once this issue was brought to the attention of the steering committee, they made further contact with clinicians requesting assistance in recruitment. This strategy proved useful as more participants came forward. In total, 58 people participated in the focus groups. Table 1 provides a more detailed breakdown of participant numbers.

TABLE 1. NUMBER OF FOCUS GROUPS BY TYPE AND NUMBER OF PARTICIPANTS IN EACH

GROUP	NUMBER OF FOCUS GROUPS	TOTAL NUMBER OF PARTICIPANTS
Users of services	7	30
Family	7	21
Clinicians	1	7

The focus group discussion was guided by a topic guide developed by the project workers in conjunction with the clinical sub-group and addressed issues around recovery, staying well and information needs. To facilitate clinicians who were unable to attend the focus group an e-version questionnaire based on the topic guide was also distributed.

Key outcomes of users of services and family focus groups as perceived by the project workers

Overall, participants engaged proactively in the focus group discussions. The project workers reported that the user and family member groups were characterised by accounts of loss, grief, trauma and frustration. Both family member and user participants reported that there were few outlets where they could discuss their emotions and deal with their problems. Counselling was either too difficult to access, too expensive or had a long waiting list. As a result, the project workers heard some distressing stories and reported the overriding emotion in both groups as one of grief. This grief manifested itself in terms of a sense of loss, anger and powerlessness. The project workers responded to the outpouring of emotions by allowing participants to express their emotions for a period of time and then gently and sensitively re-focusing the person to the aims of the focus group. In addition to this strategy, the project workers also invited each person, at the end of the discussion to write how they felt the group went. In situations where the project workers had concerns about a participant, they informed the clinical team.

The grief expressed by the users of services appeared to be associated with their 'illness' and diagnosis. They spoke of experiencing shame and regret over their 'illness', and grieved the negative impact that their mental health problem had on their life and relationships. Users of services were frustrated with the perceived over-emphasis on medication within services and the absence of information on other forms of therapies. In addition, they expressed frustration at the lack of consultation and involvement in their medication regime.

Despite the distressing stories recounted by the users of services, the project workers found that they *"were remarkably measured in their responses, even in relation to their grievances with the mental health services"*. They found that participants were reconciled with their experiences, forward looking, very motivated towards recovery and wanting to move on with their lives. They requested information on how to manage their mental health problem or 'condition'. Specifically, they wanted information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with 'symptoms', 'medication side-effects', low self-esteem, negative attitudes from others and the shame they experienced as a result of having had a psychotic episode. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment, or as in the words of one project worker, they wanted to *"get on with things and lead their life."*

In contrast, the project workers reported that family focus groups were characterised by the expression of far greater amounts of anger, grief, trauma and loss. The family members were grieving the loss of their relative who they felt had, metaphorically, 'died'. Family members were stressed about their caring role and felt angry with the lack of support from the mental health services. Family members felt *"stuck, caught, lost"* and *"left out"* by the mental health system. They were angry with a system that did not consult them around decisions made about the care of their family member or provide them with information that might help them in their caring role. This lack of consultation and information further compounded their distress and added to their confusion, anger and disempowerment. The following two quotes were indicative of what the project workers heard:

> *"No one seems to take the time to explain, 'This is how the system operates. This is what we do. This is how we do it.'"*
>
> *"It's really a case of having to stand your ground, having literally to bang on the table and say, 'I'm not going from here until I get what I want.'"*

Family members, therefore, wanted to meet with a psychiatrist and to be given more information on their family member's 'illness', treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.

Detailed analysis of the focus groups indicated common themes across both the user and family groups; however, each had a very different emphasis and focus. Consequently, it was decided that the needs and wants of users of services and family members were so diverse that two separate programmes needed to be developed and delivered. Findings from the users groups also confirmed the previous decision to combine people with different diagnosis (schizophrenia and bipolar disorder). The overall themes identified from each group focus group are summarised in Table 2.

TABLE 2. THEMES IDENTIFIED IN USERS OF SERVICES AND FAMILY MEMBER FOCUS GROUPS

USERS OF SERVICES GROUP	FAMILY MEMBERS
Medication, its positive benefits and its side effects	Coming to terms with family member 'illness'
Diagnosis	How to deal with anger and anguish
Rights and advocacy	Understanding how the mental health service works
Asking questions of clinicians	Skills to ask questions of clinicians
Staying well and recovery	Opportunity to speak to doctors about diagnosis and medication
Community integration	Opportunity to discuss experiences
Sharing stories	

Key outcomes of clinician focus group and e-survey as perceived by the project workers

One clinician focus group was held with members of mental health teams located in the HSE Kildare and West Wicklow area with the aim of exploring their views on the content and structure of the programme. Participants in this group strongly supported the development of the programme as they were of the view that communication with family members was lacking across all teams. They also felt that in addition to giving information to users and family members, the education programme should support participants to gain the confidence to ask questions of practitioners.

As an outcome of the focus group and e-survey, a number of ideas for the development of information handouts were identified, such as information handouts on common clinical terms, questions to ask about 'illness' or medication and descriptions of the role of each team member. Participants were of the view that information on these issues might help to *"demystify the language and process"* for users and family members and encourage participants to be proactive about empowering themselves into the future.

Designing the education programme: Core philosophy

Although the programme was designed to be primarily focused on disseminating information and, consequently, was to be instructional in nature, special emphasis was to be placed on the ethos of adult learning principles (Knowles 1970). Knowles is credited with devising the basic model of Andragogy [1] in the 1970s, which is generally considered to be both a philosophy and a practice of adult learning. Its logic rests on the assumptions that as a person matures: (1) they become more self-directing in their learning; (2) their wealth of personal experience needs to be acknowledged as a resource for learning; (3) their learning is oriented toward performing roles and tasks; (4) they have an increased need to apply their learning to immediate real life situations and, accordingly; (5) the person's orientation toward learning is problem centred (Knowles 1970; Knowles et al. 2005). Thus, emphasis within the programme was to be placed on creating a mutually co-operative learning environment by adhering to the values of voluntary participation, mutual respect, a collaborative spirit, action, critical reflection and self-direction (Brookfield 1988). It was hoped that this approach would enable participants to feel more empowered in their subsequent dealings with the mental health services.

Designing the education programme: Content, format and teaching strategies

The content to be included in the information programme were based on the thematic analysis of the information from the focus groups. The analysis and development of the information programme was overseen by the clinical subgroup. Deciding on the depth and breadth of each topic required consideration of how best to reflect the participants' needs with due considerations of the time constraints and resources available. This aspect of the project was particularly challenging for the project workers and clinical subgroup as the timeframe for completion was extremely short (less than 2 months).

Each session was designed to be 90 minutes in duration, and consisted of input from the facilitators, learning activities, opportunity for questions and answers and some personal sharing and reflection. The learning activities were to be done in groups, pairs and individually, with the facilitators moving through the groups supporting participants as they worked through each activity. Thus, each session was to include elements of self-directed learning and some peer learning with an emphasis on the application to one's own life experience. At the end of each session, participants were requested to do a piece of work for the next session. This strategy was included in the hope that participants would be encouraged to become more proactive in sourcing information and interacting with practitioners.

In addition, participants were given detailed written handouts with information on the topic addressed during the session. It was hoped that at the end of the programme participants would have a personal resource manual that they could revisit or share with their family members and friends. The written handouts were voluntarily submitted by members of the team including a psychiatrist, pharmacist, solicitor and advocate. In keeping with the principles of adult learning, the concepts of empowerment, recovery and advocacy were to underpin each session.

In addition to input from the clinical and peer facilitators, a number of other people were to attend the information sessions and provide input. It was clear from the users and family member focus groups that they would like to meet with 'experts'. To access experts to speak to eight different groups in four different locations was a challenge. A number of psychiatric consultants volunteered to speak on diagnosis, treatment and medication. Inputs were also to be given by Community Welfare Officers, occupational therapists, social worker and psychologists. These speakers were drawn from the local mental health service in the hope of increasing the chance that the participants would identify with them and, subsequently, have less difficulty approaching them.

The user programme ran over eight weeks and addressed information on mental health service provision, diagnosis, treatment, medication and care, strategies to maintain relapse prevention, advice on pro-active engagement with mental health services, sources of self-help information, support groups and agencies, personal stories, statutory rights and entitlements, and the Mental Health Act.

The family programme ran over seven weeks and the main topics included were strategies to attain and maintain a good quality of life for family members, information on mental health service provision, diagnosis, consultations, medication, treatment and care, reliable sources of information, communication and engagement with services, advocacy, coming to terms with living with mental health difficulties, legal and statutory rights, and positive stories.

As stated at the outset, the timeframe for developing and rolling out the programme was approximately eight months. This timeframe resulted in the project workers developing and writing aspects of the programme (information handouts and activities) as it was being rolled out. Consequently, facilitators had little time to familiarise themselves with some aspects of the content and may have only received the information on the day of that particular session. In view of this and to ease the delivery of the programme, the project workers did develop guidelines for the facilitators. The guidelines were to provide direction to the facilitators on how to introduce, facilitate and close each session. In addition, direction was given on the duration of time to be spent on each activity.

Recruiting and training the facilitators

Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users or family members). Clinicians brought their clinical expertise, while users and family members brought a wealth of personal knowledge and experience.

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1. Andragogy is a term frequently used to denote adult learning.

Due to the previously noted time pressure, there was no formal application or interview process to select suitable facilitators; it was more a case of who was available and willing to volunteer. The majority of family member and user facilitators were recruited through their participation in the focus groups, with some having been approached and recruited by members of mental health teams. The clinical facilitators were recruited from the clinical teams within the services.

Educating the facilitators was considered to be crucial to the success of the programme. However, due to time constraints and clinical pressures, it was only possible for facilitators to receive a two day training programme. The first day of training centred on facilitation skills and was delivered by a private organisation that was skilled in delivering facilitation programmes. The second day focused on helping the facilitators to familiarise themselves with the facilitator handbook and the content of the programme materials developed (see Table 3). In total, 13 clinicians and 10 peer facilitators attended the training.

TABLE 3. TOPICS FOR FACILITATOR TRAINING

DAY 1	DAY 2
Agreeing principles and values	Information on aim, objectives and content of each module
Stages of group development	Demonstration of one module by the project workers
Responding to process challenges	Practice demonstration by clinician and peer facilitator
Listening and clarifying skills	
Working with a co-facilitator	

Rolling out the programmes

A separate programme for family members and users of services was delivered in four centres in the Kildare and West Wicklow Mental Health Services area (Kildare, Athy, Maynooth and Naas) throughout the months of July and August 2011.[2] Programmes were run in venues independent of the health services, which included hotels and community centres. Throughout the programme, the facilitators were supported by the project workers, along with the Assistant Director of Nursing. This level of support was necessary to ensure that practicalities, such as an absence of facilitators, transport for participants, organising guest speakers and photocopying, could be responded to in a timely and efficient manner. In addition, the Assistant Director of Nursing acted as a point of clinical contact, advice and liaison with the mental health teams if the facilitators became concerned about any participant.

A number of strategies were used to recruit user and family member participants for the information programme. Users were recruited by the clinical teams, by posters within the mental health services and through a presentation to EVE mental health support services in county Kildare. Family members were also recruited through clinical teams and by posters within the mental health services.

Summary

- The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental difficulties (medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members in the HSE Kildare and West Wicklow area.
- The project was managed by a steering group that included clinicians, users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team. Two project workers were also employed.
- Collaborative principles guided all stages of the project. To generate support for the project, presentations on the aims and objectives of the project were made to members of the clinical team, the community and voluntary sector. In addition, focus groups (n = 15) were conducted with users of services, family members and clinicians to identify the information needs of users of services and family members.
- Users of services expressed a desire for information on how to manage their mental health or 'condition', as well as information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with 'symptoms', 'medication side-effects', low self-esteem, and negative attitudes from others. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment.
- Family members wanted to meet with a psychiatrist and to be given more information on their family member's 'illness', treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.
- Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres in the Kildare and West Wicklow Mental Health Services area (Kildare, Athy, Maynooth and Naas) throughout the months of July and August 2011.
- Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users ofservices or family members), who attended a two day training programme.

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[2] Due to low attendance rates, the family member course at one location was discontinued.

CHAPTER 3

Research methodology

INTRODUCTION

In this chapter the study aims, objectives, study design, methods and ethical procedures are described.

Aims and objectives of evaluation

The aims of the evaluation were to explore participants' experience of their involvement in a collaborative user and clinician led information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia, bipolar disorder or related 'illness') and to evaluate the impact of the EOLAS Project on participants' perceived knowledge, attitudes and well-being.

Specifically, the objectives of this evaluation were:

- to investigate the impact attending the information programme had on users of services, and family members' perceived knowledge, attitudes towards recovery, hope, support, advocacy and well-being;
- to explore participants' experience of being involved in the information programme;
- to explore the experiences of both the clinician and peer facilitators in the delivery phase; and
- to determine ways of improving and developing the EOLAS information programme.

Design

This evaluation used a sequential mixed method design involving the collection of both quantitative and qualitative data. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the programme of participants, facilitators and project workers.

Data collection methods

Data were collected using a combination of questionnaires and interviews. Data on the impact of the EOLAS Project were collected using pre and post programme questionnaires. Questionnaires were completed by participants prior to starting the information programme (pre-programme), at the end of each information session and immediately after completion (post-programme).

A post-programme semi-structured interview was used to explore the participants', facilitators' and project workers' experiences and opinions of the EOLAS Project, including their suggestions for improving the programme.

Questionnaire design

The surveys examined the possible outcomes of participating in the programme, such as increased hopefulness, increased knowledge of mental health issues and improved attitudes towards recovery. The post-programme questionnaires also explored the participants' satisfaction with the EOLAS Project, including content and process of delivery. There were two versions of the questionnaire developed: one version for users of services and the other for the family member EOLAS participants.

Pre-programme questionnaire

The pre-programme user questionnaire consisted of seven sections. Demographic data were gathered in sections A and G, including information on age, gender, civic status, living circumstances, employment status, level of education and daily living activities. The medical diagnosis for the participant's mental health difficulty was asked about in section A.

Section B consisted of a 15-item scale on which participants rated their level of perceived knowledge of mental health issues including symptoms, coping skills, relapse triggers and roles within the community mental health team. The questions in this section were scored using a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree).

Section C comprised the Recovery Attitudes Questionnaire 7 (RAQ-7), which consisted of a 7-item scale developed by Borkin et al. (2000). The RAQ-7 has been used and tested with people with self-experience of mental health issuse, carers, their families and mental health practitioners. The scale had a Cronbach's alpha of 0.70 and a test-retest reliability coefficient of 0.67 in a sample of 844 (Borkin et al. 2000). It is deemed to be appropriate to assess attitudes toward recovery and to differentiate between those who are familiar with and positive towards the idea of recovery from those who are not (Borkin et al. 2000). Based on discussions by the members of the EOLAS research sub-committee, three additional items were added to this section. These items examined perceptions of how interpersonal relationships impact on recovery. The questions in this section were 5-point Likert scale questions ranging from 1 (strongly agree) to 5 (strongly disagree).

Section D (views on hope in your life) used the Herth Hope Index (HHIndex). This instrument measures the respondent's level of hopefulness for the future. The response format of the HHIndex is a 4-point scale from 1 (strongly agree) to 4 (strongly disagree). Herth (1992) initially tested the HHIndex in a convenience sample of 172 adults (70 acutely ill, 71 chronically ill and 31 terminally ill patients). Internal consistency was estimated by a Cronbach's alpha of 0.97, with a 2-week test-retest reliability of 0.91 (Herth 1992). Concurrent criterion-related validity was supported by demonstrating moderate to high correlations between the HHIndex and the original HHScale (r = .92), the Existential Well-being Scale (r = .84) and the Nowotny Hope Scale (r = .81).

Section E (self-advocacy) asked participants to rate their views on being able to advocate for themselves in relation to their mental health issue. The 10 items were scored on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). These 10 items were taken from the 12 item Brashers et al.'s (1999) Patient Self-Advocacy Scale (PSAS). These items were selected by the EOLAS research sub-committee and reworded for the Irish context (e.g. physician was changed to mental health team/worker). The PSAS has demonstrated good reliability (Cronbach's alpha = 0.78) and validity (criterion and construct) in two samples, one of 174 adults from an HIV-AIDS population and 218 adults from a general population (Brashers et al. 1999).

Section F (drug attitudes) included five items taken from the 10-item Drug Attitude Inventory (DAI-10) (Hogan et al. 1983). The purpose of this section was to examine the participant's attitudes towards medication for mental health difficulties. The original inventory included a true/false response format. The research team and the EOLAS research sub-committee decided that a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree) would be more appropriate to measure attitudes in this study. The DAI-10 has consistently demonstrated good internal consistency and high test-retest reliability (e.g. Cronbach's alpha 0.83 in a sample of 157 by Yoon et al. 2005).

The pre-programme family member questionnaire consisted of eight sections. This version of the pre-programme survey used the same scales as the users version in sections A (background information), B (knowledge of mental health issues), C (recovery attitudes), D (self-advocacy), F (views on hope in your life), and H (additional background information). The only difference being that the items were reworded to link the questions to their family member's experience of their relative's mental health difficulty. It was emphasised throughout the survey that the questions refer to the respondent's own views and attitudes and not that of their relative who uses the mental health services.

Additional scales that were included in the family member the questionnaire included section E (social network of support) and section G (your general health). The Social Network of Support scale was created by the members of the EOLAS research sub-committee and refined by the research team for the purposes of this study. This six item scale examines the family member's or friend's perceptions of the social support that is available to them to help them cope with their caregiving responsibilities, as well as to deal with their own needs. The social networks that were specified in these items included other members of their own family, friends, other families and members of the mental health team. The six items were scored on a 5-point Likert scale ranging from strongly agree (1) to strongly disagree (5).

Section G featured the 12 item version of the General Health Questionnaire (GHQ-12). The GHQ-12 is an extensively used self-report instrument for the detection of mental health issues in the community and non-psychiatric clinical settings (e.g. primary care). It refers to the severity of psychological complaints relative to the person's normal situation. Reliability and validity of this instrument has been consistently demonstrated. Schmitz et al. (1999) demonstrated a Cronbach's alpha of 0.91 in a sample of 408 randomly selected sample adult outpatients from 18 primary care centres in Dusseldorf, Germany; furthermore, evidence of concurrent and criterion validity has also been reported (Schmitz et al. 1999).

Post-programme questionnaires

For comparative reasons, the post-programme questionnaires (both for users and family members) repeated all the questions included in their respective pre-programme questionnaires without alteration. The post-programme questionnaires (both users and family member) contained an additional section towards the end of the survey. This section (satisfaction with EOLAS Project) was designed to evaluate the programme in terms of participants' perceptions of the operation of the programme, learning tools and teaching methods. The section consisted of a number of new 5-point Likert questions, ranging from 1 (strongly agree) to 5 (strongly disagree). Two 5-point Likert scale items were also added to this section to elicit participants' overall satisfaction and enjoyment of the programme scored from 1 (extremely low) to 5 (extremely high). Participants were also given an opportunity to write free responses to a question asking for any other comment they would like to make about the EOLAS Project.

Pilot of questionnaires

Data collection tools were developed after several refinements and iterations in conjunction with the EOLAS research sub-committee. The surveys were also piloted with a group of users and family members. The feedback from the pilot indicated that the questionnaires were user-friendly and could be completed within the suggested timeslot of 20 minutes. The participants in the pilot study made several recommendations for some minor rewording and formatting alterations. The survey instruments were subsequently adjusted on foot of this feedback.

End of session feedback forms

Data were also collected using individual feedback forms that facilitators asked participants to complete at the end of each EOLAS session. The feedback forms asked about their likes and dislikes in relation to the session attended and were used to supplement the data generated in the questionnaires and interviews.

Interviews

Post-programme semi-structured interviews were used to elicit the participants' and facilitators' views of and experiences of the EOLAS Project. A series of interviews were also undertaken with the project workers at various intervals during the span of the project in order to learn about their experiences and views.

Separate interview topic guides were developed for each of the four cohorts of interviewees (users, family member, facilitators and project workers), as each cohort had a different focus for the interviews. The interview guide for the users of services focused on the impact of the programme on their daily living, well-being and the experience of being in a group of peers with similar mental health difficulties. The interview topic guide for the family members concentrated on the impact of the programme on their ability to deal with their caregiving responsibilities, their own distress and the experience of being in a group with other family members caring for someone who has experienced a mental health difficulty. The interview guide for the facilitators closely examined their experiences of being a co-facilitator, their preparation for the role and what helped or hindered them in this role. Finally, the interview guide for the project workers examined their experiences of developing the project, rationale for decision making, challenges encountered and strategies for overcoming them, and strengths and limitations of the programme.

Participant recruitment strategies

Participants for the EOLAS Project were recruited by the mental health service funding the project. This occurred independent of the researchers. During the recruitment process, potential participants were informed from the outset in advertising literature and by the programme organisers that the programme was being evaluated by an independent external group from Trinity College Dublin. At this time, the participants were given an information brochure prepared by the researchers. The information brochure informed potential participants of the details of the study including its purpose, process, potential benefits and harms, data collection procedures, time commitment, voluntary participation, the right to withdraw without prejudice, assurance of confidentiality (including in study publications), the lead researcher's contact details and an offer to answer any questions. Participants were also informed that they could participate in the EOLAS Project without obligation to participate in the evaluation.

EOLAS participants had at least a week to read the information before the start of the programme. On the first day of the programme, participants were given a pre-programme questionnaire in an envelope along with a research information sheet. They were requested to complete the questionnaire if they wished to be involved and return it in the envelope provided. Participants were informed not to write their names or any other personal information on the questionnaires. Participants who did not wish to complete the questionnaire were also advised that they could return the questionnaire without completing it. In this way, people who did not wish to participate could do so without feeling pressured by their peers.

The pre-programme pack that was distributed in the first session of the programme also included an opt-in form for the post programme semi-structured interviews. With this form, participants could indicate their willingness to be part of an interview. Each form had an accompanying stamped envelope addressed to the researchers. Those who chose to be interviewed were contacted by a member of the research team who answered any questions they had.

The post-programme questionnaires were distributed by the researchers at the end of the final EOLAS session. Interview opt-in forms were again included in these survey packs so as to maximise the numbers of interviewees.

The facilitators (user and clinical) were recruited at the facilitator training programme. A member of the research team gave a presentation on the rationale behind the EOLAS evaluation, as well as detailing the methodological tools that would be used and the underlying ethical principles to which they would adhere. In particular, the voluntary nature of engaging in the research aspect of the EOLAS Project was stressed by the researchers. During the facilitator training programme, each facilitator was given an information pack containing a research information sheet and a post-programme interview opt-in form with accompanying stamped envelope addressed to the TCD research team.

Sample

In total, 30 users of services attended the first session of the EOLAS Programme across the four project areas. Of these, 28 users of services completed the pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Twelve users of services completed both questionnaires. Response rates of 93% and 40%, respectively, can be estimated for service user questionnaires pre and post course. In total, 25 family members attended the first session of the EOLAS Programme across the four project areas. Of these, 25 family members completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. Of these, eight completed both questionnaires. Response rates of 100% and 72%, respectively, can be estimated for family member questionnaires pre and post course.

In total, 34 people participated in interviews. The interviews lasted between 20 and 90 minutes. They were conducted at a place of convenience for the interviewee.

Pre-survey sample

Users of services

In total, 28 users of services completed the pre-survey. Of the 25 participants who provided information, 72% (n = 18) had not attended the EOLAS focus group. Their demographic information and diagnoses are presented in Table 4. Nearly three-quarters were male and participants ranged in age from 23 to 80. Nearly half were single and 30% were either married or had a partner. Approximately equal percentages had completed third level, upper secondary level or lower secondary level. The majority of the sample reported that they had received a diagnosis for their mental health issue. Of these participants, approximately half had been diagnosed with schizophrenia and an additional 28% with bipolar disorder. Eight percent of participants had been diagnosed with schizoaffective disorder and the remaining 8% with depression or severe depression.[3]

TABLE 4. DEMOGRAPHIC AND CLINICAL PROFILE OF PRE-PROGRAMME SURVEY SAMPLE: USERS OF SERVICES

VARIABLE	N (%)
Gender	
Male	20 (74%)
Female	7 (26%)
Civic status	
Single	13 (48%)
Married	5 (19%)
Separated	3 (11%)
Divorced	2 (7%)
Widowed	1 (4%)
Partner	3 (11%)
Level of schooling completed	
Primary	3 (12%)
Lower secondary	8 (32%)
Upper secondary	7 (28%)
Third level	7 (28%)
Received a medical diagnosis for mental health problem	
Yes	24 (92%)
No	2 (8%)
Diagnosis received	
Bipolar	7 (28%)
Schizophrenia	14 (56%)
Schizoaffective	2 (8%)
Depression	2 (8%)

Information on the domestic details and daily activities of the pre-programme users of services is presented in Table 5. Of the 26 who provided information about their living situation, just over 60% were living with family members. About one-quarter lived alone. The greatest proportions lived either in a home either they or their family owned or were paying the mortgage for. Approximately one-quarter of the participants were renting either from local authority or privately. Participants were involved in a wide variety of daily activities.

TABLE 5. DOMESTIC DETAILS AND DAILY ACTIVITIES OF USERS OF SERVICES

VARIABLE	N (%)
Current living arrangements	
Alone	6 (23%)
Family members	16 (62%)
Non-family members	4 (15%)
Type of housing	
Home that is owned/paying mortgage for	9 (36%)
Home that family member owns/paying mortgage for	7 (28%)
Renting from local authority	4 (16%)
Renting from private landlord	2 (8%)
Living in community housing/hostel	3 (12%)
Typically spend the day	
Meeting friends & family	11 (42%)

(Continued on next page...)

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[3] This is a self-reported diagnosis. Participants' records may have recorded other diagnoses but this was not checked. In addition, participants had the option of ticking more than one diagnosis.

(...Table 5 continued)

Involved in other hobbies/interests	10 (39%)
Reading books/magazines	10 (39%)
Looking after home/family	9 (35%)
Watching T.V.	15 (58%)
Attending day programme	6 (23%)
Working for payment (full/part-time)	6 (23%)
Attending school/college	2 (8%)
Other	
– Horses	1 (4%)
– Internet	1 (4%)
– Listen to radio	1 (4%)
– Rehabilitating	1 (4%)
– Sleeping/avoiding contact	1 (4%)

Family

In total, 25 family members completed the pre-survey. One-third had attended the EOLAS focus groups and over half heard about the EOLAS programme from a mental health care worker. Of those who provided information about their gender, 75% were female. Participants ranged in age from 31 to 70. Approximately three-quarters of the sample were married. In terms of education, just under half had completed third level education. Of those who described their relationship to the person they were caring for, the majority were parents (40%), partners (30%) or siblings (25%). The majority of the sample reported that their family member had received a diagnosis and the most commonly reported diagnosis for their family member was schizophrenia. Further details are presented in Table 6.

TABLE 6. DEMOGRAPHIC PROFILE OF PRE-PROGRAMME SURVEY SAMPLE OF FAMILY

VARIABLE	N (%)
Gender	
Male	6 (25%)
Female	18 (75%)
Civic status	
Single	3 (12%)
Married	18 (72%)
Separated	3 (12%)
Divorced	-
Widowed	-
Partner	1 (4%)
Level of schooling completed	
Primary	6 (24%)
Lower secondary	5 (20%)
Upper secondary	3 (12%)
Third level	11 (44%)
Relationship to users of services	
Parent	10 (42%)
Spouse/partner	7 (29%)
Sibling	6 (25%)
Other family relationship	2 (7%)
Received a medical diagnosis for family member's mental health problem	
Yes	22 (92%)
No	2 (8%)
Diagnosis received for family member	
Bipolar	2 (9%)

(Continued on next page...)

(...Table 6 continued)

Schizophrenia	8 (36%)
Schizoaffective	2 (9%)
Other	10 (46%)
– Morbid jealousy	3 (33%)
– Psychosis/delusional disorder	3 (33%)
– Yes and No- diagnosis varies by doctor	1 (11%)
– Depression	1 (11%)
– PTSD/generalised anxiety disorder	1 (11%)
Attend pre EOLAS focus group	
Yes	8 (33%)
No	16 (67%)
Where EOLAS was heard about from:	
Mental health care worker	13 (54%)
Family member/friend with mental health problem	5 (21%)
Other	6 (25%)
– Care worker	1 (17%)
– District nurse	1 (17%)
– From support	1 (17%)
– Medical team of parent	1 (17%)
– Support group in Naas	1 (17%)
– Wife	1 (17%)

Post-survey sample

Users of services

In total, 12 users of services completed the post-programme survey. Of those who provided information about their gender, the respondents were evenly split between males (50%; n = 5) and females (50%; n = 5). The age range was between 30 and 63 years. All of these respondents attended over six EOLAS sessions: 30% (n = 3) attended six, 20% (n = 2) attended seven and 50% (n = 5) attended eight.

Family

In total, there were 18 family members who completed the post programme survey. Of those who provided information about their gender, 76% (n = 13) were female and 24% (n = 4) were male. All were between 31 and 68 years of age. All respondents had attended four or more EOLAS sessions: 11% (n = 2) attended four, 33% (n = 6) attended five, 33% (n = 6) attended six and 22% (n = 4) attended seven.

Interview sample

In total, 32 people (19 programme participants, 11 facilitators and 2 project workers) participated in 34 interviews (19 programme participants, 11 facilitators and 4 project workers).

Programme participant sample

In total, 19 programme participants were interviewed. Of these programme participants, 11 were family members. The family member programme participants were approximately evenly split between females (n = 6) and males (n = 5) and all were between the ages of 22 and 66 years. These participants were mostly parents (n = 7), split approximately evenly between mothers and fathers. There were also two siblings, one husband and one wife of user participants. There were eight users of services who participated in the interviews, four males and four females.

Programme facilitator sample

In total, 11 facilitators participated in interviews: seven clinicians, two users of services and two family members. Of the seven clinicians, there were roughly half males (n = 3) and half females (n = 4), all between the ages of 25 to 45 years. Of the users of services, one was a 35-year old female and the other was a 27-year old male. The two family facilitators were both females in their fifties and mothers of users of services.

Data analyses

All participants were given a numeric code to assist in the matching of questionnaires. Quantitative data were entered into the Statistical Package for the Social Sciences version 18 (SPSS) for analysis. Both descriptive and inferential statistics were generated. Categorical data are summarised in terms of percentages and continuous data were summarised using means and, where appropriate, medians. Ranges and standard deviations provided an index of variability within the data. To examine changes over time, Wilcoxon signed rank tests were conducted on continuous data due to the small number of participants completing both pre and post EOLAS measures. In addition, as the GHQ scores can be categorised into clinical cases, a McNemar test examined change in categorisation over the programme of the EOLAS Project. Questionnaires that could not be matched were excluded from these analyses. For all inferential analyses, statistical significance was set at .05. Where percentages in the findings chapters are presented, unless stated otherwise, these percentages have been calculated out of the total N, including both users of services and family members.

All interviews were audio recorded and transcribed verbatim for analysis using a thematic approach. The qualitative data were entered into the data management software package NVivo version 8. The transcripts were checked for accuracy and cleared of any identifying information. The analytical process involved listening to the audio recordings, while systematically coding the written transcripts for emerging themes and ideas. Codes were compared for similarity and differences and merged into higher themes. The overall analytic approach was guided by the constant comparative process (Glaser and Strauss 1967). To enhance the rigour of the analysis, data were analysed by more than one researcher and findings compared. All interview participants were given codes to protect confidentiality. The codes include SU for user of services and SU F for user of services facilitator; F for family member and FF for family member facilitator; and CF for clinical facilitator.

Ethics and privacy

Ethical approval to conduct the study was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin and the ethics committee associated with the service where the information programme was developed and delivered. The rights and dignity of participants were respected throughout by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality and withdrawal without prejudice.

Consent was viewed as an ongoing process, which required negotiation throughout all aspects of the study. Return of the completed questionnaires was taken as consent. All participants were asked to sign a written consent form prior to interview, consenting to be interviewed and tape-recorded.

Participants were reassured that information that may identify them would not be used in any presentation or publication resulting from the study. They were also reassured that their non-participation in the evaluation would not jeopardise in any way their involvement in this, or subsequent programmes, should they become available.

Summary

- The evaluation used sequential mixed method design involving both quantitative and qualitative approaches. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the EOLAS Project of participants, facilitators and project workers.
- Ethical approval to conduct the study was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin.
- In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Of these, twelve completed both questionnaires. In addition, 25 family completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. Of these, eight completed both questionnaires.
- In total, 34 interviews were conducted. Of these, 19 were with programme participants, 11 were with facilitators and four interviews were conducted with the two project workers.
- Quantitative data were entered into the Statistical Package for the Social Sciences version 18 (SPSS) for analysis. Both descriptive and inferential statistics were generated. To examine changes over time, Wilcoxon signed rank tests were conducted on continuous data due to the small number of participants completing both pre- and post EOLAS measures.
- All interviews were audio recorded and transcribed verbatim. The qualitative data were entered into the data management software package NVivo version 8 and analysed using a thematic approach.

CHAPTER 4

Findings – Overall satisfaction and impact of the programme

INTRODUCTION

This section reports the findings on participants' overall satisfaction with the EOLAS Project and discusses the findings of the pre and post questionnaires in relation to impact on perceived knowledge, support, advocacy, recovery attitudes and hopefulness. In addition, qualitative data from the interviews are included to support or challenge the quantitative findings.

Overall satisfaction and enjoyment with the programme

A very positive result of the survey is that all of the post-programme participants (n = 26), including users and family members, reported that they would recommend the programme to others. This positive outcome was also reflected in the interviews:

> *"I found it very helpful. I couldn't find anything negative about it at all." (F 2)*

> *"I thought it was a very good course. It served its purpose." (SU 4)*

Supporting these positive results, the vast majority of participants who completed the survey found EOLAS very enjoyable and were highly satisfied with it. Nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) as high or extremely high (see Table 7). Only small proportions rated their satisfaction and enjoyment of the programme as low or neutral, with the majority of neutral and low ratings in the family member sample.

TABLE 7. OVERALL SATISFACTION AND ENJOYMENT OF THE EOLAS PROJECT

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	High or extremely high	Neither high nor low	Low or extremely low	High or extremely high	Neither high nor low	Low or extremely low
Overall satisfaction (N = 29; n = 11, 18)	100% (11)	0% (0)	0% (0)	84% (15)	11% (2)	6% (1)
Overall enjoyment (N = 29; n = 11, 18)	91% (10)	9% (1)	0% (0)	94% (17)	0% (0)	6% (1)

Impact of the programme on perceived knowledge of mental health issues

Findings from the qualitative interviews suggested that both the users and family participants perceived that the majority of the information they received was very helpful and informative. Both groups spoke of gaining a *'better understanding'* of either their own or another's mental health problem. The sessions on medication, stress and relaxation techniques and the role of team members in the multidisciplinary team were highlighted as particularly informative:

> *"The one on medication was good...and I suppose the one the stress, you know the definitions of stress and how to recognise it, that type of stuff was good." (SU 2)*

> *"It was also useful to know about all the different services that are out there, you know, which a lot of people wouldn't have been aware of." (F 3)*

> *"Clients definitely gained more understanding of what their illness is, what the teams do." (CF 2)*

> *"Now I understand why I have a diagnosis. I have now decided to start my own road to recovery I am now going to do something about it myself" (SU survey)*

A number of guest speakers attended various sessions throughout the EOLAS Project. The majority of family and user participants found the session with the psychiatrist guest speaker to be extremely informative and helpful. The benefits of this session were strongly described as relating to the fact that participants were given an opportunity to ask questions about diagnosis and medication and receive answers. The quotes from the end of session feedback sheets also mirrored this interview feedback.

> *"The day the psychiatrist came to discuss was an absolute, oh, it was like doors being opened or something. That was the one that we just said, 'If only we could have even spoken to a psychologist or whatever in the beginning,' and that was fantastic and he discussed medications and discussed [other] things...so that night was the best." (F 6)*
>
> *"The information was useful, especially about diagnosis and symptoms...It was the type of thing that was always fuzzy in my mind...I felt I picked up a lot from that...sort of put it all together." (SU 6)*
>
> *"Consultant's discussion excellent, gained great information, got answers from questions I didn't know who to ask...simplified complicated things with good examples." (SU feedback sheet)*

Some user participants spoke very positively about the relapse prevention session facilitated by the psychologist and felt they benefited from discussion on 'triggers' and 'early warning signs'. While recognising that learning relaxations techniques took time, the emphasis on strategies other than medication was viewed as positive.

> *"They tell you to relax and don't be worrying about, you know just focus on what you have to do, don't be over doing it and running a mile...This is the way it is, if you think that you are going to be as high as a kite, kind of do your breathing exercises... and take it easy and if you have any problems talk to your doctor...It helped me to understand myself better because I'd be really hard on myself." (SU 2)*
>
> *"It was the type of thing you could walk away with and when I'm sitting on a train or bus, I could practice myself, which was great...I found that it isn't all about medication. It's not about mental health. It is actually about your day-to-day, how you go about things and how you think certain things...I suppose that before we would have talked about medication as a fix up, whereas medication is a tool. There's more tools used than just medication." (SU 6)*

The findings from knowledge section of the questionnaire supported the interviews, with family data showing a statistically significant change in overall perceived levels of knowledge post EOLAS (Wicoxon z (7) = 2.39, $p < .05$). Of note, in relation to the knowledge items, family participants rated that they had a better understanding of their relative's legal rights in the mental health services (Wilcoxon z (12) = 2.57, $p <.01$), they knew how to help their relative deal with voices (Wilcoxon z (11) = 2.23, $p<.05$) and that they were more familiar with strategies for helping their relative get involved in the local community (Wilcoxon z (12) = 2.00, $p <.05$) (more details are included Appendix II). Although it was not possible to examine changes in total perceived knowledge for users of services as only two participants provided complete data, the interview findings discussed indicate that users of services learned knowledge, skills and techniques from the EOLAS Project.

One of the hoped for outcomes of the EOLAS Project was that it would improve the health and well-being of the participants. While the General Health Questionnaire (GHQ-12) showed no statistically significant overall change (Wilcoxon z (4) = -1.81, p = NS) for family members, findings from the users interviews indicate that the lifestyles of some participants had been enhanced as a result of attendance at the programme. For example, one user reported that he was made aware through the programme that he was *'isolating himself from others'* and has since taken *'steps to connect'* (SU 5) and engage with other people. In another case, the person stated that:

> *"I think it not only makes you feel empowered...I think it affects your behaviour in a way that improves your mental health and makes it kind of an opportunity where it [relaxation] will be more consistent." (SU 6)*

The value of the programme as a source of information was also reiterated by the clinical facilitators who viewed the programme as filling a major gap within the services.

> *"We were providing something that's largely been absent. It's [education] not been available for relatives. It may or may not have been available to service users in a less formal sense, but certainly for the family members I think it was well-received because it was filling a vacuum." (CF 4)*

Impact of the programme on self-advocacy

Issues of empowerment and self-advocacy are at the heart of the drive towards equal involvement of users of services and carers within the mental health services (McDaid 2006). Findings from the user interviews did suggest that following the programme they had greater confidence in approaching and asking questions of practitioners. They spoke of feeling more empowered to question practitioners about their medication, request a reduction in the dosage and talk about relapse triggers.

> *"Well at least now I know that I have the right to ask certain questions." (SU 6)*
>
> *"I didn't know much about it kind of, but now it's kind of, yeah, you don't mind asking questions or reading through the thing." (SU 1)*
>
> *"You feel empowered in a couple of ways. One is to talk about your medication and another is to be a bit more open about what your thought process is, that's causing the episodes...the triggers that causes it is very similar in each of my cases. I do feel that I can talk to the psychiatrist or the doctor about that [medication and triggers] now and him to have an input on that." (SU 8)*

Although participants spoke of enhanced self-advocacy, there were no statistically significant changes on the Self-Advocacy Scale for either family members (Wilcoxon z (8) = 1.71, p = NS) or users of services (Wilcoxon z (8) = 0.70, p = NS).

Impact of the programme on family members feelings of support

It was clear from the interviews that family participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Although there were no statistically significant overall changes on the Social Network of Support Scale for family members (Wilcoxon z (7) = .034, p = NS), family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.

> *"It was great that everybody could come together and you know learn from each other, you know that was useful." (F 1)*

> *"I think that's all people want...they want information and they want to meet other people who are in similar boat. I think people feel very isolated." (F 2)*

Many family member participants described how hearing other family's stories 'normalised' and validated their own experiences.

> *"It makes you realise, as well, no matter how bad your problems are, if you throw all the problems everybody in the room had into the middle of the room, you'd take back your own. You know if you live with your own you can deal with your own but you always think, 'God how do they cope?' and they look at you and they go, 'How do you cope?' and it's amazing isn't it? And it kind of gives you, builds you up and makes you feel a bit stronger as well. You get acknowledged. You know it's acknowledged that you're putting up with or what you're dealing with and that's a big thing." (F 6)*

> *"So I think there's that kind of, a bit of a sigh of relief...There's other people out there like us. So you know we're all in the same boat. So I think in that sense it was good. . We got information from them [facilitators] and we equally met other people but it was the other people gave us the strength." (F 9)*

Some of the family members interviewed had little previous opportunity to talk about their experiences in an open and honest manner. Family participants spoke of the difficulty in talking to people both within their own family and outside because of feelings of betrayal and the stigma associated with a mental health problem, while others were of the view that people did not have an understanding of mental illness.

> *"I suppose families of people with mental health issues live in a kind of world of their own. You certainly can't talk to the other person's family, in my case anyway. You can't really talk to your own family because every move you make is being scrutinised as to who you're telling what to...So it [EOLAS] was the one outlet..." (F 7)*

> *"You were able to talk about things that you couldn't really talk to anyone else about because they don't really understand it like, you know, none of my friends have brothers with mental illness." (F 8)*

Similar to family members in many other studies (Mental Health Commission 2005; Kartalova-O'Doherty et al. 2008), the family members in this study were quite angry and frustrated at their marginalisation by the mental health system. They spoke of lack of information, involvement and support when family members were in crisis. They lacked direction on how to cope or respond to their family member and, at times, considered that they were abandoned by the services. The following were just some of the frustrations expressed:

> *"He had done harm in his house, he'd broke chairs and a few things and all this when three doctors were after telling me that I couldn't sign him in. It was frustrating...But what I'm saying is doctors and people like that don't seem to take any notice of relatives a lot of the time and we are closer to what's happening, you know? We have knowledge of the actual, what's happening on the ground." (F 2)*

> *"So we were having a psychotic young man in the house [family member goes on to describe the young man's behaviour] and we weren't allowed be involved in his treatment. We had to pay for everything for him, his clothes, his food and everything and he was conspiring to kill us, that was his mental thing at the time. He was totally, totally paranoid and in his head he had to kill his parents and the only thing we were told to do was call the guards and that was the answer from the health people and we couldn't do that because he was ill, he wasn't a criminal." (F6)*

Some family members faced major stress when their family member was about to be discharged home because they not been prepared for the future.

> *"I begged the hospital)...'Please hold him for tonight...Whatever you do don't let him out tonight.' They did [keep him for the night] but they let him out at seven o'clock the next morning and when our other son went up, he was wandering the car park with his clothes in his hands...and when I rang the hospital they told me I had two choices: take him home or there was an old man's hostel that opened at five o'clock." (F 8)*

Consequently, for the vast majority of family members the EOLAS Project provided a well-needed 'safe space' where they could vent their strong emotions and give voice to their feelings of grief, frustration and anger. It was also a place where they reported not feeling guilty about 'complaining'.

> *"To go and be able to talk about it with somebody else knowing like it's private and you know that what you say in the room... stays there...It was like you were able to open up and dig in there and get them feelings out, that you harbour for a long time. So I think that's what the other people got out of it as well." (F 1)*

> *"I mean you always feel bad about complaining about your loved one or your family member but I mean you just have to get it off your chest sometimes...But as I say you do feel like, do feel a bit as if you're betraying somebody when you're moaning about them but you know you just have to." (F 5)*

However, in contrast some participants felt that they were betraying their family member by talking about their issues in a group context.

> *"There was also within the group and possibly it's the reason for the group, a bit of a bitching session about spouses and a bit of kind of, yeah, a bit of a bitching session, bit of kind of telling tall tales out of school and things like that. Now I know the whole thing was confidential, people need to get things off their chest and things like that but it just kind of didn't sit well." (F 7)*

Sibitz et al.'s (2007) study emphasised the value and benefits of exchanging information with peers during a psychoeducational programme. Their study reported that peer interaction enhanced self-esteem, social interaction skills and improved participants' social networks. Although the primary focus of EOLAS was on providing information, user participants also spoke of the support they received from meeting other people with similar experiences.

> *"The group sharing was good...and say you had a break for your coffee and the whole lot and it was quite nice...We could share whatever and somebody would say, 'Oh yes I know, that happened to me, I do this or I do that', like there was a lot of communication." (SU 2)*

> *"It was fabulous to have that experience, especially from someone who had been there and done that, been down the same road you've been down and found tools...And that had helped them, so it wasn't just pie in the sky things, these things have actually, other people had found [them] useful." (SU 6)*

> *"Knowing you're not the only one out there with this problem." (End of session feedback sheet)*

The quantitative data also strongly supported the view that hearing other people's stories was helpful (see Table 8). A clear majority of participants agreed that that hearing other service user/family member stories was supportive (93%; n = 28) and an effective way of learning (93%; n = 27).

TABLE 8. HEARING OTHERS' STORIES

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Hearing other service users' / family members' stories was supportive (N = 30; n = 12, 18)	92% (11)	8% (1)	0% (0)	94% (17)	6% (1)	0% (0)
Hearing other ' / family members' stories was an effective way of learning (N = 29; n = 11, 18)	91% (10)	9% (1)	0% (0)	94% (17)	6% (1)	0% (0)

Impact of the programme on recovery attitudes and hopefulness

The concept of hope is emerging within the recovery literature with a number of researchers viewing hope as central to people's recovery journey. Higgins and McBennett (2007) identify the common themes underpinning the writings of people who have described their own individual recovery journey. Universal in all the writings is the issue of hope and optimism (Higgins and McBennett 2007). Discussions on the concept of hope and hopefulness about the future emerged within the interviews. Some family members spoke of leaving the sessions more hopeful about their and their family member's future as a result of listening to the facilitators and other participants. For example, this family member described how through the programme she was reassured about her concerns and given hope that her relative could someday have a job and a family.

> *"Oh they [facilitators] were very, very good and certainly very uplifting...like if you came in feeling really shite and not knowing that there was any hope, they'd certainly bring you back up...and sort you out, definitely. I thought they were very good like that. So coming in as a newcomer, I would say they would be brilliant at giving hope. Like I mean at one stage I thought, I mean, there is no cure for schizophrenia and at one stage I thought terrible thoughts, 'You'll [referring to child] never be married, never have kids. I'll never be a grandmother and all this kind of stuff,' and I was put right back in my place and said, 'Don't ever say there's no hope'...I was told there are people who go out and get jobs and do this and do that and I said, 'Oh yeah, well yeah, so I have to sort of stop that'...But it was all done in, you know, a good uplifting sort of, 'Come on. Cop on' and 'It's not like that at all.'"(F 6)*

In contrast to these statements, other family members appeared to leave having absorbed a narrative of despair or hopelessness. The subliminal message received appears to be centred around *'no happy ending'* and *'life time of medication'* for their family member. The source of this narrative of hopelessness appears to have been certain clinical facilitators and guest speakers rather than the actual EOLAS manual. In addition, the session on medication did not appear to present an option for users to 'come off' medication. The following are indicative of some of the comments made:

> *F: "We had great hopes that eventually [names user of service] would be able to get off the medication and stuff like that but now we've come to accept that he's not, he's like this for the rest of his life, you know."*
>
> *I: "Based on the EOLAS Project or just based on your own...?"*
>
> *F: "Well [name of psychiatrist guest speaker] came to talk to us about...and he gave a very interesting lecture and it was kind of starting to sink in with me then that, you know, because we were able to ask questions and things like that, kind of asking you know questions like, I was thinking from [name of service user]'s point of view, will he ever be able to come off the medication and I thought maybe someday they'd be able to take him off it, but now I see that that's not going to be the case. [Name of service user] is going to be on this medication forever and a day." (F 3)*
>
> *"There was a few things in that now that was a bit scary, you know, about the medication, and more or less that you hoped they would be able to come off the medication at some stage, whereas [EOLAS Project] left little light at the tunnel for that, you know." (F 1)*
>
> *"I left the first session with very, very mixed feelings about the whole thing...I remember at one stage we were just talking about various things and the nurse [clinical facilitator] came up and said, 'You almost have to mourn the fact that you never have a proper relationship with your spouse,' which obviously caught me by surprise and something very unsettling...So that really kind of, I suppose I kind of accepted that fact, anyway, but hearing it out and out in the open wasn't that easy. So I was kind of, I spent the rest of the week kind of wondering would I go back or wouldn't I?" (F 7)*

In the questionnaires, the Recovery Attitude Questionnaire (RAQ-7) was used to measure attitudes towards recovery and the Hearth Hope Index (HHIndex) was used to measure any increase in hopefulness. There were no statistically significant changes on RAQ-7 for family members or users and no statistically significant changes on the HHIndex for family members or users. The interview findings perhaps shed light on why these findings were not significant, with participants reporting receiving mixed messages around hope and recovery from facilitators.

Impact of the programme on drug attitudes of users of services

There was no statistically significant overall change on the Drug Attitude Inventory (DAI-10) for users. However, as discussed, they did suggest within the interviews that they were more knowledgeable on the medication prescribed for them and more willing to ask questions about their medication.

Summary

- All participants would recommend the programme and nine out of ten participants rated their satisfaction (90%; n = 26) and enjoyment (93%; n = 27) of the programme as high or extremely high.
- In terms of perceived knowledge, family members reported significantly higher levels of knowledge post EOLAS. Although it was not possible to examine changes in total knowledge for users of services, findings from the qualitative interviews suggested that both the users of services and family participants perceived that the majority of the information they received was very helpful and informative.
- While the General Health Questionnaire (GHQ-12) showed no statistically significant overall change for family members, findings from the users of services interviews indicate that the lifestyles of some participants had been enhanced as a result of attendance at the programme.
- There were no statistically significant overall changes on the Social Network of Support Scale for family members. However, it was clear from the interviews that family participants benefited from having a space where they could meet people in similar circumstances and share their personal experiences. Family member participants spoke of how the programme enabled them to empathise, learn from each other, form social bonds within the group and feel less isolated.
- A clear majority of participants felt that that hearing other users / family member stories was supportive (93%; n = 28) and an effective way of learning (93%; n = 27).
- There were no statistically significant changes on Recovery Attitude Questionnaire (RAQ-7) for family members or users of services. Similarly, there was no statistically significant overall change on the Drug Attitude Inventory (DAI-10) for users of services.
- There were no statistically significant changes on the Hearth Hope Index (HHIndex) for family members or users of services. While some family members spoke of leaving the sessions more hopeful about their and their family member's future, other family members appeared to leave having absorbed a narrative of despair or hopelessness.

CHAPTER 5

Findings – Facilitation and teaching strategies

INTRODUCTION

The design, presentation and delivery of the programme were to be based on the principles of adult education. To achieve this, a number of different teaching and facilitation strategies were employed. This chapter focuses on these strategies, as well as the successes and challenges encountered.

Creating an atmosphere of trust: Being respected and valued

Interview data suggest that the group rules about behaviour, attitudes and engagement that were drawn up by participants at the first session contributed to the constructive and respectful atmosphere that was created within the group. The ground rules related to confidentiality, respecting others' opinions and allowing others to voice their views. These ground rules enabled the development of an atmosphere of trust, confidentiality and openness, as described by these participants:

> *"They [ground rules] were all sound like...You felt, you know, comfortable there." (SU 5)*
>
> *"Like if you didn't want to say anything, you didn't have to, you know, and it was nice..." (SU 2)*

Supporting these qualitative findings, survey participants were asked whether they felt their views and opinions, as well as their knowledge, were respected throughout the programme. The vast majority of participants (97%; n = 29) felt that their views and opinions were respected, with 87% (n = 26) of participants reporting that their knowledge was respected. Further details are presented in Table 9.

TABLE 9. FEELING RESPECTED

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Participants' views and opinions were respected (N = 30, n = 12, 18)	100% (12)	0% (0)	0% (0)	94% (17)	6% (1)	0% (0)
Participants' knowledge was respected (N = 30, n = 12, 18)	92% (11)	8% (1)	0% (0)	83% (15)	17% (3)	0% (0)

Satisfaction with programme content and objectives

Participants were asked how much they agreed or disagreed with two statements about the programme objectives and content (see Table 10). The results were very positive as nearly all of the participants (97%; n = 29) agreed that the objectives of the programme were clear and more than 90% (n = 27) felt that the content of the programme was clearly presented.
One service user described, *"I think the course did exactly what it said on the tin, you know?" (SUF 2)*

TABLE 10. PROGRAMME OBJECTIVES AND CONTENT

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The objectives of the programme were clear (N = 30; n = 12, 18)	100% (12)	0% (0)	0% (0)	94% (17)	6% (1)	0% (0)
The content was clearly presented (N = 29; n = 12, 17)	100% (12)	0% (0)	0% (0)	88% (15)	6% (1)	6% (1)

While participants were of the view that the content was clear, a number of family members, especially those who had years of experience with the mental health care system, perceived the content of the programme to be the idealised theory as opposed to the reality of how the system operates. For some, this led to feelings of irritation and anger as they did not feel the programme content reflected their experiences of feeling marginalised and excluded within the system. This is exemplified in the following comment:

> *"Sometimes you felt it was just an exercise...You were doing A, B, C, D and E. We're here to tell you A, B, C, D and E. I suppose the hard part for anybody, even within the group, would have been that, as I said to you Monday to Friday [there are no services], nothing, after 4 o'clock and if I hear recession and if I hear cut backs and there's no funding, that would annoy you...I suppose the people we met were excellent. The information you got was good to a degree and then again there was always the negative, the negative always kept coming out, no funding, no money, no help...That was something they [the programme facilitators] kept saying, 'You need your own space,' and, 'You need to have time for yourself,' and, 'You need this.' How are you supposed to get that? Who is giving us the support? There is no respite." (F 9)*

Satisfaction with depth of programme content

Interview participants spoke of needing more information on a number of issues. One of the family participants suggested that including a solicitor with expertise in family law as a guest speaker would be particularly useful:

> *"We did say it would have been good to have a night where a solicitor would be involved...because the psychiatrist was brilliant but an evening with a solicitor maybe to find out what are your legal, 'What do you do to legally get somebody committed? Can you not...? Are you legally allowed to do...?' What ifs." (F 6)*

Written feedback included comments such as:

> *"Suggest a further visit by consultant/doctor" (End of session feedback sheet)*
>
> *"Would like to have more time allowed with the Doctor – maybe could come back for full session." (End of session feedback sheet)*

In line with these comments, approximately one in five participants felt the programme content was insufficient (20%; n = 6) and repetitive (23%; n = 7). Further details are presented in Table 11.

TABLE 11. PROGRAMME DEPTH AND REPETITION

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The depth of the content on the programme was sufficient (N = 30; n = 12, 18)	84% (10)	8% (1)	8% (1)	67% (12)	6% (1)	28% (5)
The content of the programme was repetitive (N = 30; n = 12, 18)	25% (3)	8% (1)	67% (8)	22% (4)	11% (2)	67% (12)

Group work

Participants were also asked how effective they found group work as a way of learning. A clear majority of participants agreed that group work was an effective way of learning (87%; n = 26) (see Table 12). While some participants felt neutrally about these statements, just 3% (n = 1) disagreed with this statements.

TABLE 12. GROUP WORK

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Group work was an effective way of learning (N = 30; n = 12, 18)	92% (11)	8% (1)	0% (0)	83% (15)	11% (2)	6% (1)

In relation to group process, participants found that the group sharing experience was sometimes dominated by one personality, which diminished their enjoyment and contribution. Despite the efforts of the facilitators to refocus the group to the topics under discussion and prevent some participants from 'over-speaking' and dominating the discussions, their strategies did not always work.

> *"In some cases, one or two individuals just took the floor and held the floor …I'm sure it can be difficult for a psychiatric nurse to referee in a situation like that because you know you want to give this individual their time and it's probably quite difficult to kind of cut them off and hand over to somebody else." (F 7)*
>
> *"I think what actually happened was, this [person] would go on and on, but you'd have, not a word was kind of said [by facilitator]...[person] had a domineering opinion." (SU 3)*
>
> *"Some people going on too long and not considering other people" (End of session feedback sheet)*

Facilitators also identified this issue as a challenge.

> *"It was an information providing service, not a therapy service, and that was a bit difficult at the start because people were there and wanted to vent their anger and frustration at the services." (CF 2)*

Written learning materials and information handouts

As stated all participants were given written information handouts, which meant that over the duration of the programme, participants could build up a resource pack on the different topics discussed. The user participants found the information handouts very helpful as they could refer back to them after the programme was complete.

> *"You could go back and have a look and say, 'Well that's me or that's not me'...so it was quite good." (SU 1)*
>
> *"You'd sort of forget what you had done so it's nice to have it [handouts] there that you can look back again." (SU 7)*

Although the family members found the information handouts beneficial, they did express annoyance that they had to attend the programme to access written information. They were of the view that this information should be available to everybody once they attended the service.

> *"The idea of it [information handout] is good. It should be available much more widely. There should certainly be an information booklet and the basic information for everybody...for a family of somebody who has a mental illness there should be an information booklet...I have found over the years that doctors are very reluctant even to explain." (F 4)*

Survey participants were also asked to comment on the written learning materials in relation to usefulness and ease of navigation (see Table 13). More than 80% (n = 23) of the sample felt that the planning sheets and learning materials used were easy to navigate. Whilst all of the users of services agreed the learning materials were easy to navigate, some of the family members and friends felt neutrally about this and one disagreed. While 79% (n = 22) of the sample felt that the planning sheets and learning materials were an effective way of learning, 21% (n = 6) felt neutrally about this. Again, a greater proportion of family members and friends reported feeling neutrally.

TABLE 13. WRITTEN LEARNING MATERIALS

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
The planning sheets / learning materials were easy to navigate (N = 28; n = 10, 18)	100% (10)	0% (0)	0% (0)	72% (13)	22% (4)	6% (1)
The planning sheets / learning materials were an effective way of learning (N = 28; n = 10, 18)	90% (9)	10% (1)	0% (0)	72% (13)	28% (5)	0% (0)

Surprisingly, although their ease of navigation was rated highly in the survey, during the interviews it emerged that family members felt that some of the programme materials were inaccessible, being too text heavy and using language that was overly technical.

> *"Certainly either pare down the materials or just bring it down to kind of bullet point, PowerPoint kind of stuff, you know, as opposed to just reams upon reams of paragraphs. I would say the handouts need to be shortened." (F 7)*

Participants suggested that the manner in which the written information was used during the programme could also be improved. It was felt that the amount of paperwork and reading may have intimidated and undermined the confidence of some participants, especially if they had literacy issues. In some cases 'public reading' in which each group member took turns reading sections of the text out loud was used. This was a consequence of time delays in delivering session materials, nevertheless it was viewed as an unappealing and uninteresting way to present information. It could also be viewed as an inappropriate method, especially given the underlying adult education philosophy of the programme, with many participants reporting that reading out loud felt like *'being back at school'* and felt the time spent reading affected the time available for group discussions. The following are reflective of comments made.

> *"We all kind of went around in a circle and read a paragraph and just went around and around and around…it was basically like English class on a few occasions. It was more reading a handout as opposed to discussing and having an interactive dynamic…I think maybe one or two of them…might have been a bit of literacy problem there." (F7)*

> *"It's something that's very dry, just sitting down and reading." (SU 6)*

Occasionally, it appeared that some facilitators used their own initiative to introduce exercises to increase participant engagement and understanding. These initiatives were very much appreciated by the participants, as this family member described:

> *"I know one of the days she [facilitator] talked about people hearing voices and she had us going to groups and one of us had to talk down to someone there while having a conversation. So that was a good idea really because it just gives you an idea, just a little exercise, what it can be like and, of programme, some well known people have written about their experiences, [but] it's hard to imagine it if you've never had it I suppose." (F 5)*

Application of EOLAS programme to own life

Of the 28 participants to respond, three quarters (75%; n = 21) felt that they were encouraged to apply the content of the programme to their own circumstances (see Table 14). However, a greater proportion of family members was neutral or disagreed with the statement.

TABLE 14. I WAS ENCOURAGED TO APPLY THE CONTENT OF THE EOLAS PROGRAMME TO MY OWN CIRCUMSTANCES

USERS OF SERVICES (N = 10)			FAMILY MEMBERS AND FRIENDS (N = 18)		
Agree	Neutral	Disagree	Agree	Neutral	Disagree
80% (8)	20% (2)	0% (0)	72% (13)	17% (3)	11% (2)

In addition to applying the programme information to one's own life, it appeared from the interviews that the content of the programme and the learning materials supplied were also used as information resources within the community. Participants, particularly family members, described how they passed on the information to other members of the family to heighten awareness and understanding:

> *"Oh yeah, [the materials are] very good because we were able to read through afterwards and go through everything afterwards because we got to take them home with us. So we've a full binder full of literature, and as well as that, if anybody else ever asks questions, I can say, 'Here, have a read through that.'" (F 6)*

Summary

- The vast majority of participants (97%; n = 29) felt that their views and opinions were respected, with 87% (n = 26) of participants reporting that their knowledge was respected.
- Nearly all of the participants (97%; n = 29) agreed that the objectives of the programme were clear and more than 90% (n = 27) felt that the content of the programme was clearly presented. A number of family members, especially those who had years of experience with the mental health care system, perceived the content of the programme to be the idealised theory as opposed to the reality of how the system operates.
- Whilst the majority of the sample felt that the depth of the programme content was sufficient (73%; n = 22) and not repetitive (67%; n = 20), approximately one in five participants felt the programme content was insufficient (20%; n = 6) and repetitive (23%; n = 7).
- Although a clear majority of participants agreed that group work was an effective way of learning (87%; n = 26), some found the discussion was sometimes dominated by one personality, which diminished their enjoyment and contribution.
- While 79% (n = 22) of the sample felt that the planning sheets and learning materials were an effective way of learning and found the written information handouts very helpful, family members found some of the programme materials inaccessible, being too text heavy and using language that was overly technical. They also expressed annoyance that they had to attend the programme to access written information and were of the view that this information should be available to everybody once they attended the service.

CHAPTER 6

Findings – Structural issues

INTRODUCTION

In this third chapter of findings, structural issues of the EOLAS Programme are discussed. They are discussed under six headings: timing of the EOLAS Programme, open nature of the group, duration of sessions, number of participants, venues and evaluation process.

Timing of EOLAS information

There was a sense from both family members and user participants that the information in the EOLAS Programme would be most beneficial to 'newcomers' in the mental health system. The majority of the family members had been involved with the mental health services for several years and had developed their own ways of negotiating the system and sourcing information *'the hard way'*. Consequently, although they found the programme beneficial, they were of the view that the EOLAS Programme was more suitable for people who are new to the system.

> *"We found it helpful to a point but I think it would be great for people who are beginning in the mental health system. It would be great if there was more information within the group, the EOLAS, that there was more information to hand out to say newcomers because when you're starting off, pre-diagnoses, you're floundering and you don't know what's going on, you don't know where to turn...We just had to throw tantrums, scream to be heard and it was a total nightmare. There was absolutely no help anywhere, nothing, and it's only in hindsight, in the EOLAS group we kept saying, 'Well this would have been great if [given earlier]...We had to go through the hard way and find out everything the hard way." (F 6)*

Similarly, users of services also supported the idea of rolling the programme out nationally, but, again, they emphasised the need to provide the information earlier to more recently diagnosed users of mental health services. In their view, people who were attending the service for a long time had information about symptoms and treatment from their previous engagement with services.

> *"The earlier the better...this is just stuff that you need to know." (SU 7)*

Open nature of group

The open nature of the group in allowing participants to join in on any of the sessions was perceived to be problematic by the clinical facilitators as in their views it disrupted the group dynamics.

> *"People were coming in and out of the group, people who were there initially were not there in the next group and some of them joined in later on." (CF 2)*

In addition to the open nature of the group, due to it being the holiday period when the programme was rolled out and absences among facilitators, some groups experienced different facilitators delivering the programme. This *'chopping and changing'* (F 4) of facilitators was viewed negatively by participants as they felt that it did not lend itself to consistency and relationship building within the group.

> *"Ok, it was July, August. It was holiday time. She [clinical facilitator] was perfectly entitled to take her leave but I think it kind of upset the flow because we were kind of getting used to somebody new and then she was back I think for the last two sessions." (F 7)*

Insufficient time to address issues

The lack of time and time constraints were a recurring theme within all of the interviews and were also evident in the end of session feedback sheets. One of the main benefits of the programme was the opportunity to explore the session topics and share experiences. However, participants were of the view that there was insufficient time to address all of the content associated with each session and, consequently, sessions felt rushed, with inadequate time for in-depth discussion or for participants to share their views and experiences. In many cases, the session ran over the allotted 90 minutes. This was particularly the case when there were guest speakers, with many participants complaining that that these sessions were too short.

> *"Just like you know if you're having a bad day, you know you could talk a small bit about it but not enough time..." (SU 5)*
>
> *"The time thing definitely wasn't enough. There was an hour and a half per session. It's definitely not enough." (CF 2)*

> *"Ran overtime...Not finishing on time...Some left early because of time over run...Time constraints – doesn't really allow for an in-depth discussion on the topic." (End of session feedback sheet)*

The lack of time was also evident in the fact that conversations continued between participants in the car parks after the end of sessions.

> *"We all parked in the car park and the discussions kept on going on for 20 minutes, half an hour afterwards. I think purely because...there simply wasn't enough time within it [the programme]." (F 7)*

The dissatisfaction with the time available was also reflected in the survey data. While half of the survey participants (n = 15) felt there was adequate time for discussion, 43% (n = 13) disagreed. As can be seen in the table, a greater proportion of family members did not feel there was adequate time for discussion (see Table 15).

TABLE 15. THERE WAS ADEQUATE TIME FOR DISCUSSION

USERS OF SERVICES (N = 12)			FAMILY MEMBERS AND FRIENDS (N = 18)		
Agree	Neutral	Disagree	Agree	Neutral	Disagree
59% (7)	8% (1)	33% (4)	44% (8)	6% (1)	50% (9)

Referral system: Low numbers on EOLAS programme

The referral system was considered disappointing in so far as the numbers enlisted to some of the programmes were low. The project workers found that recruitment depended on the enthusiasm of the mental health teams about the purpose and aim of the programme and, in many situations, referrals rested on the shoulders of already over-stretched and under-resourced nurses. Some participants were of the view that the low numbers negatively impacted on the group dynamics and was a reflection of inadequate advertising and limited referral or enrolment routes.

> *"I'm sure the people running it would be disappointed that the attendance fell off...It's a bit of a waste of resources...Like I got nothing about it, I just got a phone call and then the nurse came out and got me to fill in a form with her...like you're either interested or you're not." (F 4)*

> *"I just thought there wasn't very many there, I just thought that was a shame you know...Even if it had been in the local paper or even on the local parish newsletter...say, 'This is coming up,' and 'It's confidential,' and this kind of thing, you know?"(F 5)*

Venues

It was felt that some of the venues worked well, while others were perceived as being too small to accommodate the group.

> *"Like that it was a lovely venue...It was comfortable...It was lovely you know. It just made you feel very relaxed." (Interviewee identifier removed as it compromises participant's anonymity)*

> *"The size of the room was way too small...a huge amount of clutter... there was lot of kind of just general clutter...It got very, very warm at times." (Interviewee identifier removed as it compromises participant's anonymity)*

Evaluation process

The distribution of the pre and post programme questionnaires, as well as the end of session feedback sheets, was viewed negatively by programme participants. Participants were of the view that there were too many questions and questionnaires to be completed, which interfered with the 'flow' of the programme or may have been challenging for people who had literacy issues.

> *"I don't like these questionnaires where you have to tick where you 'strongly agree' and all this kind of thing, hate them." (F 5)*

> *"I think it was necessary...I know we were asked first, there was a questionnaire, our likes and dislikes...One of the fellas for dislikes wrote, 'dislike filling in forms'...So I think there is a feeling that too much paper work." (SU 8)*

A sense of urgency: Unrealistic timeframe

As highlighted, the timeframe to complete the project was very ambitious. Project workers spoke of feeling under immense pressure to meet the various timelines. Clinicians were under pressure to include recruiting of participants and facilitators as another role to their over-stretched agendas. This sense of time urgency was also apparent on the EOLAS steering group committee. While the following comment by a member of the steering committee is very complimentary, it does highlight the degree of pressure experienced due to the severe time constraints.

> *"From my part, it was a pleasure working with all the people on the EOLAS committee and it's good to see people at that level and immersed in their profession and that they push themselves to work outside their normal working hours to get jobs done." (SU representative)*

Summary

- There was a sense from both family members and user of services participants that the information in the EOLAS Programme should be delivered immediately to 'newcomers' in the mental health system.
- The low numbers on the programme in some areas and the open nature of the group in allowing participants to join in on any of the sessions were perceived to be problematic as they were felt to be disruptive to the group dynamics. In addition, the *'chopping and changing'* among facilitators in some programmes was viewed negatively as participants felt that it did not lend itself to consistency and relationship building within the group.
- While half of the survey participants (n = 15) felt there was adequate time for discussion, 43% (n = 13) disagreed. Interview participants also commented on the lack of time available to fully address the content associated with each session or to allow for in-depth discussion and sharing of views and experiences.
- Participants were of the view that there were too many evaluation questionnaires to be completed, which interfered with the 'flow' of the programme or may have been challenging for people who had literacy issues.

CHAPTER 7

Findings – Peer and clinician involvement

INTRODUCTION

One of the main objectives of the EOLAS Project was the implementation of the information programme using peers and clinicians as co-facilitators. Numerous writers highlight the various challenges and road blocks to the successful involvement of user and family members as equal partners within the mental health services (McDaid 2006; McEvoy et al. 2008). This section focuses on the strengths of having a joint approach, as well as the challenges encountered with peer and clinician involvement.

Recognition of value of peer and clinician involvement

The peer aspect of the programme was described positively by both family members and users of services within the interviews. Both groups were full of praise for the peer facilitators, as they felt that not only was the peer facilitator someone who could understand and empathise with them, but also someone from whom they could take inspiration and hope.

> *"He [user facilitator] talked at your own level, you know? He talked to you as a service user when he was talking about the illness. You'd go, 'Well, I had that as well...You sort of think to yourself, 'Well if they can do it and handle their illness like that, so can I.' So you identify with that fact that they have actually taken that step to be able to come in to a meeting like that and say, 'Yes, I suffer from schizophrenia or from a mental health illness and now I'm coordinating this programme.'" (SU 8)*

> *"She [user facilitator] was so confident and then she identifies with us because she suffered like us...You know, she'd say, 'Oh I know, yeah, that's what happens.'" (SU 2)*

> *"There was a girl [family facilitator] there from [name of town]...her [names relative] has schizophrenia, as well, and she was great, you know? Outgoing and, you know, just nice to have her there because she'd a bit of experience as well...Someone who actually knows what it's like to live with it, you know what I mean?" (F 5)*

The involvement of peers also appeared to foster new understandings as people started to appreciate the person *'on the other side of the fence'*. Clinical facilitators were of the view that working with the peer facilitators promoted empathy and enabled them to relate at a more 'human' level than they felt was possible within the traditional professional role divisions. One clinical facilitator described this change in the following way:

> *"I found that [working with peer facilitators] interesting...I found that really, really interesting, even those two days [of training], you know, because you weren't like specifically talking about mental illness, you were talking about other things, like on a kind of...a more human level." (CF 7)*

Similarly, some peer facilitators referred to how being part of the steering group enabled them to understand the intensive workload that clinicians work under.

> *"Like I can see now that I've been involved in that [steering committee], I can see now why it's so difficult to get speaking to him [member of the clinical team], sure, he hasn't a minute. He was at that meeting and his phone was hopping...I can understand it now but when you're actually in that situation, on the other side of it, you don't see that, you don't really understand that. So just, yeah, different insight isn't it?" (FF 2)*

Some participants also felt that the clinicians learned a substantial amount about the experiences and situations of family members from participating in the facilitation.

> *"I think that the people [clinical facilitators] delivering the course...were maybe learning more from it than (laughs) than the carers...I'm not saying they were stunned but they were taken a bit aback because it was maybe a first time that they would have maybe heard what carers had to say." (F 4)*

Although the user participants were of the view that the clinician facilitators were *'about the cold hard facts of the illness'*, they described them as *"lovely"*, *"wonderful"* and *"brilliant"* and were of the view that having the clinician in the programme brought balance and would help in future relationships.

> *"You do need a balance in the room of both...You can identify with the clinician as well as the peer facilitator...[It] helps in future relationships." (SU 8)*

Co-facilitation challenges

From the interviews and surveys, although it was clear that the presence of a peer facilitator was seen as a valuable aspect of the programme, many also described how traditional power dynamics prevailed. For instance, one peer facilitator described how the clinical facilitator consistently referred to the participants as *'patients'* and often referred to the service where she worked and where some of the participants were clients. It was felt that these references reinforced the power dynamic of the clinician as the authority and the participant as the subordinate. Consequently, this person was of the view that future programmes should not have a clinician, a person of "authority", from the same service that participants attended. While she generally described her working relationship with the clinical facilitator as *'brilliant'* and *'very good'*, she perceived this power differential through the symbolism of the clinician holding the keys to the EOLAS venue:

> *"She [clinical facilitator] always had the keys (laughs). I actually laugh at these bundles of keys, you know, that people take around with them. It's a sign of power." (SUF 1)*

Although the feedback from participants suggested that the peer facilitators had high credibility and were perceived as role models for hope, similar to the users of services in McDaid's (2006) study, the peer facilitators tended to reflect the wider social norms of over-valuing clinical expertise and professional training and devaluing their own experiential knowledge. Participants spoke of lacking what they perceived as resources for participation in facilitation, such as knowledge of 'illness', pharmacology, and treatments; consequently, they tended to defer to the 'medical expertise' of the clinicians.

> *"I had my humanity and I had the experience of doing it [caring] but I didn't have the medical background and that's what I was lacking, more knowledge of that...He had medical background , I just ...gave him the space to do it...As a facilitator I didn't have much to do. So in that sense, the lay people weren't involved. You need...you have to have clinicians. If you're going to do it in the same way, you'd have to have clinicians on board all the time to deliver the information." (FF 1)*

> *"I remember there was one part and I said, 'Oh...I can't do that,' because if they ask me a question on that I wouldn't really know how to answer it because I wasn't a professional clinician basically. So she did that and she was asked questions on that. I'm glad I didn't do that bit." (FF 2)*

The lack of true involvement by some of the peer facilitators was also commented on by the participants. They suggested that the peer facilitator's own personality and confidence seemed to impact greatly on how they engaged in the co-facilitation process, with those who valued their self-knowledge on par with clinical knowledge and who had greater confidence being more likely to share their experiences and engage with the participants on the programme. Others did not relate any of their own experiences and were seen as more hesitant in their engagement, leading to their sessions being mainly clinician led.

> *"The family facilitator never even spoke. She was quiet. Maybe she was very nervous...She was a kid. She was a lovely girl. A bit shy I suppose reading in front of people..." (F 10)*

> *"She [service user facilitator] used to read out things and you know she didn't talk too much [service user facilitator]." (SU 5)*

> *"She did a lot of reading... didn't do so much talking really...Some days the [peer] facilitator just read through stuff." (SU 7)*

In their interviews, the clinician facilitators also revealed that they were aware of these issues but were at a loss on how to change the dynamics. They appeared to lack the facilitation skills necessary to enable co-facilitators to participate on an equal basis.

> *"It was difficult at times when the difficult questions were there and she [peer facilitator] was just looking across at me...You felt you were on your own because the [peer facilitator] didn't really have the confidence or didn't have the knowledge or didn't have, not the ability but just, you know, 'What will I do next?' Like I mean it was new for everybody but you pushed on or referred to the lesson plan and, 'This is what we're doing next', because it was supposed to be, 'I do part A. You do part B. I do part C. You do part D,' and I found myself kind of like, 'Well ok, I better push on." (CF 2)*

In their interviews, clinical facilitators described the time constraints and pressure they felt during their training that seemed to create a sense of urgency around the EOLAS Project. Many felt that the working aspects of co-facilitation had not been given sufficient thought and discussion during the training days and, consequently, there was a lack of clarity about the role of the peer facilitator.

> *"I don't think we fully thought through or it [role of the peer facilitator] hadn't been made fully explicit or maybe we didn't know, the co-facilitators didn't know where to put themselves in the delivery of the group." (CF 4)*

> *"I found that there was frequently a lack of clarity about the role of the co-facilitator... And it led to them kind of taking a step back and deferring almost to the staff member which is fine but then it led to the group in some cases being solely led by me and the co-facilitator not really having an input beyond welcoming people...the co-facilitators didn't know where to put themselves in." (CF 6)*

Developing the skills of co-facilitation requires time, reflection and, above all, an opportunity for the co-facilitators to meet up and to get to know each other, engage in discussion about the process and to plan on how to conduct and facilitate each session. The participants in this study commented on the lack of time to meet up with their co-facilitator prior to the programme and how it impacted negatively on their ability to clarify their roles and to make plans on how to work together in a cohesive manner.

> *"It was left till very late to organise who is going where and who is doing what...if you know who you're facilitating, co-facilitating with, you could in practice meet up with them beforehand and try and get to know them and come up with a plan on how you're going to conduct the group and how you're going to facilitate the group on the day. So definitely that should be looked at...so that you can prepare better." (CF 1)*
>
> *"We weren't really given enough time between the facilitation training and when the actual thing was starting." (CF 5)*

As a consequence of lack of facilitation skills, confidence and minimal time spent together prior to the programme, peer facilitators appeared to have been responsible for more task-oriented roles, such as welcoming participants and making tea, rather than leading the programme.

> *"The peer facilitator, her job boiled down to kind of making tea, giving out the handouts, reading paragraphs every now and then. She was very much a halfway house between the family member side of the house and the nurse or the health care professional side of it. I think the group would have worked every bit as well had she not been there and that's no slur on the individual herself but in that incidence." (F 7)*
>
> *"I don't think they [participants] really looked at me as a facilitator; they looked to me as a parent who was just helping [name of clinical facilitator], if you know what I mean, which was lovely, because it took the pressure off me altogether." (FF 2)*

Another issue that may have contributed to placing the clinical facilitator as 'expert,' which family members experienced, was the challenge of positioning their individual identities within the new role of co-facilitator. Some spoke of the difficulty they had of separating and reconciling their usual role (family carer) from and with their new co-facilitator role. This difficulty appeared to arise due to the fact that in many cases family co-facilitators were hearing and learning the information themselves for the first time.

> *"I found it a little bit strange really because in one sense I was a facilitator and in the other sense I was a parent...Where I was sitting down listening to maybe [name of clinical facilitator], who I was doing it with, who was brilliant, and listening to her, and then I'd listen to maybe a guest speaker. I was the parent then in that room. Do you know what I mean?" (FF 2)*

The responses from survey participants appear to reflect the findings of the qualitative interviews. While survey participants generally agreed that having a peer as a facilitator on the programme was a positive experience (79% n = 23), the remaining 21% (n = 6) felt neutrally about having a peer facilitator on the programme (see Table 16).

TABLE 16. PEER FACILITATORS

	USERS OF SERVICES			FAMILY MEMBERS AND FRIENDS		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Having a service user / family member facilitator on the programme was a positive experience (N = 29, n = 12, 17)	92% (11)	8% (1)	0% (0)	70% (12)	30% (5)	0% (0)

Summary

- Survey participants generally agreed that having a user of services or family member as a facilitator on the programme was a positive experience (79% n = 23). However, the remaining 21% (n = 6) participants felt neutrally about having a peer facilitator on the programme.
- Both groups felt the peer facilitators were people who understood and empathised with them but also people from whom they took inspiration and hope. The involvement of peers also appeared to foster new understandings as people started to appreciate the person *'on the other side of the fence'*.
- Many participants also described how traditional power dynamics prevailed, which positioned the clinicians as the leaders, with their clinical expertise and knowledge predominating resulting in the self-experience of peer facilitators not being equally valued. In some groups, the peer facilitators appeared to be responsible for more task-oriented jobs.
- Time constraints were an underlying challenge for the facilitators as it was felt that due to lack of time, the co-facilitators were not able to thoroughly discuss and prepare for how they would share their facilitating duties.

CHAPTER 8

Summary and recommendations

INTRODUCTION

This is the first study in Ireland that evaluated a peer and clinician led mental health information programme for people experiencing mental health difficulties (schizophrenia and bipolar disorder). Overall, it can be said that the EOLAS Project was an ambitious venture given the complexity of the objectives and the short timeframe available for its completion (less than one year).

Aim and objectives of project

The aim of the EOLAS Project was to develop, deliver and evaluate a mental health information programme on recovery from the experience of mental health difficulties (medical diagnosis of schizophrenia or bipolar disorder) for users of services and family members in the HSE Kildare and West Wicklow area.

The objectives of the project were to:

- design an information programme in collaboration with users and family members that would be beneficial and relevant to the needs of all the participants;
- deliver the information programme using a co-facilitation model involving both clinicians and peer facilitators;
- recruit and educate both clinician and peer facilitators from within the service; and
- conduct an independent evaluation of the programme from the perspectives of all stakeholders.

Development of information programme

Collaborative principles guided all stages of the project. The project was managed by a steering group that included clinicians, users of services, family members, representatives from Shine and Kildare Youth Services, and members of the evaluation/research team. Two project workers and two researchers, including a researcher with experience of using the mental health services were also employed. To identify the information needs of users of services and family members a number of focus group interviews were conducted with the users of services, family members and clinicians.

Users of services expressed a desire for information on how to manage their mental health or 'condition', as well as information on recovery, relapse prevention skills, treatment options available other than medication, legal issues, causes of mental health problems, and techniques for how to deal with 'symptoms', 'medication side-effects', low self-esteem and negative attitudes from others. They also wanted to hear personal recovery stories and learn more about peer supports. In addition, they wanted help to develop their life skills, particularly in the area of relationships, education and employment.

Family members, in contrast, wanted to meet with a psychiatrist and to be given more information on their family member's 'illness', treatment approaches and how to navigate the services. In addition, they wanted information on how to cope and respond to their family member when they were distressed, hearing voices and angry.

Although there were commonalities across both family and users of services focus groups, their needs were found to be so diverse that two separate programmes were developed and delivered in four centres. Adhering to the principles of collaboration, the programme was co-facilitated by clinicians and peers (users of services or family members), who were recruited from within the service and attended a two day training programme.

Evaluation methodology

The evaluation component used a sequential mixed method design involving both quantitative and qualitative approaches. Data were collected using pre and post programme questionnaires followed by an integrated qualitative component to explore the experiences and views of the programme of participants, facilitators and project workers. In total, 28 users of services completed pre EOLAS questionnaires and 12 completed post EOLAS questionnaires. Of these, twelve completed both questionnaires. In addition, 25 family members completed pre EOLAS questionnaires and 18 completed post EOLAS questionnaires. In total, 34 interviews were conducted. Of these, 19 were with programme participants, 11 were with facilitators and 4 were with the 2 project workers. Both descriptive and inferential statistics were generated. All interviews were audio recorded and transcribed verbatim. The qualitative data were entered into the data management software package NVivo version 8 and analysed using a thematic approach. Ethical approval to conduct the evaluation was granted by the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin and the ethics committee for the service.

Discussion of findings

Overall, it can be said that the EOLAS Project was a success and achieved its key objectives. While a number of the survey instruments did not show a statistically significant change, findings from the interviews suggest that the programme had a number of positive outcomes, including increases in perceived knowledge, empowerment and support. Both groups of participants spoke of leaving the programme with a 'better understanding' of either their own or another's mental health problem. In addition, users of services, in particular, spoke of feeling more empowered to question practitioners about their care and treatment. The sessions on medication, stress and relaxation techniques, and the role of team members in the multidisciplinary team were highlighted as particularly informative. Participants also highlighted the value of having the opportunity to ask a psychiatrist questions about diagnosis and medication. However, despite the satisfaction of the participants with the information received, both family members and user participants were of the view that the EOLAS Programme should be available to everybody immediately when they attend the mental health service, as part of an everyday quality service.

A number of studies have highlighted the supportive nature of peer groups (Rappaport 2000; Finn et al. 2007; Sibitz et al. 2007; Barber et al. 2008; Resnick and Rosenheck 2008) and findings from this evaluation were no different. Although EOLAS was primarily an information programme, the supportive space created appeared to fill a significant need for emotional support. Participants valued the opportunity to meet people in similar circumstances, share their experiences, learn from each other and provide mutual support. Both family members and users had experienced a lot of grief, shame, anger and loss. Family members spoke of lacking support networks both within and outside the mental health services and consequently valued a 'safe' place to vent their frustrations and concerns, and gain support. Indeed, a recent report by the Inspector of the Mental Health Commission Ireland (2010) on talking therapies identified poor availability of psychological therapies throughout the mental health services, with a waiting time of up to 2 years for therapy. In this context, it is not surprising that the level of family distress and emotion expressed within the group was high, and that they expressed a desire to increase the duration of sessions to facilitate a more in-depth discussion. In addition, given the short timeframe available to prepare facilitators for their role, it is equally unsurprising that some facilitators found it challenging to facilitate discussion in a supportive manner and manage the group dynamic, while simultaneously maintaining the focus on information sharing.

Principles of adult learning underpinned the development of the EOLAS Project. In other words, facilitators would seek to enable mutual co-operation with adult learners by adhering to the values of voluntary participation, mutual respect, a collaborative spirit, action and reflection and self-direction (Brookfield 1988). Findings indicate that participants valued the various teaching strategies used, including discussion groups, activities and information sheets. Hearing other people's stories was also considered a helpful learning strategy. However, some participants were of the view that they lacked time within sessions to address the content in-depth or to allow for discussion and sharing of views and experiences. Other issues that appeared to impact negatively on learning and group dynamics were the low numbers on some of the programmes, the open nature of the group, the changing of facilitators and the manner in which some of the learning materials were used. All of these issues require consideration for subsequent programmes.

As highlighted, time was a crucial factor in the programme. The brevity of time available to complete the project impacted negatively of the quality of the written information materials. Some participants found the written materials inaccessible, too text heavy and using language that was overly technical. However, since the initial EOLAS pilot programme and following some preliminary feedback from the research team, a second edition of the information handouts and facilitator's manual have been developed and evaluated by users and family members. Findings from these focus group discussions revealed that participants welcomed and were very enthusiastic about the revised information materials. They spoke of finding the language, content and layout to be more user-friendly, readable and informative. The revised facilitator handbook provides clearer guidelines on literacy issues, supporting participants in carrying out activities, and using the written information handouts as prompts for discussion as opposed to 'public reading'.

Findings from this study support previous Irish research that indicates there is minimal information given to users and family members as part of routine practice within mental health care (Mental Health Commission, 2005; Brosnan, 2006). Although benefiting from the EOLAS programmes, both groups of participants (users and family) indicated their desire to receive the information much sooner in their journey through the services and were adamant that the programme should be provided to people, as a matter of routine practice, once they attend the service.

Recruiting users and family members to the programme was carried out by clinicians from the various mental health teams. It was thought that this process would 'screen out' any user that might be too 'vulnerable' to attend. It could be said that this is an overly paternalistic attitude and has the potential to negate the right of users to be considered as full adult citizens capable of making their own decisions (Bracken and Thomas 2005). It also takes away any means of spontaneity and diminishes the voluntary participative aspect so inherent to adult learning. Rather than being considered as people first and foremost with a mental health problem, they are considered to be primarily a 'patient' whose mental health difficulties impacts negatively on their decision-making ability and, consequently, the inherent power imbalance that currently exists within mental health services is maintained. Furthermore, if the only mechanism for users to be referred onto the programme is through their clinicians, there is a risk that user participants perceive the programme to be a clinical-focused programme rather than a collaborative effort between peers and clinicians.

User and carer involvement is frequently introduced into practice as intrinsically worthwhile. Involvement is thought to lead to empowerment, increased access to social contacts, and reduce inequalities between users and practitioners, thus improving relationships with service providers (Simpson and House 2003; McEvoy et al. 2008; McDaid 2009). In many cases this was true for the current study, as many peers and participants (users and family) spoke of the positive outcomes of having been involved. However, one of the core differences between the EOLAS Programme and other programmes evaluated in the literature is the dual nature of the facilitation as it incorporated both peer and clinician facilitation. Overall, participants were positive about the dual nature of the facilitation and valued the role of each facilitator for different reasons. In their view, peers had credibility by virtue

of self-experience and provided hope and inspiration. In contrast, the clinicians came with 'clinical expertise' that they also valued. Having said this, findings indicate that due to a variety of reasons including insufficient preparation of facilitators around power dynamics, the value of self experience over clinical expertise, and strategies for co-facilitation, on occasion, traditional power dynamics prevailed within the group. Consequently, the clinical facilitators were positioned as the 'leaders', with clinical knowledge becoming more valuable than the voice of self-experience. As McDaid (2006: 58) points out "simple equality of presence…will not ensure equal participation"; thus, the over-referencing of professional expertise and the delegation of 'trivial tasks' to peers are issues that requires urgent attention in subsequent facilitator training programmes. McDaid (2006, 2009) advocates for greater capacity building among users of services and practitioners by retraining professionals to value experiential knowledge and rebalancing power relations through assigning users of services authority. Without this, there is a danger that participants leave the programme with a message that reinforces the lack of power of users and their family members to influence and effect change within the mental health services. It may also deter other users and family members from becoming involved as facilitators in other projects for fear of tokenism.

Previous published studies appear to confine the delivery of programmes to people who had received a very specific diagnosis, with a reluctance to combine people from different diagnostic groups (Rummel et al. 2005). Indeed in the early phase of the EOLAS Project there were some concerns among practitioners around mixing people with different diagnoses. Practitioners were concerned that the 'stigma' attached to a diagnosis of schizophrenia may inhibit people who had a diagnosis of bipolar disorder attending, and that their information needs would differ. This study demonstrates that combining people with different 'diagnoses' offers a promising approach, especially when there may not be enough potential participants to make organising diagnosis-specific groups a feasible option. Findings from this study would also support Rabovsky and Stoppe's (2006) view that there are many aspects of information needs common to users of services with a variety of diagnoses, including their desire for information on medication, diagnosis, service provision, advocacy, warning signs, family relationships and recovery.

In addition, previous studies reviewed tended to use highly structured methodologies for their evaluations, which were dominated by quantitative tools. By adopting a more mixed methods approach within this evaluation and through integrating more qualitative approaches, this study enabled a different perspective on the programme to emerge, complementing the existing literature. The flexibility of the interview shed light on unexplored or previously unexamined perspectives, such as co-facilitation challenges.

Overall, the EOLAS Project embodied the nature and principles of collaboration. The complete project was developed in conjunction with users, family members and clinicians. Its success in meeting its objectives and producing a high quality information programme was due in no small way to people's commitment to the principles of collaboration. The team produced clear manuals that can be accessed and used by other services. Indeed, services can be confident that the content of the manuals is based on the voice of users and family members, as opposed to the 'expertise' of practitioners, which has characterised the vast majority of the programmes documented in the literature. The EOLAS Project clearly demonstrates and reinforces the importance of engaging with all stakeholders, and hearing the voice of users and families if changes in mental health services are to be achieved and sustained.

In addition to producing a set of manuals, feedback from all stakeholders also indicates that the EOLAS Project was a positive initiative within the service as it commenced a dialogue on the importance of user and family involvement. The project design, governance, delivery and evaluation strategies as described in the report offers a blueprint for future developments that are collaborative in nature and provides a framework by which other services can work towards achieving a number of the quality standards as laid down by the Mental Health Commission (2007); namely standards 3.3, 3.4, and 6.1. Standard 3.3 states that "peer support/ advocacy is available to service users of services"; standard 3.4 indicates that "a clear accessible mechanism for participation in the delivery of mental health services is available to service users"; and standard 6.1 states "families, parents and carers are empowered as team members receiving information, advice and support as appropriate" (32-40). Despite the limitations of the project and the need for further capacity building among facilitators, there is no doubt that the EOLAS Project is a step in the right direction towards making users and their families equal partners within the mental health services.

Limitations

As stated, overall the results of the evaluation are quite positive; however, they need to be interpreted in light of the following issues:

- Participants volunteered to take part in the information programme and this may have attracted people who were more interested and positive about this form of development. In addition, participants volunteered for the evaluation interviews and this may have biased the data toward people with more positive experiences or participants who wished to present the service in a favourable light. Therefore, it cannot be assumed that they represent the general population of users, family members or clinicians.
- The overall numbers of participants who completed the programme and completed both the pre and post questionnaires were smaller than anticipated, thus minimising the likelihood of finding any statistical difference in the pre and post measures. Due to the small sample size, caution should be taken when interpreting any statistical findings.
- A key limitation of the present study relates to the relationship between some of the measures and the content of the intervention. Some measures reflect quite general psychological constructs (e.g. recovery, hope and self-advocacy) and the item content of the measures may not have reflected the specific content of the intervention. The measures were selected on the basis of assessing a clinically relevant construct and having established use in the research literature. In selecting such measures it was hoped to demonstrate the effectiveness of the intervention and to be able to benchmark such changes with other studies in the literature; however, the items from such scales may not have been that sensitive to change as the intervention sessions may not have addressed issues pertinent to the items. Similarly, it is possible that some measures (e.g. GHQ) were inappropriate given the content of the intervention.
- The study did not include a control group for comparison and long term outcomes were not evaluated.

Recommendations

Bearing in mind that the written materials (information leaflets and facilitator manual) for the programme have been revised and subsequently evaluated by a cohort of users and family members, the researchers make recommendations under a number of key areas:

- The revised programme should be offered to users and family members both within and outside the Kildare and West Wicklow services to cater for those who did not get the opportunity to attend.
- Subsequent programme delivered should give consideration to:
    - Expanding recruitment strategies to include extensive advertising in community, user and advocacy organisations.
    - Extending the duration of each session to two hours to enable participants to engage in more in-depth discussion about people's personal and individual experiences.
    - Including a solicitor with expertise in family and mental health law as a guest speaker and potentially including sessions on self-advocacy.
    - Including in future programmes a session on how to set up a support group and list those organisations that may be able to assist and provide advice should family members wish to proceed with this initiative.
    - Providing time for each co-facilitation pair to meet and discuss strategies that would facilitate the smooth roll out of the programme.
    - Minimising the number of facilitators who facilitate on any one programme.
    - Exploring the creative use of learning strategies, such as video, PowerPoint and case studies.
    - Sending new editions of written information handouts to NALA who, for a fee, will screen the literature and assess for user-friendliness.
- Future training programmes of facilitators should:
    - Incorporate in-depth discussion and reflection on the inherent power differentials between clinicians and peer facilitators and explore strategies of how to minimise such issues.
    - Incorporate awareness raising exercises that would emphasise the unique and valuable contribution peer facilitators bring to programme delivery.
    - Include skills training on how to manage group dynamics and respond to individuals who may dominate group discussion, perhaps through employing more role play training within the programme.
    - Explicitly encourage facilitators to deploy an ethos of hope and recovery into programme delivery.
    - Provide opportunities for participants to practice peer facilitation and receive feedback in a learning context.
    - Encourage guest speakers to attend the complete facilitation training or at least the session that provides an overview of the programme so that they might gain a holistic understanding of the programme structure and ethos.
- The revised facilitators training programme should be given recognition by an appropriate accrediting and training body.
- In view of the unique need of the users of the services, consideration should be given to:
    - Providing all users of services with relevant written information based on the EOLAS Project handouts.
- In view of the unique needs of family members identified in the study, consideration should be given to:
    - Providing all family members on their first encounter with mental health services relevant written information based on the EOLAS Project handouts.
    - Providing family members with information on support groups and free and accessible counselling services within their region as a matter of course once they attend the mental health services.
    - Appointing a key worker who would act as a 'mediator' between families, users of services and mental health services.
- The revised programme be further evaluated and consideration be given to:
    - Using a larger cohort of users of services and family members and evaluating within a greater number of services to ensure that statistical findings are robust.
    - Further testing and examining the quantitative measures to identify those that would be most suitable in evaluating the efficacy of the EOLAS. For example, the qualitative interviews noted the value of enhanced social support, which was not assessed in the battery of questionnaires used. Similarly, coping strategies and goal setting were not assessed, which may have proved more sensitive to what the intervention could achieve.
    - Evaluating the impact and effect of different modes of delivery of the information programme, such as face-to-face peer and clinician led versus online delivery.
    - Including outcomes, such as knowledge, self-advocacy, hope, sense of support, help seeking behaviour and perspective on willingness to engage and collaborate with service providers.
    - Evaluating the long-term benefits of these interventions using longitudinal study designs.
    - Devising evaluation strategies that require shorter self-completion questionnaires.
    - Securing funding in order to enable the roll out and further evaluation to occur at a national level.

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Appendix I: Studies identified for review

NAME	POPULATION	DURATION OF INTERVENTION	CURRICULUM CONTENT	TEACHING METHODS	THEORETICAL PERSPECTIVE	OUTCOMES MEASURES	OUTCOMES OF INTERVENTIONS	MAIN FINDINGS
Dixon et al (2004)	Family-to-family. 95 family members of those with severe mental illness from 15 different class groups across the state of Maryland U.S.A.	12 weeks of 2-3 hour sessions	Info on mental illnesses, treatments, medication & rehabilitation. Learn about self-care, mutual assistance & communication skills, problem-solving strategies, advocacy & emotional insight.	Trained family volunteers. Highly structured, scripted manual.	Based on theories of stress and coping, trauma recovery, adaptation and support. Family well-being primary concern.	Structured telephone interviews at 4 time intervals (waitlist, pre, post and 6 months post). Family Experience interview schedule: Family Impact Survey and Family Empowerment Scale. Data collectors had family members who had mental illness.	FFEP associated with reduced subjective burden reduce worry, increase knowledge of mental illness, mental health system & self-care.	Family-to-Family peer taught psychoeducation programs improve well-being of family members and increase their understanding of mental health. No significant reduction in these effects 6 months after the programme
Pickett-Schenk et al (2008)	Family-led intervention.231 intervention group. 231 waiting list. Family members of adults with mental illness in Louisiana, U.S.A. 3 intervention sites. Randomized control trial	8 weeks. 2hr sessions. Taught in non-clinical settings. Free to all participants. Class sizes 10-15.	Biological causes & standard treatment of various mental illnesses. Problem-solving skills. Coping strategies. Normative reactions to mental illness. Self-care. Community treatment progs & consumer recovery.	Trained volunteers who have adult family member with mental health difficulty. Team of two instructors. Manual-led.	Programme appears to be mostly recovery-oriented.	In person structured interviews at 3 time intervals (1month before intervention (baseline control), post-programme (3 months post-baseline control), 6 months post-programme (8months post-baseline control). Family knowledge scale. Family information needs scale	Intervention group – greater knowledge increases. Information need decreases. These gains were maintained after 6 months	Family- led education interventions provide families with the info they need to better cope with relative's mental health problem
Druss et al (2010)	80 participants to both intervention & waiting list groups from Urban community mental health centre in southern states USA	6 sessions	Self-management of disease. Medications, upcoming appointments, dietary intake, physical activity, connection b/n mind & body	Team of two peer educators Manualised intervention	Bio-medical model appears to predominate. Focus on medication management. HARP is an adaptation of Chronic Disease Self-Management Program	Baseline and 6 months post. Physical health related quality of life (HRQOL).Patient Activation Measure. Behavioural risk factor surveillance system.	Intervention group greater improvement in patient activation, medication adherence & physical activity	HARP (health & recovery peer program) improves a range of outcomes, esp. those with chronic medical co-morbidity
Rummel et al (2005)	2 peer moderators. 58 patients. 4 outpatients & 54 inpatients of open psychiatric ward of university psychiatric hospital, Munich, Germany.	7 groups of 8 sessions. 2 sessions per week. 1 hour each.	Symptoms/diagnosis/ causes of schiz. Medication effects & side effects. Psychosocial therapy. Warning signs & contingency plan. Dealing with schiz & influence of family & friends.	Two peer co-moderators, with physician present at beginning of training	Biomedical model Feasibility study of pilot programme	Baseline and endpoint questionnaire to group participants. Knowledge of Illness about schizophrenia and disease concept scales. Subjective feedback sheet on moderators' knowledge, empathy, pedagogical abilities, practical experience)	Knowledge & concept issues improve. Trust in doctor and medication increased. Positive subjective assessment of peer moderators	Peer-to-peer psychoeducation in schizophrenia is feasible. Peers are credible role models

Appendix I: Studies identified for review (Continued)

NAME	POPULATION	DURATION OF INTERVENTION	CURRICULUM CONTENT	TEACHING METHODS	THEORETICAL PERSPECTIVE	OUTCOMES MEASURES	OUTCOMES OF INTERVENTIONS	MAIN FINDINGS
Resnick & Rosenheck (2008)	Vet-to-Vet (War veterans with mental health difficulties, many homeless) 3 cohorts. 1 standard care (N=78). 2 intervention (N=218). 3 attended more than 10 sessions (N=102).	Runs 5 days a wk. attendance voluntary	Read & discuss format for established curriculum of recovery oriented publications	Peer provided Read and discuss format	Explicitly collaborative / partnership model between users of services and clinicians Recovery approach	3 cohorts. 1 standard care. 2 interventions. 3 attended more than 10 sessions. Follow up interviews at 1, 3 and 9 months by experienced, independent rater. Measures of recovery orientation, confidence & empowerment Recovery attitudes Questionnaire: mental health confidence scale, making decisions scale, empowerment over illness scale, activities of daily living, global assessment of functioning. Addiction severity index, brief psychiatric rating scale etc	Cohort 2 and 3 superior outcomes on all outcomes, especially among cohort 3 who attended most regularly.	Participation in peer-led psychoeducation enhances well being – in both recovery and traditional clinical measures
Barber et al 2008	1, 847 anonymous surveys from 38 various Vet-to-Vet programmes in U.S.	Runs 5 days a week. attendance voluntary	Read and discuss format for established curriculum of recovery oriented publications	Peer provided Read and discuss format	Explicitly collaborative / partnership model between users of services and clinicians Recovery approach	Level of participation on programme and any facilitation. Satisfaction with programme. Veteran recovery attitudes. Spirituality. Engagement in meaningful personal activities.	Programme positive experience. High satisfaction with programme linked to stronger sense of recovery and engagement. Payment of facilitators.	Paper demonstrates a monitoring system of peer support on Vet-to-Vet
Pickett et al (2010)	160 participants in Building Recovery of Individual Dreams & Goals (BRIDGES) ed prog. U.S.A.	8 week programme	Recovery focused	Trained instructors who publically disclose that they are in recovery from mental illness	Recovery-focused	Structured interviews (pre and 1 month post-programme). Symptoms, hopefulness, social support, self-advocacy, empowerment, adaptive coping	Post-BRIDGES fewer psychiatric symptoms, decrease maladaptive coping, increased hopefulness, self-advocacy, empowerment and recovery.	Peer-led education interventions valuable resource. More research into long-term benefits required.
Pickett-Schenk et al (2006)	Family-led education intervention – Journey of Hope 462 participants (relatives of those with mental illness) Chicago, U.S. A.	3 months programme	Carer coping strategies, Stress management, Recovery, relationships, hopefulness	Trained family carers	Recovery-focused	Randomly assigned control (waitlist) and treatment group followed for 9 months. Pre, post and post-6 months. Caregiving satisfaction scale. Family information needs scale – problem management and social functioning subscales.	Treatment group showed a marked improvement in caregiving satisfaction & info needs after programme & continuously 6 months after.	Education and support from other family members in structured programme is effective in meeting caregiving needs
Cook et al (2010)	381 WRAP participants from Vermont & Minnesota	7 day programme	Self-management of mental illness to people in mental health Recovery	Trained peers	Recovery-focused	Pre and post programme surveys. 3 dimensions of self-management: attitudes, knowledge and skills.	Significant increases in hopefulness, awareness of warning signs & symptom triggers, use of wellness tools, crisis plan, soc support & take responsibility for wellness	This study contributes to the evidence base for peer-led programmes

Appendix II: Detailed statistical findings

Users of services

SUMMARY STATISTICS FOR MEASURES OVER TIME

	PRE EOLAS MEAN (SD)[MEDIAN]	POST EOLAS MEAN (SD)[MEDIAN]
Knowledge (n=2)	44.13 (3.83)[44]	67.5 (10.61)[67.5]
Recovery Attitude Questionnaire (n=8)	40.81 (4.06)[39]	44.75 (5.00)[46]
Patient Self-Advocacy Scale (n=8)	32.63 (7.08)[32.5]	34.63 (5.62)[34.5]
Drug Attitude Inventory (n=8)	18.25 (2.55)[17.5]	18.13 (3.09)[17.5]
Hearth Hope Index (n=7)	30.86 (5.45) [30]	33.29 (4.07)[34]

KNOWLEDGE

	PRE EOLAS (N = 25, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I understand why I am on medication.	12 (48%)	10 (40%)	1 (4%)	2 (8%)	-	7 (58%)	4 (33%)	1 (8%)	-	-
I know about stress management techniques for myself.	5 (20%)	12 (48%)	3 (12%)	4 (16%)	1 (4%)	3 (25%)	6 (50%)	3 (25%)	-	-
I understand what my relapse triggers are. (Pre n=22)	5 (23%)	10 (46%)	4 (18%)	2 (9%)	1 (5%)	2 (17%)	8 (67%)	1 (8%)	1 (8%)	-
I know how to access mental health services for myself (Pre n=23)	8 (35%)	12 (52%)	3 (13%)	-	-	6 (50%)	6 (50%)	-	-	-
I know what the role of each member of the multi-disciplinary team is (e.g. nurse, etc).	7 (28%)	10 (40%)	7 (28%)	1 (4%)	-	5 (42%)	6 (50%)	-	1 (8%)	-
I know how to ask questions of the multi-disciplinary team members. (Pre n=23)	6 (26%)	8 (35%)	5 (22%)	3 (13%)	1 (4%)	4 (33%)	6 (50%)	2 (17%)	-	-
I understand my legal rights in the mental health services.	4 (16%)	5 (20%)	10 (40%)	5 (20%)	1 (4%)	5 (42%)	6 (50%)	-	1 (8%)	-
I know how to deal with voices (if appropriate). (Pre n=15; Post n =10)	5 (33%)	7 (47%)	2 (13%)	1 (7%)	-	3 (30%)	2 (20%)	4 (40%)	1 (10%)	-
I know how to deal with strange thoughts (if appropriate). (Pre n=20; Post n = 11)	5 (25%)	8 (40%)	1 (5%)	4 (20%)	2 (10%)	3 (27%)	4 (36%)	4 (36%)	-	-
I know how to deal with family conflict/ interactions. (Pre n=23; Post n =10)	4 (17%)	9 (39%)	4 (17%)	4 (17%)	2 (9%)	3 (30%)	4 (40%)	1 (10%)	2 (20%)	-
I know how to cope with the side effects of my medication. (n=24)	5 (21%)	9 (38%)	6 (25%)	3 (13%)	1 (4%)	3 (25%)	5 (42%)	4 (33%)	-	-
I know how to cope with changes in my mood.	4 (16%)	9 (36%)	5 (20%)	5 (20%)	2 (8%)	2 (17%)	8 (67%)	2 (17%)	-	-
I am familiar with strategies for seeking employment.(Pre n=21; Post n =11)	6 (29%)	3 (14%)	8 (38%)	2 (10%)	2 (10%)	3 (27%)	4 (36%)	4 (36%)	-	-
I am familiar with strategies for getting involved in the local community (Post n =11)	5 (20%)	6 (24%)	6 (24%)	6 (24%)	2 (8%)	3 (27%)	5 (46%)	2 (18%)	1 (9%)	-
I am familiar with strategies for establishing friendships/relationships.	4 (16%)	8 (32%)	8 (32%)	4 (16%)	1 (4%)	2 (17%)	7 (58%)	3 (25%)	-	-

RECOVERY ATTITUDE QUESTIONNAIRE

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
People in recovery sometimes have set backs.	15 (58%)	11 (42%)	-	-	-	8 (67%)	4 (33%)	-	-	-
To recover requires belief that I can recover.	15 (58%)	10 (39%)	1 (4%)	-	-	8 (67%)	4 (33%)	-	-	-
Stigma associated with mental health problems can slow down the recovery process. (n=24)	11 (46%)	9 (38%)	2 (8%)	2 (8%)	-	6 (50%)	5 (42%)	-	-	1 (8%)
Recovery can occur even if symptoms of mental health problems are present. (n=25)	10 (40%)	8 (32%)	4 (16%)	2 (8%)	1 (4%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)	-
Recovering from mental health problems is possible no matter what you think may cause it.	8 (31%)	14 (54%)	4 (15%)	-	-	5 (42%)	5 (42%)	2 (17%)	-	-
All people with serious mental health problems can strive for recovery.	11 (42%)	15 (58%)-	-	-	-	7 (58%)	4 (33%)	-	1 (8%)	-
People differ in the way they recover from a mental health problem.	10 (39%)	16 (62%)	-	-	-	7 (58%)	5 (42%)	-	-	-
My relationship with the mental health team contributes to recovery.	12 (46%)	14 (54%)	-	-	-	7 (58%)	5 (42%)	-	-	-
I am responsible for my own recovery.	10 (39%)	10 (39%)	5 (19%)	1 (4%)	-	6 (50%)	6 (50%)	-	-	-
My relationship with my family contributes to my recovery.	12 (46%)	9 (35%)	4 (15%)	1 (4%)	-	6 (50%)	6 (50%)	-	-	-

HEARTH HOPE INDEX

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)				POST EOLAS (N = 12, UNLESS OTHERWISE STATED)			
	SA	A	D	SD	SA	A	D	SD
I have a positive outlook toward life. (Pre n=27)	4 (15%)	16 (59%)	6 (22%)	1 (4%)	4 (33%)	6 (60%)	2 (17%)	-
I have short and/or long-range goals.	5 (19%)	16 (62%)	3 (12%)	2 (8%)	4 (33%)	7 (58%)	-	1 (8%)
I feel all alone.(Pre n=25)	5 (20%)	5 (20%)	12 (48%)	3 (12%)	1 (8%)	2 (17%)	8 (67%)	1 (8%)
I can see possibilities in the midst of difficulties.	7 (27%)	14 (54%)	5 (19%)	-	6 (50%)	6 (50%)	-	-
I have a faith that gives me comfort.(Pre n=25)	10 (40%)	10 (40%)	2 (8%)	3 (12%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)
I feel scared about my future. (Pre n=25)	6 (24%)	12 (48%)	5 (20%)	2 (8%)	4 (33%)	4 (33%)	4 (33%)	-
I can recall happy/joyful times.(Pre n=27)	11 (41%)	12 (44%)	4 (15%)	-	6 (50%)	6 (50%)	-	-
I have deep inner strength.	8 (31%)	14 (54%)	2 (8%)	2 (8%)	6 (50%)	5 (42%)	1 (8%)	-
I am able to give and receive caring/love.(Pre n=27)	10 (37%)	13 (48%)	4 (15%)	-	6 (50%)	4 (33%)	2 (17%)	-
I have a sense of direction	8 (31%)	12 (46%)	5 (19%)	1 (4%)	4 (33%)	6 (50%)	1 (8%)	1 (8%)

PATIENT SELF-ADVOCACY SCALE

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I believe it is important for people with psychosis to learn as much as they can about their mental health problems and treatments. (Pre n=27)	18 (67%)	8 (30%)	1 (4%)	-	-	7 (58%)	5 (42%)	-	-	-
I actively seek out information on my mental health problem	9 (35%)	10 (39%)	3 (12%)	2 (8%)	2 (8%)	3 (25%)	6 50%)	3 (25%)	-	-
I don't get what I need from my mental health team because I am not assertive enough. (Pre n=27)	4 (15%)	8 (30%)	8 (30%)	6 (22%)	1 (4%)	1 (8%)	2 (17%)	3 (25%)	5 (42%)	1 (8%)
I am more assertive about my mental health care needs than most Irish citizens.(Pre n=25; Post n =11)	2 (8%)	6 (24%)	12 (48%)	5 (20%)	-	1 (8%)	5 (46%)	5 (46%)	-	-
I frequently make suggestions to my mental health team about my mental health care needs.	5 (19%)	10 (39%)	5 (19%)	6 (23%)	-	2 (17%)	7 (58%)	2 (17%)	1 (8%)	-
If my mental health team prescribes something I don't understand or agree with, I question it. (Pre n=27)	12 (44%)	10 (37%)	2 (7%)	2 (7%)	1 (4%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)	-
Sometimes there are good reasons not to follow the advice of a mental health team.	1 (4%)	6 (23%)	9 (35%)	6 (23%)	4 (15%)	1 (8%)	2 (17%)	3 (25%)	5 (42%)	1 (8%)
Sometimes I think I have a better grasp of what I need medically than my mental health team does.	5 (19%)	6 (23%)	5 (19%)	7 (27%)	3 (12%)	2 (17%)	3 (25%)	1 (8%)	5 (42%)	1 (8%)
If I am given a treatment by my mental health team that I don't agree with, I am likely to not take it.	5 (19%)	6 (23%)	3 (12%)	11 (42%)	1 (4%)	1 (8%)	1 (8%)	2 (17%)	6 (50%)	2 (17%)
I don't always do what my health care worker has asked me to do.	4 (15%)	5 (19%)	5 (19%)	11 (42%)	1 (4%)	1 (8%)	4 (33%)	1 (8%)	5 (42%)	1 (8%)

DRUG ATTITUDE INVENTORY

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)					POST EOLAS (N = 12, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
For me, the good things about medication outweigh the bad. (n=27)	11 (41%)	10 (37%)	4 (15%)	1 (4%)	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-	-
I take medications of my own free choice.	12 (46%)	9 (35%)	3 (12%)	2 (8%)	-	5 (42%)	5 (42%)	1 (8%)	1 (8%)	-
I take medication only when I feel ill.	1 (4%)	2 (8%)	3 (12%)	15 (58%)	5 (19%)	2 (17%)	-	1 (8%)	7 (58%)	2 (17%)
Taking medication will prevent me from having a breakdown/becoming unwell.	17 (66%)	5 (19%)	4 (15%)	-	-	5 (42%)	7 (58%)	-	-	-
It is unnatural for my mind and body to be controlled by medications.	6 (23%)	4 (15%)	6 (23%)	9 (35%)	1 (4%)	1 (8%)	3 (25%)	3 (33%)	2 (17%)	3 (25%)

Family and friends

SUMMARY STATISTICS FOR MEASURES OVER TIME

	PRE EOLAS MEAN (SD) [MEDIAN]	POST EOLAS MEAN (SD) [MEDIAN]
Knowledge	45.14 (7.27) [45]	55 (8.22) [51]
Recovery Attitude Questionnaire	40.81 (4.06) [39]	43 (3.61) [44]
Patient Self-Advocacy Scale	34.75 (3.28) [33.5]	37.75 (2.49) [38.5]
Social Network of Support Scale	19.14 (4.02) [20]	19.42 (3.05) [20]
Hearth Hope Index	37.71 (3.59) [38]	40.14 (4.06) [4]
General Health Questionnaire	11.25 (5.19) [9]	9.5 (5.68) [7]

KNOWLEDGE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I understand why my relative/friend is on medication (Pre n =25)	12 (48%)	12 (48%)	1 (4%)	-	-	12 (67%)	6 (33%)	-	-	-
I know about stress management techniques for myself	4 (17%)	8 (33%)	6 (25%)	3 (13%)	3 (13%)	4 (22%)	5 (28%)	6 (33%)	3 (17%)	-
I understand what my relative/friend's relapse triggers are (Pre n =25; Post n =17)	6 (24%)	9 (36%)	4 (16%)	5 (20%)	1 (4%)	4 (24%)	6 (35%)	3 (18%)	4 (24%)	-
I know how to access mental health services for my relative/friend (Pre n =23)	3 (13%)	11 (48%)	3 (13%)	2 (9%)	4 (17%)	7 (39%)	8 (44%)	-	1 (6%)	2 (11%)
I know what the role of each member of the multi-disciplinary team is (e.g. nurse, social worker, psychiatrist, psychologist)	2 (8%)	6 (25%)	9 (38%)	2 (8%)	5 (21%)	6 (33%)	6 (33%)	1 (6%)	3 (17%)	2 (11%)
I know how to ask questions of the multi-disciplinary team members	4 (17%)	2 (8%)	12 (50%)	3 (13%)	3 (13%)	4 (22%)	5 (28%)	7 (39%)	1 (6%)	1 (6%)
I understand my relative/friend's legal rights in the mental health services	3 (13%)	2 (8%)	7 (29%)	4 (17%)	8 (33%)	7 (39%)	6 (33%)	2 (11)	3 (17%)	-
I know how to help my relative/friend deal with voices (if appropriate) (Pre n =22; Post n=17)	1 (5%)	2 (9%)	9 (41%)	4 (18%)	6 (27%)	4 (24%)	4 (24%)	8 (47%)	1 (6%)	-
I know how to help my relative/friend deal with strange thoughts (if appropriate)	1 (4%)	10 (42%)	5 (21%)	5 (21%)	3 (13%)	3 (17%)	8 (44%)	4 (22%)	3 (17%)	-
I know how to deal with family conflict/ interactions	2 (8%)	7 (29%)	6 (25%)	6 (25%)	3 (13%)	4 (22%)	7 (39%)	3 (17%)	3 (17%)	1 (6%)
I know how to help my relative/friend cope with the side effects of their medication (n=25)	1 (4%)	4 (16%)	10 (40%)	7 (28%)	3 (12%)	-	11 (61%)	4 (22%)	2 (11%)	1 (6%)
I know how to cope with changes in my relative/ friend's mood	2 (8%)	5 (21%)	8 (33%)	5 (21%)	4 (17%)	2 (11%)	8 (44%)	5 (28%)	1 (6%)	2 (11%)
I am familiar with strategies for helping my relative/friend seek employment (Pre n=21; Post n =17)	-	2 (10%)	6 (29%)	5 (24%)	8 (38%)	1 (6%)	2 (12%)	7 (41%)	4 (24%)	3 (18%)
I am familiar with strategies for helping my relative/friend get involved in the local community	-	3 (13%)	8 (33%)	5 (21%)	8 (33%)	-	6 (33%)	5 (28%)	4 (22%)	3 (17%)
I am familiar with strategies for helping my relative/friend establish friendships/relationships (Pre n =25)	2 (8%)	4 (16%)	9 (36%)	4 (16%)	6 (24%)	1 (6%)	5 (28%)	5 (28%)	6 (33%)	1 (6%)

– Items with significant changes are in bold.

RECOVERY ATTITUDE QUESTIONNAIRE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
People in recovery sometimes have set backs	12 (50%)	10 (42%)	1 (4%)	-	1 (4%)	10 (56%)	8 (44%)	-	-	-
To recover requires service users to believe themselves that they can recover	12 (50%)	11 (46%)	1 (4%)	-	-	9 (50%)	9 (50%)	-	-	-
Stigma associated with mental health problems can slow down the recovery process	10 (42%)	11 (46%)	2 (8%)	-	1 (4%)	5 (28%)	8 (44%)	4 (22%)	1 (6%)	-
Recovery can occur even if symptoms of mental health problems are present	6 (25%)	11 (46%)	4 (17%)	2 (8%)	1 (4%)	5 (28%)	10 (56%)	2 (11%)	1 (6%)	-
Recovering from mental health problems is possible no matter what you think may cause it (Pre n =23)	7 (30%)	6 (26%)	7 (30%)	2 (9%)	1 (4%)	3 (17%)	11 (61%)	3 (17%)	1 (6%)	-
All people with serious mental health problems can strive for recovery	5 (21%)	15 (63%)-	3 (13%)	-	1 (4%)	6 (33%)	8 (44%)	4 (22%)	-	-
People differ in the way they recover from a mental health problem	9 (38%)	13 (54%)	2 (8%)	-	-	8 (44%)	10 (56%)	-	-	-
A service user's relationship with the mental health team contributes to their recovery	11 (46%)	11 (46%)	2 (8%)	-	-	10 (56%)	6 (33%)	-	1 (6%)	1 (6%)
The service user is responsible for their own recovery (Pre n =23)	3 (13%)	6 (26%)	9 (39%)	4 (17%)	1 (4%)	5 (28%)	5 (28%)	3 (17%)	3 (17%)	2 (11%)
The service user's relationship with their family contributes to their recovery	9 (38%)	13 (54%)	2 (8%)	-	-	11 (61%)	7 (39%)	-	-	-

HEARTH HOPE INDEX

	PRE EOLAS (N = 26, UNLESS OTHERWISE STATED)				POST EOLAS (N = 12, UNLESS OTHERWISE STATED)			
	SA	A	D	SD	SA	A	D	SD
I have a positive outlook toward life. (Pre n=25)	7 (28%)	17 (68%)	1 (4%)	-	7 (58%)	5 (42%)	-	-
I have short and/or long-range goals.	3 (13%)	19 (79%)	2 (8%)	-	4 (33%)	7 (58%)	-	1 (8%)
I feel all alone.	5 (21%)	5 (21%)	13 (54%)	1 (4%)	1 (8%)	3 (25%)	7 (58%)	1 (8%)
I can see possibilities in the midst of difficulties.	4 (17%)	19 (79%)	1 (4%)	-	3 (25%)	9 (75%)	-	-
I have a faith that gives me comfort.	3 (13%)	14 (58%)	4 (17%)	3 (13%)	4 (33%)	6 (50%)	2 (17%)	-
I feel scared about my future. (Pre n=23; Post n =11)	6 (26%)	10 (44%)	6 (26%)	1 (4%)	1 (9%)	1 (9%)	9 (82%)	-
I can recall happy/joyful times. (Post n =12)	9 (38%)	14 (58%)	-	1 (4%)	6 (50%)	6 (50%)	-	-
I have deep inner strength. (Post n =12)	10 (42%)	13 (54%)	-	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-
I am able to give and receive caring/love.(Post n =12)	11 (46%)	12 (50%)	1 (4%)	-	7 (58%)	5 (42%)	-	-
I have a sense of direction (Post n =12)	4 (17%)	16 (67%)	3 (13%)	1 (4%)	7 (58%)	4 (33%)	1 (8%)	-
I believe that each day has potential. (Pre n =23)	4 (17%)	18 (78%)	1 (4%)	-	5 (42%)	7 (58%)	-	-
I feel my life has value and worth.	13 (54%)	10 (42%)	1 (4%)	-	6 (50%)	6 (50%)	-	-

– Items with significant changes are in bold.

PATIENT SELF-ADVOCACY SCALE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 18, UNLESS OTHERWISE STATED)				
	SA	A	N	D	SD	SA	A	N	D	SD
I believe it is important for people with psychosis to learn as much as they can about their mental health problems and treatments.(Pre n =25)	14 (56%)	10 (40%)	1 (4%)	-	-	12 (67%)	5 (28%)	1 (6%)	-	-
I actively seek out information on my family member/friend's mental health problem	8 (33%)	10 (42%)	4 (17%)	2 (8%)	-	7 (39%)	9 (50%)	2 (11%)	-	-
I don't get what I need from my family member/ friend's mental health team because I am not assertive enough.(Pre n =23)	5 (22%)	1 (4%)	11 (48%)	4 (17%)	2 (9%)	1 (6%)	3 (17%)	9 (50%)	4 (22%)	1 (6%)
I am more assertive about my family member/ friend's mental health care needs than most Irish citizens.	3 (13%)	5 (21%)	13 (54%)	2 (8%)	1 (4%)	3 (17%)	9 (50%)	4 (22%)	2 (11%)	-
I frequently make suggestions to the mental health team about my family member/friend's mental health care needs. (Pre n =23)	3 (13%)	4 (17%)	7 (30%)	8 (35%)	1 (4%)	1 (6%)	7 (39%)	6 (33%)	3 (17%)	1 (6%)
If the mental health team prescribes something for my family member/friend that I don't understand or agree with, I question it. (Pre n =25)	9 (36%)	11 (44%)	4 (16%)	1 (4%)	-	3 (17%)	10 (56%)	5 (28%)	-	-
Sometimes there are good reasons not to follow the advice of a mental health team.(Pre n =23)	2 (9%)	8 (35%)	8 (35%)	3 (13%)	2 (9%)	2 (11%)	-	10 (56%)	5 (28%)	1 (6%)
Sometimes I think I have a better grasp of what family member/friend needs medically than their mental health team does.(Pre n=25)	6 (24%)	5 (20%)	8 (32%)	6 (24%)	-	2 (11%)	4 (22%)	6 (33%)	5 (28%)	1 (6%)
If my family member/friend is given a treatment by their mental health team that I don't agree with, I encourage them not to take it.	-	1 (4%)	6 (25%)	12 (50%)	5 (21%)	-	2 (11%)	4 (22%)	9 (50%)	3 (17%)
I don't always do what my family member/ friend's mental health care worker has asked me to do.(Pre n=22)	1 (5%)	3 (14%)	4 (18%)	11 (50%)	3 (14%)	-	2 (11%)	3 (17%)	10 (56%)	3 (17%)
I ask questions about my family member mental health problems from the mental health team (Pre n =22; Post n =13)	7 (32%)	9 (41%)	6 (27%)	-	-	6 (46%)	5 (39%)	2 (15%)	-	-

– Items with significant changes are in bold.

SOCIAL NETWORK OF SUPPORT SCALE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)					POST EOLAS (N = 11)				
	SA	A	N	D	SD	SA	A	N	D	SD
I feel supported by the mental health team in relation to my family member's mental health problem.	3 (13%)	5 (21%)	5 (21%)	6 (25%)	5 (21%)	2 (18%)	3 (27%)	2 (18%)	3 (27%)	1 (9%)
I feel supported by other families in relation to my family member's mental health problem.	3 (13%)	3 (13%)	11 (46%)	3 (13%)	4 (17%)	2 (18%)	3 (27%)	2 (18%)	4 (36%)	-
I feel supported by my own family/friends in relation to my family member's mental health problem. (Pre n =23)	5 (22%)	9 (39%)	5 (22%)	-	4 (17%)	3 (27%)	5 (46%)	-	3 (27%)	-
I feel supported by the mental health team in meeting my own needs	2 (8%)	-	10 (42%)	6 (25%)	6 (25%)	1 (9%)	2 (18%)	2 (18%)	5 (46%)	1 (9%)
I feel supported by other families in meeting my own needs	4 (17%)	4 (17%)	9 (38%)	3 (13%)	4 (17%)	1 (9%)	1 (9%)	4 (36%)	5 (46%)	-
I feel supported by my own family/friends in meeting my own needs	5 (22%)	8 (35%)	6 (26%)	1 (4%)	3 (13%)	1 (9%)	4 (36%)	3 (27%)	3 (27%)	-

GENERAL HEALTH QUESTIONNAIRE

	PRE EOLAS (N = 24, UNLESS OTHERWISE STATED)				POST EOLAS (N = 11, UNLESS OTHERWISE STATED)			
Been unable to concentrate on whatever you are doing? (pre n =23)	Better than usual 1 (4%)	Same as usual 16 (70%)	Less than usual 3 (13%)	Much less than usual 3 (13%)	Better than usual 1 (9%)	Same as usual 7 (64%)	Less than usual 2 (18%)	Much less than usual 1 (9%)
Lost much sleep over worry?	Not at all 6 (25%)	No more than usual 8 (33%)	Rather more than usual 6 (25%)	Much more than usual 4 (17%)	Not at all 3 (27%)	No more than usual 7 (64%)	Rather more than usual 1 (9%)	Much more than usual -
Felt that you are playing a useful part in things? (post n =9)	More so than usual 6 (25%)	Same as usual 12 (50%)	Less so than usual 5 (21%)	Much less than usual 1 (4%)	More so than usual -	Same as usual 7 (78%)	Less so than usual 1 (11%)	Much less than usual 1 (11%)
Felt capable of making decisions about things? (Pre n =25)	More so than usual 5 (20%)	Same as usual 19 (76%)	Less so than usual 1 (4%)	Much less than usual -	More so than usual -	Same as usual 8 (73%)	Less so than usual 3 (27%)	Much less than usual -
Felt constantly under strain?	Not at all 3 (13%)	No more than usual 12 (50%)	Rather more than usual 4 (17%)	Much more than usual 5 (21%)	Not at all 1 (9%)	No more than usual 5 (46%)	Rather more than usual 4 (36%)	Much more than usual 1 (9%)
Felt you couldn't overcome your difficulties?	Not at all 6 (25%)	No more than usual 11 (46%)	Rather more than usual 6 (25%)	Much more than usual 1 (4%)	Not at all 2 (18%)	No more than usual 6 (55%)	Rather more than usual 3 (27%)	Much more than usual -
Been able to enjoy your normal day-to-day activities? (Pre n =23)	*More so than usual* *2 (9%)*	*Same as usual* *13 (57%)*	*Less so than usual* *7 (30%)*	*Much less than usual* *1 (4%)*	*More so than usual* *1 (9%)*	*Same as usual* *7 (64%)*	*Less so than usual* *2 (18%)*	*Much less than usual* *1 (9%)*
Been able to face up to your problems?	*More so than usual* *6 (25%)*	*Same as usual* *13 (54%)*	*Less so than usual* *5 (21%)*	*Much less than usual* *-*	*More so than usual* *-*	*Same as usual* *8 (73%)*	*Less so than usual* *3 (27%)*	*Much less than usual* *-*
Been feeling unhappy and depressed?	*Not at all* *5 (21%)*	*No more than usual* *12 (50%)*	*Rather more than usual* *5 (21%)*	*Much more than usual* *2 (8%)*	*Not at all* *4 (36%)*	*No more than usual* *5 (46%)*	*Rather more than usual* *2 (18%)*	*Much more than usual* *-*
Been losing confidence in yourself? (Pre n =23)	*Not at all* *10 (44%)*	*No more than usual* *8 (35%)*	*Rather more than usual* *2 (9%)*	*Much more than usual* *3 (13%)*	*Not at all* *5 (46%)*	*No more than usual* *3 (27%)*	*Rather more than usual* *3 (27%)*	*Much more than usual* *-*
Been thinking of yourself as a worthless person?	*Not at all* *14 (58%)*	*No more than usual* *6 (25%)*	*Rather more than usual* *4 (17%)*	*Much more than usual* *-*	*Not at all* *7 (64%)*	*No more than usual* *2 (18%)*	*Rather more than usual* *2 (18%)*	*Much more than usual* *-*
Been feeling reasonably happy, all things considered?	*More so than usual* *3 (13%)*	*Same as usual* *12 (50%)*	*Less so than usual* *9 (38%)*	*Much less than usual* *-*	*More so than usual* *2 (18%)*	*Same as usual* *6 (55%)*	*Less so than usual* *3 (27%)*	*Much less than usual* *-*

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